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**PLACING THE LIVED EXPERIENCE(S) OF TB  
IN A REFUGEE COMMUNITY IN AUCKLAND,  
NEW ZEALAND**

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A thesis submitted in partial fulfillment  
of the requirements for the degree  
of Doctor of Philosophy in  
Geography

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# ABSTRACT

Although rates of tuberculosis (TB) in much of the western world have steadily declined since the Second World War, this infectious disease remains a leading cause of death among those living in impoverished circumstances. Social science perspectives have argued that TB is as much a reflection of socio-economic inequality and the uneven distribution of power and resources as it is about biological processes. In this thesis I explore the lived experience of TB within the Somali refugee community in Auckland, New Zealand. While migrants and refugees are frequently blamed for the resurgence in TB in Western countries, very little is known about the determinants that underlie this manifestation of the disease. The present research addresses this gap in the literature by employing a transdisciplinary social science approach that considers the determinants of health and illness that range across the social, cultural economic and political domains of human experience. The geographical underpinnings of the work are borne out in the fundamental goal: to (literally and metaphorically) place the lived experience of health, disease (and particularly TB) within the Somali refugee community in the wider context of migration and resettlement. Employing qualitative methods I draw upon participants' narratives to highlight the different ways in which Somali health beliefs and experiences have been shaped by wider structural forces. I demonstrate that within Auckland, Somalis encounter multiple and overlapping layers of disadvantage. The combined impacts of this disadvantage have a profound influence on their health and illness experience, particularly in terms of the development and ongoing occurrence of TB. Respondents with TB recounted widespread stigma that exacerbated the harm incurred by the illness itself. Although Somalis are highly marginalised, the thesis acknowledges the agency and creativity exerted by people in fashioning the course of their life within the context of considerable structural constraints.

Keywords: tuberculosis, health, illness, migration, resettlement, Somalis, refugees, Auckland

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## LIST OF ABBREVIATIONS

ACC	Auckland City Council
ADHB	Auckland District Health Board
AIDS	Acquired Immunodeficiency Syndrome
ARMS	Auckland Regional Migrant Service
ASCA	Auckland Somali Community Association
ARPHS	Auckland Regional Public Health Service
BBC	British Broadcasting Corporation
BCG	Bacille Calmette-Guerin Vaccination
CAU	Census Area Units
DOL	Department of Labour
DOTS	Directly Observed Therapy Short-course
ESOL	English as a Second Language
FAO	Food and Agriculture Organisation
FGM	Female Genital Mutilation
FRST	Foundation for Research Science and Technology
GP	General Practitioner
HDI	Human Development Index
HIPPY	Home Interaction Programme for Parents and Youngsters
HIV	Human Immunodeficiency Virus
HoP	Hauora o Puketapapa
LTSA	Land Transport Safety Authority
MDRTB	Multi Drug Resistant TB
MRRC	Mangere Refugee Reception Centre
MSD	Ministry of Social Development
NFD	Northern Frontier District
NGO	Non-governmental Organisation
NZIS	New Zealand Immigration Service
OEA	Office of Ethnic Affairs
ON TRACC	Transcultural Care Centre for Children
PHN	Public Health Nurse
PTSD	Post Traumatic Stress Disorder
RAS	Refugees as Survivors
RMS	Refugee and Migrant Service
SARS	Severe Acute Respiratory Syndrome
SNM	Somali National Movement
TB	Tuberculosis

TBD	TB Disease
TBI	TB Infection
TEC	Tertiary Education Commission
TNC	Transnational Corporation
UK	United Kingdom
UN	United Nations
UNDP	United Nations Development Program
UNFPA	United Nations Population Fund
UNHCR	United Nations High Commission for Refugees
USC	United Somali Congress
WHO	World Health Organization

# Chapter 1: Introduction

*“... tuberculosis has not been generally seen as a problem requiring attention and public resources so long as it was confined to the poor and disempowered populations in the city” (Curtis, 2004:241)*

## Introduction

Although TB has long been associated with poverty, the resurgence of the disease since the 1980s has resulted in renewed efforts to find a biomedical ‘magic bullet’ to eliminate this scourge once and for all. Despite this focus on biological processes and biomedical interventions, TB (and health more generally) cannot be understood or explained in isolation from the social, cultural, political and economic contexts with which it is inexorably intertwined. This thesis explores the lived experiences of TB within the Auckland Somali refugee community. Refugees and migrants are frequently blamed for the ‘TB problem’ within both political and academic circles however such aspersions tend to be infused with wider discourses about ‘otherness’, identity and fear of contagion. While epidemiological data indicates that some migrant groups do in fact experience a high burden of TB, little is known about the mechanisms that contribute to this situation.

Employing qualitative methods including interviews, participant observation and focus groups, I have analysed the TB experiences of one refugee community residing in Auckland, New Zealand’s largest and most ethnically diverse city. It is no coincidence that Auckland also has the highest rate of TB in the country (15.8 cases per 100,000) compared with the national average of 10 cases per 100,000 (Thornley and Pikhholz, 2007). Somali people first arrived in New Zealand in significant numbers in response to the outbreak of civil war in Somalia in 1992. As in other countries of resettlement, such as Canada, many Somalis have faced considerable difficulty dealing with trauma from the past, as well as the challenges of resettling in New Zealand, which has been experienced as a very foreign, and at times, unwelcoming country. Such experiences of marginality have been reinforced across every sphere of life including employment, housing, language and education. These challenges, I argue, have a profound influence on health and illness, particularly with regard to the development and experience of TB.

For the purposes of this thesis, I have contextualised the experience of TB within the Auckland Somali community in terms of wider migration, resettlement and health influences. This study represents the first exploration of these dimensions within an African refugee and migrant group living in New Zealand and provides information and analysis that is relevant to New Zealand while also contributing to current scientific knowledge in this international field.

This chapter sets out the purpose and objectives of the thesis in addition to outlining key conceptual strands that will be used to weave an account of Somali experiences of health and illness. Finally, an outline of the thesis is presented as a metaphorical roadmap in order to assist the reader in the navigation of the complex and diverse terrain of migration, health and TB.

## **How I came to this topic**

In the summer period of 2002-2003 I received a Health Research Council summer studentship. During this time I undertook research based at a small community health clinic called *Hauora o Puketapapa* located in Mt Roskill, Auckland (Lawrence and Kearns, 2005). After the clinic opened in 2000, the patient population was very different from what had been expected by the founders, with a large proportion of refugees presenting at the clinic (Exeter, Collins and Kearns, 1999). This situation presented a number of challenges for practitioners and those delivering health services. The purpose of my summer studentship was to consider the perspectives of both providers and users (i.e. patients) of the clinic, situated within analysis of the changing ethnic composition of the clinic catchment area. During the process of this research I had the good fortune of interviewing nine refugee community representatives from countries throughout Africa, the Middle East and Asia. As I spent time with these people a multitude of important issues emerged from these discussions on health and health care. The results emphasised that health is not determined simply by access to, and availability of medical resources, but by a wider set of determinants such as family networks, affordable and adequate housing, employment and meaningful employment, certainty about immigration status and language acquisition. I was touched by the stories of these people. As one key stakeholder told me, 'Refugees are survivors' and indeed these stories of survival were profoundly moving. My interest in refugee issues, particularly those related to health, began at this point and after the project had been completed, I began the process of raising awareness of the issues and lobbying for greater equity and justice in the accessibility, appropriateness and affordability of health services for refugee people. Indeed, this 'mission' continues today and this thesis is one example of my efforts to actively engage with social justice and ethical concerns (Valentine, 2003).

Given my interest in the above-mentioned issues I decided to further my postgraduate studies and applied to be part of a research project examining TB in five different population groups in Auckland. Two of these groups were to be from a refugee/migrant background, and it was this component of the research project that led me to apply for a scholarship. I was fortunate to receive funding and began my PhD studies in March 2003. Ethics approval was granted for this study by the Auckland Ethics committee in March 2003 (Approval AKX/03/01/003).

Prior to beginning my research at the Mt Roskill clinic, my knowledge of Somalia was limited to television images of scores of emaciated children starving in sprawling refugee camps. Africa as a

continent was very much outside my 'worldview'. Closer to home, I was aware that there were Somali people living in New Zealand but had given no thought to the issue apart from following media coverage of ethnic rivalry between Somalis and Pacific Islanders that had led to the death of one man in 2001.

Like many New Zealanders, I had thought TB was a disease of the past conquered by modern medicine. The advertisement for the TB project was the first time I had given any serious thought to the question of TB; but having read the background material to the research project I realised that it was, and still is, entrenched within certain population groups. In social settings, I found that my early perceptions of TB were shared. However, an interesting contradiction arose following my response to questions about the topic of my thesis. When I explained that I was looking at the issues surrounding TB in an African refugee group approximately half of those listening would gasp in horror and ask why on earth I was considering carrying out research on a disease that had been wiped out decades ago. The other half would say "Oh TB!" and proceed to tell me how a relative had suffered from TB, nursed TB patients, been to a sanatorium or moved to New Zealand to 'take in the air'. Clearly, a supposedly 'non-existent' disease has touched the lives of many.

## **Objective**

The objective of this thesis is to consider the lived experience of TB within the Auckland Somali population contextualised within people's life histories and also within wider social, economic, political and cultural influences. In order to encompass the breadth and complexity of my objective, a transdisciplinary approach is used. In a recent publication from the influential Institute of Medicine of the National Academies, it is argued that it is imperative to consider the interactions between social, behavioural and genetic factors when considering the health of individuals and populations (Institute of Medicine of the National Academies, 2006). In order for this to be achieved, researchers need to work across disciplines rather than be confined to a narrow disciplinary approach. In recognition of this contention, this thesis is a transdisciplinary study of TB that draws upon concepts, tools and approaches from throughout the social sciences. Although I have been trained in geography, being involved in a multi-disciplinary project unified in the common goal of better understanding the human 'face' of TB, has exposed me to historical, anthropological, political and sociological perspectives on health, disease and TB. The value of such diversity is that it enhances our ability to consider the interactions between the different factors that contribute to the complexities of diseases such as TB. Consequently, this study is a multi-level ecologically framed analysis of agency and meaning construction of Somali people in Auckland around the issue of TB, taking into account the structural constraints under which their life-courses and communities have developed.

One of the key ways in which this thesis addresses its overall objective is through the analysis of participants' lived experiences. This is one of the primary concerns of phenomenology, a

philosophical movement that seeks to uncover the “fundamental structures of intentionality, consciousness and the ‘life-world’ (Lebenswelt) of man (sic)” (Kuper and Kuper, 1985:587). Phenomenological approaches place value on the way in which people understand, value and make sense of the world around them. A strength of this thesis research is that I endeavour to couple the examination of Somalis’ lived experience with recognition of the wider structural constraints that have shaped people’s lives.

In order to describe the relationship between migration, resettlement and health, I draw upon participants’ narratives to assist in accessing their worlds. Although interviewing has long been a well-established methodological tool employed by qualitative researchers, there has been a renewed interest in narrative theory within the social sciences (Kearns, 1997). Drawing on the work of Gubrium and Holstein (1994), Wiles et al. suggest that narratives “make visible the unseen personal realms of experience, and embody social contexts such as family, home and community. For research and analysis, experiences and perspectives become accessible because, through narrative, people attach meaning and understanding to experience” (Wiles, Rosenberg and Kearns, 2005:89). The creation of narratives also raises methodological issues such as those of representation, contextualisation and influence of the researcher (Emerson, Fretz and Shaw, 1995; Dowling, 2000). In recent times there has been a greater emphasis on exploring the conditions under which stories are produced, in other words, the focus has been not only on the account that is narrated but how the story is told. Furthermore, there is recognition that narratives are not simply catalogues of events and experiences in people’s lives but are constitutive of identity, selfhood and the means through which people form and maintain social relationships (Riessman, 1993; Morris, 2002).

## **Aims**

In order to consider the lived experience of TB amongst Somali people within the context of wider structural constraints, the specific aims of this thesis are:

1. To describe how migration and resettlement processes influence Somalis’ experiences of health and wellbeing
2. To understand the everyday geographies, sense of place and experiences of Auckland Somalis as a transnational population group
3. To document Somali health beliefs and practices
4. To consider the ways in which Somali ideas about TB influence the way in which people both understand and respond to the illness
5. To understand the different stages of Somalis’ TB journey and identify the factors that contribute to successful treatment outcomes

The first aim seeks to uncover the inter-relationships between migration, resettlement and health through analysis of participants' lived experiences. This draws upon the premise that health is influenced by a wide-ranging set of determinants and is bounded both in space and time. In many cases it is difficult to disentangle temporal and spatial dimensions since in the case of health and disease, they are inextricably intertwined.

The second aim builds upon the first by using geography as a lens through which to consider the everyday worlds, sense of place and experiences of the Somali population as a transnational group in an increasingly multicultural city. This follows in the footsteps of Isabel Dyck who similarly considered the "everyday spaces and experiences of migrancy – as women work, raise children, make friends and manage family life as these are clearly implicated in the reworking of health beliefs and practices" (Dyck, 2006:2).

The third aim of this thesis is to document Somali health beliefs and practices as they form an important backdrop upon which specific issues related to TB can be considered. Health beliefs not only influence the way in which people understand and respond to illness in their own lives, but also how they respond when illness strikes other people.

Although much of the literature on TB focuses on biomedical approaches to the disease, some published research suggests that socio-cultural factors are important both in terms of explaining the distribution of the disease and in ensuring successful treatment outcomes (Rubel and Garro, 1992; Sumartojo, 1993; Farmer, 1997; Gandy and Zumla, 2002a). This thesis research similarly aims to consider the lived experience of the disease from the perspective of Somali refugees. I aim to put a human face on the otherwise anonymous epidemiological data that highlights the high rates of illness amongst such groups. I do this by considering Somali people's ideas about the disease and the different stages of the illness process from the illness recognition phase through to diagnosis, treatment and recovery. As I will demonstrate, TB has an enormous impact on people's health with some individuals continuing to live with the effects of the illness long after completing TB treatment.

These objectives are addressed in the chapters that follow through the analysis of interview data and other fieldwork material generated from extensive engagement with the Somali community over a three-year period. Through this analysis readers will gain an in-depth understanding of the lived experience of TB within the social, political, cultural and economic structures that shape people's lives. It is by no means a complete picture of Somali life but rather aims to reflect some of the ways in which Somalis make sense of the world around them.

## Conceptual coat-hooks

### *Space/Place*

As the health and resettlement experiences of refugees are firmly rooted within both space and time, ideas relating to these dimensions of human experience are used throughout this thesis in order to consider the geographical dimensions of Somali experiences of health, illness and TB. For many years, medical geographers approached space as a passive backdrop upon which human activity occurred. Since the early 1980s, proponents called for a re-conceptualisation of space and place as part of a shift to a 'new medical geography', or health geography, as it is often called (Jones and Moon, 1987; Gesler, 1992; Kearns, 1993). Work by authors such as Soja (1985) and Dear and Wolch (1989) proposed that space is socially constructed and is both the medium and the outcome of social processes. Such ideas contributed to renewed interest in the concept of 'place', defined as 'bounded settings in which social relations and identity are constituted' (Duncan, 2000:582). According to Kearns and Joseph:

*"...space is merely the container within which diseases are transmitted and treatment opportunities present themselves. However, when the concept of space is extended to incorporate recent social constructions of space, the points of contact between place and space become more complex and more significant. Space is no longer merely a container, but rather a medium through which the character of places is reproduced, both in the tangible landscape and in the consciousness of individual residents" (Kearns and Joseph, 1993:715).*

In other words, focusing on place considers issues of identity, values and the meanings people attach to particular locations. In reviewing the establishment of health geography, Kearns and Moon (2002) chart the use of 'place' as a framework for the consideration of health, including studies of health issues facing particular localities, landscapes of health and illness, and multilevel modelling.

Within this study, notions of space and place are particularly important when considering the experiences of Auckland Somalis. Migration in itself is an inherently spatial process that not only involves movement of bodies but also of ideas, beliefs, values and experiences. Of particular relevance to this thesis is the research of Isabel Dyck who has published extensively on the inter-relationships between culture, place and health focusing on immigrant women (Dyck, 1995; Dyck, Lynam and Anderson, 1995; Dyck, 2006). Dyck contends that health and illness experiences are firmly embedded in the experience of place, both materially and socially.

Work on transnationalism will be used to situate the Somali population group in Auckland as a 'dis'-placed and 're'-placed population through processes of forced migration and resettlement.

Transnationalism broadly refers to the 'multiple ties and interactions linking people or institutions across the borders of nation states' (Vertovec, 1999). Within literature on transnational communities, a number of groups have been studied, for example the dispersal of the Jewish people from their homeland in Israel through to labour migrants in the US. More recently, there has been interest in refugee groups and the extent to which they demonstrate transnational qualities. For example Al-Ali, Black and Koser (2001) provide case studies of Bosnian and Eritrean refugees in Europe and the UK in order to consider the extent to which these groups can be classified as being 'transnational'. In New Zealand, there has been some work on transnationalism particularly with regard to Pacific Island peoples (MacPherson, 2001; Spoonley, 2001), Indian and Chinese population groups (Ip and Friesen, 2001; Friesen, Murphy and Kearns, 2005), however there has been much less consideration of African and/or refugee people groups. One exception is a paper by Chile (2002) that explores the disadvantage experienced by black African refugees. There remains considerable scope to explore the extent to which the Auckland Somali population group can be considered a transnational community.

Yet while migration is significant, the actual places people occupy play an important role in terms of health and wellbeing. According to Curtis "The process of migration is less important in the epidemiology of this disease [TB] than living conditions for migrants in the 'host' country" (Curtis, 2004:234). This observation is of particular relevance to the present study which seeks to consider the everyday lived experiences of Somalis living in Auckland. One avenue which I will explore is the everyday geographies of Auckland Somalis and the way in which they interact with their environment – both physical and social. It is important to consider the resettlement process of Somalis and the way in which this is mediated through space. Eyles' notion of 'place-in-the-world' is particularly relevant in this case (Eyles, 1985). He contends that sense of place is influenced not only by people's experience of literal places but also their perceived place-in-the-world. In other words a person's socio-economic position and place of residence impacts upon the spaces and places he/she can access and utilise. This notion draws upon the idea that place is forged through intersections of both global and local factors (Massey, 1994).

Geographical perspectives informed by ideas about space and place have also contributed to research on geographies of communicable diseases. Though there has been little research explicitly focused on TB (but see Elender, Bentham and Langford, 1998; Kistemann, Munzinger and Dangendorf, 2002; Oppong et al., 2004), geographies of communicable diseases such as Human Immunodeficiency Virus (HIV), provide a useful conceptual framework for connecting people, diseases and places. The theorisation of space and place has changed considerably over the decades, mirroring wider disciplinary shifts from concerns with disease ecology to focusing on more humanistic concerns (Jones and Moon, 1987; Gatrell, 2002). In addition the notion of health and wellness is emphasised as opposed to a narrow focus on disease. As will be discussed further in Chapter Four, there remains much scope for health geographers to engage with issues surrounding TB.

## *Structure/Agency*

As this thesis aims to consider both lived experiences and the wider social, economic and political structures that influence such experiences, the structure/agency continuum is a valuable conceptual tool both theoretically and epistemologically. The structural perspective suggests that underlying forces in society such as political, economic and social constraints shape people's lives. In terms of health, considerable research has demonstrated how poverty influences health (National Health Committee, 1998) and also wider health restructuring (Joseph and Kearns, 1996). On the other hand the concept of agency is infused with humanist concerns with meaning, symbols, identity and the exploration of a person's ability to make choices. Examples of research considering agency within the context of health include the meanings people attach to places of health care (Kearns, 1991) and resistance to health services restructuring (Joseph and Kearns, 1996). Giddens (1984) sought to address this dualism through the concept of structuration which attempts to balance and reconcile the demands of both structure and agency. Although this approach has been critiqued, the structure-agency continuum continues to be a useful means through which to consider the multiple influences upon health and illness

Similar debates about the influence of structure and agency can be found in a number of research traditions. Of relevance to this research is discussion within refugee studies about the way in which these populations have been cast as passive and helpless victims to larger social, political and economic forces. Horst (2005) aims to overcome the stereotypes of refugees as 'vulnerable victims' or 'cunning crooks' through consideration of the agency of refugees. She suggests that refugees do not passively accept their circumstances but rather actively try to access and maximise available opportunities. Expressing agency relies on power and the ability to make choices. Refugees do possess some degree of power to make decisions about their lives, although these decisions may be constrained. Throughout this thesis, I consider not only the structural factors that constrain the lives of Somali refugees living in New Zealand but also their agency and the choices they make in determining their own lives. This is a conceptual tool as well as a methodological stance. Where possible I make space for individuals' own accounts as an active and conscious decision in order not to represent my research participants as helpless and passive victims of wider forces.

## *Community and Representation*

The term 'community' is used throughout this thesis. It is, however, a somewhat nebulous term due to its frequency of use in a wide range of settings. Within political and public discourses, 'community' often refers to shared identity whether that be country of origin, residential location or as an item of special interest. While this terminology serves practical purposes, some suggest that the discourse of 'community' amongst refugee peoples assumes an organic wholeness among members while excluding others on the basis of ethnic, cultural and racial divisions (White, 2002). The reliance on the idea of refugee communities masks the political and historical divisions and

tensions that exist amongst groups of people both between and within nations (White, 2002). Lynette Kelly (2003) studied Bosnian refugees residing in Britain and describes the dominant perception in Britain where groups of migrants are thought of as being a community. Yet in the course of her research, Kelly found that community associations were formed because of the advantages that can be obtained, rather than due to a group-wide sense of belonging and interconnectedness. She argues that typically, refugee groups are characterised by factionalism and division as opposed to community. Kelly states “The existence of community associations is, therefore, not a reflection of the needs of a community, but, instead, an artificial construction responding to a social policy based on an assumption that communities exist” (Kelly, 2003:46).

Many of these issues are particularly pertinent for the Somali community whose arrival in NZ was precipitated by the complications of clan-based politics. Somalis, like many small ethnic groups, are frequently referred to as a ‘community’, a term imbued with a sense of homogeneity, co-operation and shared identity. While this is true to some extent, the Somali population is as much identified by division as by unity as would be expected, given that the warring clan groupings are represented in Auckland. During the course of my fieldwork it was interesting to me that, in public or formal contexts, Somali people promoted the concept of ‘the Somali community’ to attract and legitimate the acquisition of resources. Similarly at times I observed particular individuals repeatedly using the label of ‘refugee’ and presenting particular aspects of being a refugee (i.e. high needs, at-risk) in order to garner much-needed support and resources. I suggest that because of the Somali population’s marginality, compared with other ethnic groups, leaders have realised that it is necessary to present a unified front to government agencies and funding bodies. This realisation occurred at the same time that government agencies were increasingly required to consult with ethnic groups.

Throughout this thesis I use the phrase ‘community’ to refer to the group of people with whom I work. One reason I have employed this term is because many of my participants use this term also in describing themselves. While the term is repeatedly used throughout this thesis, its usage does not overlook the fact that considerable tension and division remains. This often appears to stem from underlying clan conflict but also relates to the scarcity of resources available in New Zealand and the problems in the distribution of resources, as will be described in greater detail in Chapter Six.

In addition to challenging the notion of ‘community’ it is also important to note that issues of representation emerge when describing the experiences of a diverse population group. While small-scale studies such as this one yield in-depth, detailed information, this is not necessarily representative of the experiences of every Somali living in Auckland (Jacobsen and Landau, 2003). Although there are a number of trends and similarities, the resettlement issues described in later chapters cannot automatically be generalised across the community as a whole. In other words, there is no one “Somali story” as people’s experiences are shaped along fissures of power, class

and gender. In recognition of this situation, I attempt to acknowledge the diversity of experiences throughout this thesis.

## **Thesis Overview**

The remainder of this thesis is organised into nine chapters. In Chapter Two, I consider how concepts such as globalisation, transnationalism and diaspora offer potential for the study of the experiences of refugee communities such as the Somali population. I then move from the global to the national scale by considering the subject of migration to New Zealand and the way in which migration policies and processes have changed over time. In particular, I focus on the place of refugees within New Zealand and highlight some of the resettlement issues they face. The third part of the chapter considers the inter-relationships between the global and the local through the case-study of transnational Auckland.

In order to understand Somalis' resettlement experiences, it is important to understand the political, economic and social context from which they originate. Building upon this increasing connectedness between people and places, Chapter Three is largely descriptive and sets the scene for later analysis through establishing the context from which Somalis originate. This is followed by discussion of the Somali diaspora and research that has been undertaken internationally. I then shift focus to the local scale through considering the 'place' of Somalis in New Zealand by surveying the published research on Somali refugees with particular focus on Auckland. This chapter concludes with the observation that very little is known about the experiences of Somalis living in Auckland within 'mainstream' NZ public discourse and scholarship.

Chapter Four changes direction in order to draw in the subject focus of this thesis, namely that of TB. Prefaced by discussion of the way in which health and medical geography has dealt with communicable diseases such as TB, I summarise the vast literature on the disease with particular focus on TB's resurgence and the way in which migrants and ethnicity have been the continued subject of attention. Attention is paid to the increasing number of studies that consider the experiences of particular cultural groups, a task similar to my own.

Chapter Five provides an account of the methodological approaches that were used in this thesis. Due to the complex and personal nature of the research objectives, qualitative methods including interviewing, participant observation and focus groups were used when considering Somali experiences of migration, resettlement and TB. The chapter also engages with literature on the dynamics of conducting research with particular emphasis on issues to do with ethics, positionality and reflexivity.

Drawing upon participant narratives, Chapter Six discusses the resettlement experiences of Somalis. This chapter is divided into four sections. The first considers how issues from the past

have a significant influence on a person's ability to settle in New Zealand. This sense of dislocation and isolation has led to a sense of disappointment for those who hoped that fleeing to New Zealand would allow them to start a new life. This forms the second section which considers the profound resettlement challenges experienced by Somalis in every aspect of life including housing, employment, education and language. While the migration process involves the shifting of bodies from one place to another, it also includes the movement of ideas, values and experiences. Accordingly, the third section considers transformations to Somali identity and the tensions that exist when a migrant group finds itself living between two worlds. The final section describes the formation and influence of the Auckland Somali Community Association (ASCA) and is testament to that agency exerted by an otherwise marginalised group.

Chapter Seven and Eight consider the health and TB beliefs of participants in order to fully contextualise the subsequent analysis of TB journeys found in Chapter Nine. In Chapter Seven I initially outline the health issues faced by refugees, before discussing Somali health beliefs. Participants' ideas about health have been strongly influenced by the social, economic and political context in which they are situated. In addition, health beliefs and practices originating from Somalia are particularly important and have come to be re-worked and re-negotiated within a new context (New Zealand). The last part of this chapter examines the different models of health utilised by participants and the inter-relationship between these two ways of thinking.

Chapter Eight seeks to understand the different ways in which Somali people think about TB. In light of the resurgence of the disease there has been a push to understand people's beliefs and attitudes towards TB in order to eliminate incorrect attitudes through education and to improve treatment outcomes (Carey et al., 1997; Tulsky et al., 1999). My approach is somewhat different in that I assert the importance of considering people's own ideas and beliefs in their own right and that these ideas are significant in terms of the ways in which people make sense of the disease, how they respond to it, and how they relate to others with the illness. I consider the way in which people draw upon multiple explanatory models of health and illness. The implications of these ideas within the context of New Zealand are considered.

I reflect on the findings of the thesis in Chapter Nine which explores the TB experiences of Somali participants. The journey is used as a metaphor to guide our understanding through the phases and processes of the illness. Participant interactions with the health system and health professionals are addressed as being a key component of the treatment process.

## **Summary**

The purpose of this chapter has been to provide a framework for understanding the contours of this thesis. The key objectives of this research were outlined and situated within existing scholarship, addressing issues of health and illness. Key conceptual ideas that under-pin much of the analysis

that follows were also raised. Ideas about community, representation, space/place and structure/agency are important ways in which this research seeks to engage critically with the issues surrounding migration, health and TB. I also previewed the structure of this thesis contending that each chapter will add another strand to our understanding of the way in which Somali experiences of TB need to be located within broader social, economic and political contexts. Chapter Two builds upon this discussion by drawing upon an inter-disciplinary literature on globalisation, diaspora and transnationalism.

## **Chapter 2: Globalisation, transnationalism and refugee experiences in New Zealand**

*“The selection of daily life under conditions of globalisation as a kind of conceptual ‘vantage point’ ... enables, for example, processes to be conceived at multiple spatial and temporal scales. There is also an acknowledgement that visible and invisible acts, experiences, feelings, intentions and meanings are important elements of daily life. This vantage point also links together daily life and globalisation in a fluid way, with each given the opportunity of influence the other. The role of place and local context can be appreciated” (Bailey, 2001:420).*

In this study I consider the situated, in-place experience of TB within the Auckland Somali community. In many ways, TB is a lens through which we can gain insight into the inter-relationships between different political, economic and social processes operating at multiple scales (global, national and local). As the Auckland Somali population is a refugee community, issues surrounding migration are an important foundation for this research. For this reason I have situated my research in the literatures of globalisation, transnationalism and diaspora which have informed my research questions and assisted data analysis. I then focus on how these processes have influenced immigration to New Zealand. Special attention is given to the transnational character of Auckland, New Zealand’s largest and most diverse metropolitan area.

### **Globalisation**

Arguably, globalisation is the anthem of the late 20th and early 21st centuries. As a concept, it has generated an enormous amount of public attention and academic inquiry. While it is beyond the scope of this discussion to conduct an exhaustive review, the notion of globalisation is an important foundation from which to consider issues related to refugees, immigration and TB.

Globalisation has come to be used by different people to mean different things. Globalisation broadly refers to a complex series of economic, social, political and technological changes that have resulted in increasing inter-connectedness between people and places. Its characteristics include the transformation in flows of capital, trade, production and organisation of financial activities (Le Heron and Pawson, 1996), the increased speed, availability and ease of communications and information technology, heightened technological advances and the move towards a Westernized global culture (Yeung, 2003). In addition, globalisation has wrought considerable political change, as exemplified by debates regarding the supremacy of nation-states (Boyle, 2002; Lee, 2003). Yet global change has been uneven. Not all people and places have

benefited equally. Global economic growth for example has increased disparities in wealth between rich and poor (UNDP, 2005).

## **Transnationalism and diaspora**

One characteristic of globalisation is the increased movement of people across space. While migration is not a new phenomenon, the increased speed, density and frequency of interaction with the country of origin, through means such as air travel, the telephone, facsimile and forms of electronic communication, has been enabled through globalisation. This means that migrants can establish and sustain social relationships and networks more easily than previously. While diaspora is a well-established framework, the emergence of transnationalism as a new field of study in the 1990s has helped reinvigorate research in the topic. The concept of transnationalism can assist in the understanding of the way in which processes of globalisation come to influence the everyday lives of people living in diasporic communities, and how these communities relate with each other and with their country of origin. While these two frameworks share a number of similarities there are differences in the history and development of each of the areas. As a result, each concept warrants separate discussion.

### *Diaspora*

According to one commentator, "Diaspora may be the metaphor of 'our time'" (Samers, 2003:351). While diaspora has a long history, originally referring to the forced exile of the Jews from their homeland, what is new is the increasing impact of globalisation which has facilitated transnational social relationships. Today, in many cases, diaspora can be thought of as a form of transnational community (Wahlbeck, 2002).

The concept of diaspora is inherently geographical as the term itself describes a scattering of people over space and time. Drawing on Brah (1996), Blunt contends that geography clearly lies at the heart of diaspora both as a concept and as lived experience "encompassing the contested interplay of place, home, culture and identity through migration and resettlement" (Blunt, 2003:282). Furthermore, Ni Laoire (2003) suggests that diaspora studies have enabled population geography to engage with wider shifts in social theory. Diaspora bridges the gap between different fields within geography by providing a space of engagement for population geographers (focused on the experiences of migrants), social and cultural geographers (concerned with culture and identity) and political geographers (interested in the interaction of people with nations and states) (Boyle, 2001). Diaspora is also a useful concept for health geographers interested in the health and wellbeing experiences of migrant populations.

Defining diaspora is not a simple task and has resulted in considerable debate over what characterises a diaspora compared to other migratory forms. Anthias (1998) suggests that there

are two dominant approaches in the study of diaspora. The first conceptualises diaspora as a descriptive typological tool tending to focus on the characteristics required for inclusion in the category. The second trend approaches diaspora as a social condition, influenced by postmodern and post-structuralist thought. This approach understands diaspora as a condition involving “multiple allegiances, and belongings, a recognition of hybridity, and the potential for creativity in diasporas” (Ni Laoire, 2003:277). Researchers such as Brah (1996) and Clifford (1994) have contributed to this school of thought.

One of the early commentators on the concept of diaspora (Safran, 1991) exemplifies approaches of the first category. In the first edition of the journal *Diaspora*, Safran laid out the criteria for diaspora as being:

“Expatriate minority communities whose members share several of the following characteristics:

1. They, or their ancestors, have been dispersed from a specific “original” centre to two or more “peripheral”, or foreign, regions
2. They retain a collective memory, vision, or myth about their original homeland – its physical location, history, and achievements
3. They believe that they are not – and perhaps cannot be – fully accepted by their host society and therefore feel partly alienated and insulated from it
4. They regard their ancestral homeland as their true, ideal home and as the place to which they or their descendants would (or should) eventually return – when conditions are appropriate
5. They believe that they should, collectively, be committed to the maintenance or restoration of their original homeland and to its safety and prosperity
6. They continue to relate personally or vicariously, to that homeland in one way or another, and their ethnocommunal consciousness and solidarity are importantly defined by the existence of such a relationship”

(Safran, 1991:83-84)

Safran’s definition of diaspora has been criticised from a number of quarters. Clifford (1994) argues that Safran’s definition is too rigid and fails to include some groups that can be characterised as diasporas. Furthermore, he suggests that transnational connections between diasporas may be just as important as the linkage between diasporas and the real or symbolic homeland. Wahlbeck (2002) argues that diaspora should be regarded as an analytical tool and interpreted as an ‘ideal type’ according to Weberian thought (Wahlbeck, 2002).

In line with the notion of diaspora as a descriptive tool, Cohen (1997) attempts to broaden Safran’s conception of diasporas by creating a typology differentiating between diasporas. Cohen argues that diasporas are not simply population groups which have been forcibly dispersed from their country of origin but rather include a diverse range of population groups including labour and

colonial migrants. His typology includes victim (e.g. Africans and Armenians), imperial (e.g. British), trade (e.g. Chinese and Lebanese), cultural (e.g. Caribbean) and labour (e.g. Indian) diasporas. Cohen notes that these categories are not mutually exclusive and can change form or characteristics over time. In Somalia's migration history, nearly every category is represented at some stage.

Cohen's typology has been critiqued by a number of commentators. Anthias (1998) argues that simply characterising a group based on their reason for leaving their country of origin obscures analysis of their settlement, accommodation patterns and (re)formation of identity. Furthermore, this typology is critiqued for obscuring differences within each of these groups. In particular, Anthias suggests that diaspora reinforces 'ethnic essentialism' and that the overwhelming focus on ethnicity 'privileges' the point of origin, thus obscuring gender, class and other internal divisions within diasporic groups. She argues for a greater consideration of the way in which diasporas are gendered and how diasporic groups may be "subjected to two sets of gender relations: those of the dominant society and those internal to the group" (Anthias, 1998:572-573).

Van Hear's (1998) definition of diaspora while broad, addresses the above-mentioned concerns regarding the characteristics and inclusiveness of the notion of diaspora. For Van Hear, diasporas involve three criteria. The first criterion is that populations are dispersed from a homeland to two or more countries. Secondly this resettlement is seen to be enduring though not necessarily permanent. Finally, there is social, political or cultural exchange between and among diasporic populations. This conceptualisation of diaspora describes the characteristics of the Somali diaspora particularly well.

Other commentators suggest that diaspora involves two key concepts. First is the notion of a journey and a home (Brah, 1996). Others have discussed a similar notion, using instead the terms 'root' and 'route' (Clifford, 1994). The term 'root' invokes a sense of a point of origin from which people are scattered and a point to which such people hope to return. While this concept of 'root' or 'home' may simply be viewed as country of origin, it is much more. For some groups, 'home' may be imagined, a part of a collective diasporic imagination. As Brah eloquently notes "...home is also the lived experience of a locality. Its sounds and smells, its heat and dust, balmy summer evenings, somber grey skies in the middle of the day" (Brah, 1996:192).

The term 'route' however captures a sense of mobility – focusing on mobile and transcultural geographies over space and time. Routes challenge the fixed and bounded notions of home, place, culture and identity that 'root' encapsulates (Blunt, 2003:282). Brah (1996) argues that while the concept of journeying is central to that of diaspora, it is important not only to consider who travels but when, how and under what circumstances (Brah, 1996:182). Furthermore, another consideration is the ways in which these journeys conclude. Nevertheless this focus on mobility does not preclude a 'homing desire' (Brah, 1996). As Brah notes "the concept of diaspora offers a

critique of discourses of fixed origins while taking account of a homing desire, as distinct from a desire for a 'homeland'" (Brah, 1996:16). While there might be a desire to return home, not all people are able to - such as those whose 'homing desire' may be for a nation in the past. For example, as documented by Al-Ali et al. (2001), the 'home' that Bosnians used to know and identify with has disappeared due to the re-articulation of borders after the conflict in Yugoslavia and Bosnia Herzegovina.

## Refugees and Diaspora

The concept of diaspora is particularly useful when describing the situation of refugees. Originally, diaspora was seen as referring exclusively to refugees; however, it is currently used more broadly to include a variety of migrants as the above discussion highlights. Yet it is important to bear in mind that access to opportunities to migrate is unevenly distributed. Generally it is only the wealthy who have the resources to travel. The less-well off may be able to travel to neighbouring countries while the least well off remain (Van Hear, 2003). This variability of opportunity has implications for the type of person residing within refugee diasporas. De Montclos (2003) notes that many of those in the Somali diaspora are well educated with a professional background resulting in a 'brain drain' from Somalia. With the eruption of civil war in 1992, the elites with the means and resources to flee were the first to do so.

A number of ethnographic studies consider the ways in which refugee communities are connected with each other and their countries of origin (e.g. Malkki, 1992; 1995; Al-Ali et al., 2001). A book by Van Hear (1998) describes 10 examples of forced migration and the subsequent diasporic communities that have been established. In a later study he describes the Palestinian, Afghan and Sri Lankan refugee diaspora in which significant transnational links can be documented. He postulates that, in these cases, transnational networks both fuel and resolve the conflict that resulted in exile (Van Hear, 2003).

Wahlbeck (2002) suggests that using the concept of diaspora is one way to overcome the lack of conceptual rigour in much of the refugee studies literature. He continues by arguing that "the concept of diaspora, understood as a transnational social organisation relating both to the country of origin and the country of exile, can give a deeper understanding of the social reality in which refugees live" (Wahlbeck, 2002:222). Wahlbeck contends that transnationalism has implications for relationships between ethnic groups in particular localities. Using the example of Kurdish refugees living in Britain and Finland, he argues that the rise in globalisation and transnationalism has meant that, for many refugee groups, maintaining relationships with the majority/host population is not as significant as maintaining connections with other diasporic community members. Wahlbeck documents the variety of ways in which diasporic Kurds maintain close contact through television, visits, conversations and media. In a similar vein, Shandy (2003) explores transnational linkages between Sudanese refugees in the US and family and friends back

in Africa. Al-Ali (2001) considers the extent to which Bosnian and Eritrean refugees can be thought of as transnational communities.

Despite the usefulness of the diaspora concept, there is a danger that focusing on migrants and their relationship with their homeland obscures the relationship the group has with its society of settlement and the power structures involved in majority-minority relations (Wahlbeck, 2002:232). While diasporas are transnational in nature, they do operate in fixed localities. According to Wahlbeck, “we live in a ‘glocalized’ social reality where both the local and the global exist side by side and in relation to each other” (Wahlbeck, 2002:233). Diaspora can also tend to assume homogeneity when this is certainly not the case, particularly amongst refugee communities. While ethnicity or a shared homeland is a useful identifier, allegiances are often more closely aligned to political factions. As Koser (2003) demonstrated with Somalis, political tensions between sub-clans have been imported into resettlement nations and influenced subsequent community relations.

### *Transnationalism*

Closely linked to the concept of diaspora, transnationalism refers to the multiple links and ties connecting people and places throughout the world. Since the 1990s the study of transnationalism has gained momentum and become a central organising concept within the studies of migration and resettlement. Vertovec opens his review of literature on transnationalism by stating that “Today transnationalism seems to be everywhere, at least in social science” (Vertovec, 2003:641). One reason for this popularity is because transnationalism “already speaks to many crucial contemporary debates about, for example, immigration and asylum policy, changing citizenship concepts, racism and xenophobia, and social marginalisation” (Bailey, 2001:420). One indicator of the degree of interest in transnationalism is the establishment of a £3.8 million ESRC funded research programme on Transnational Communities in the United Kingdom. A total of 19 projects have been commissioned on the themes of economics, politics, society and culture and new approaches to migration (Vertovec, 1999).

Early proponents of the transnationalism concept were cultural anthropologists Glick Schiller, Basch and Szanton Blanc who in 1992 and 1994 published edited collections of conference papers based on the topic (Glick Schiller, Basch and Szanton Blanc, 1992; Basch, Glick Schiller and Szanton Blanc, 1994). Glick Schiller et al. (1992) propose that transnationalism serves as a conceptual model to interpret new migration patterns and processes. Using Haitian, Grenadian and Filipino migrants as examples, they argue that contemporary migration is different to that of the 19th and 20th century as earlier migrants tended to become incorporated within the host society, whereas, contemporary migrants are “composed of those whose networks, activities and patterns of life encompass both their host and home societies. Their lives cut across national boundaries and bring two societies into a single social field” (Glick Schiller et al., 1992:1). They define transnationalism as “the processes by which immigrants forge and sustain multi-stranded social

relations that link together the societies of origin and settlement... build[ing] social fields that cross geographic, cultural and political borders“ (Basch et al., 1994:7).

While the work of Schiller et al. is indeed critical to the study of transnationalism, it has nevertheless been critiqued. Kivisto (2001) debates their proposition that a new theoretical paradigm is required to describe these contemporary migration patterns and processes. He argues that many features of transnationalism have been documented previously by researchers writing about immigration, assimilation and ethnicity and that discussion of transnationalism is not adequately situated within existing scholarship. This critique has informed much subsequent work on transnationalism by authors such as Portes and Vertovec who endeavour to identify the hallmarks of transnationalism and establish the extent of its validity and relevance as a topic of enquiry (Portes, Guarnizo and Landolt, 1999; Vertovec, 1999; 2003).

In an attempt to establish some parameters around the study of transnationalism, Portes et al. (1999) caution against using new concepts such as ‘transnationalism’ and ‘transmigrant’ when existing terms such as ‘immigration’ and ‘immigrants’ are adequate. The authors suggest that three conditions need to be met in order for the concept of transnationalism to be meaningfully employed as a distinct category from immigration. These conditions are: firstly, that a significant percentage of immigrants are involved in the process; secondly, that the activities they engage in are sustained over time; and, finally, that existing concepts inadequately describe the nature of these activities (Portes et al., 1999). Portes et al. rightly point out that occasional contacts and activities of migrants across national borders are neither novel nor distinct enough to justify a new area of investigation. Rather, they argue that, ‘What constitutes truly original phenomena and, hence, a justifiable new topic of investigation, are the high intensity of exchanges, the new modes of transacting, and the multiplication of activities that require cross-border travel and contacts on a sustained basis’ (Portes et al., 1999:219).

In a similar vein, Vertovec (1999) suggests the hallmarks of transnationalism are the intensity and simultaneity of cross-border contact. Vertovec identifies six conceptual premises which transnationalism addresses. He suggests that transnationalism is a type of:

1. Social morphology
2. Consciousness
3. Mode of cultural reproduction
4. Avenue of capital
5. Political engagement
6. Reconstruction of ‘place’ or locality

Using Vertovec’s typology, studies relating to transnationalism will be discussed under each of these headings.

Firstly, *social morphology* refers to social structures spanning borders. Studies of ethnic diasporas are a typical instance of this. One example is the work of Al-Ali et al. (2001) who examined transnationalism within Bosnian and Eritrean refugees residing in Europe. The authors found numerous examples of transnational linkages. Amongst the Bosnian community there was evidence of remittances, regular contact and visits, the exchange of ideas and knowledge, involvement in community associations and fundraising activities for charitable activities in Bosnia (Al-Ali et al., 2001:582). In the case of Eritrean refugees, the state has also sought to institutionalize transnational activities by formalizing remittances and fund-raising activities to support the ongoing war for independence. For instance, in the most recent conflict with Ethiopia, Eritreans living abroad were requested to contribute two percent of their annual income to the state to support the war effort (Al-Ali et al., 2001). Other examples of the many studies of transnational ethnic groups include transnationalism amongst Dominicans (Itzigsohn et al., 1999), Salvadorans (Landolt, Autler and Baires, 1999) and Chinese (Olds and Yeung, 1999). Other transnational networks are also of interest including those involving terrorism, weapons, drugs, smuggling and drug trafficking (Vertovec, 1999).

Transnationalism as a *form of consciousness* refers to how transmigrants experience dual or multiple identities. In this sense, individuals are not limited to identifying with either their country of origin or country of resettlement but with both, and in many cases, multiple identities. Issues such as this have been reflected upon by commentators such as Brah (1996) and Hall (1990; 2003). Researchers have also extended this line of thinking with the notion that transnational connections are not simply tied to territories or nation states but rather that they can also be maintained and created through '...the mind, through cultural artifacts and through a shared imagination' (Cohen, 1996:516); particularly given the emergence of the internet and widespread communication technology. Consciousness can also refer to collective memories, histories and awareness which can provide powerful links to the homeland (Burrell, 2003).

Thirdly, transnationalism as a *mode of cultural reproduction* refers to the way in which different cultural phenomena are blended and reproduced to form hybrid identities. This, according to Vertovec, is often described in terms of syncretism, creolization, bricolage, cultural translation and hybridity (Vertovec, 1999:451). Transnationalism as a mode of cultural reproduction is clearly evident amongst transnational youth in the fields of fashion, music, film and visual arts where multiple cultural identities are intertwined. For example, Crang et al. (2003) examined commodity culture flows in relation to food and fashion between Britain and India. The media plays a very important role with the expansion of satellite television and electronic communication services. This is raised in a study of Polish migrants (Burrell, 2003). The creation of satellite networks including Med TV for Kurds, Zee TV for Indians and Space TV systems for Chinese, Vietnamese, Japanese and Koreans has facilitated these developments (Vertovec, 1999:452). It is important to note however that access to such opportunities is unevenly distributed particularly given the costs

of air-travel, information technology, satellite TV and telecommunications. This means that only those with the requisite financial resources are able to utilise and access these opportunities.

The fourth hallmark of Vertovec's characterization of transnationalism is the role of *finance*. Literature on transnationalism has examined how transnational corporations (TNCs) have been the driving force behind global economic change and the resulting transformations that have been observed. This is due in part to the domination of TNC's within the global economic system (Dicken, 1992). Yeung's (1998) work on Hong Kong transnational organisations and networks is one example of how TNC's dominate international business. On the micro-scale, individual remittances are having a profound global impact. While difficult to estimate accurately due to the informal nature of exchange, remittances are estimated by the World Bank as totalling 80 billion dollars in 2002, up from 48.1 billion in 1995 (World Bank, 2003). This is likely to be a conservative estimate. A number of researchers have examined the impact of remittances on the lives of individuals and those who benefit from them (Glick Schiller and Fouron, 1999; Horst and Van Hear, 2002; De Montclos, 2003). Haiti and Eritrea are two interesting examples wherein remittances have become institutionalized by the national government (Basch et al., 1994; Al-Ali et al., 2001).

The fifth component of Vertovec's typology addresses how *political engagement* to address inequality and injustice occurs on a global scale, most notably in the transnational operations of Non-Governmental Organisations (NGO's) such as the United Nations. Many diasporic communities are explicitly political in their organisation and remain connected with the political events in their homeland e.g. Kurdish (Wahlbeck, 2002), Polish (Burrell, 2003) and Bosnian (Al-Ali et al., 2001) refugees. De Montclos (2003) documents how diasporic Somalis have established political and humanitarian NGO's such as Horn Relief for the Warsangeli Darood in the United States and the Somalia Environmental Protection and Anti-Desertification Organization for the Dulbahante Darood in the United Arab Emirates. The Constitution of Somaliland also includes Somali refugees in exile as being eligible to stand for presidency (De Montclos, 2003).

The final characteristic of transnationalism focuses on the *reconstruction of place and locality*. While transmigrants are globally interconnected, they still remain situated within places which shape, and are shaped by, the activities of transmigrants (Friesen et al., 2005). This is an important aspect of transnationalism as some would argue that the focus on de-territorialised networks and processes overlooks the fact that transmigrants are still located within place. Kivisto (2001) argues that:

*“Even in transnational social spaces, place continues to count. Contrary to the image of transnational immigrants living simultaneously in two worlds, in fact the vast majority is at any moment located primarily in one place. If the location where they spend the most of their day-to-day lives is the receiving country, then over time the issues and concerns of*

*that place will tend to take precedence over the more removed issues and concerns of the homeland' (Kivisto, 2001:571).*

The degree to which transmigrants integrate with the host society is a contentious one. According to Portes et al. (1999) it has generally been assumed that once migrants arrive in a country they gradually become assimilated into the host society. This is not always the case as previously discussed in the context of diaspora, with some transmigrants being more involved with other diasporic communities around the world than their neighbours in the host society.

This discussion of place connects with research on everyday practices inherent in transnationalism (Burrell, 2003; Conradson and Latham, 2005). This is seen as one way to overcome the generality of narratives of globalisation by highlighting the “everyday texture of the globalizing places we inhabit” (Conradson and Latham, 2005:228). Conradson and Latham (2005) correctly point out that transnational mobility is dependent on a raft of seemingly mundane, but essential, activities such as phone calls, trips to travel agents, internet usage and grocery shopping. They also further the notion of ‘middling’ forms of transnationalism which seeks to expand the focus of transnational research beyond hyper-mobile elites and migrants from the developing world. They suggest that the rising popularity of ‘gap years’ overseas, study abroad and career sabbaticals amongst the middle classes are examples of such transnational activity. In a similar vein, Burrell (2003) discusses what she terms ‘small-scale’ transnationalism – seemingly banal, every-day activities that link Polish people living in Leicester with their homeland. Such activities are so ingrained in participants’ lives they are not necessarily mentioned (e.g. watching satellite television, communication with Poland, political and economic networks and travel and communication technology), in comparison to the more significant, migration act itself. Levitt rightly points out that frequent movement is not necessarily a prerequisite for transnational activities and that transmigrants may be rooted in one country, but conduct their lives in such a way as to involve themselves closely with people and resources spread throughout the world (Levitt, 1996:179). This idea is captured particularly well by Bailey (2001) in the introductory quotation for this chapter.

Nevertheless, there are some commentators who have critiqued transnationalism for similar reasons to the above-mentioned discussions on the limitations of diaspora. Pratt and Yeoh (2003) point out the way in which transnationalism is highly gendered. Burrell (2003) examines how age influences transnational linkages and suggests that second and third generations of Polish migrants are less engaged with transnational networks than their forbears. It is important to acknowledge these points of difference as transnational groups tend to be represented as homogenous entities, based on the notion of a shared homeland and a spatial dualism of ‘there’ versus ‘here’. Yet as Wahlbeck warns, “In refugee communities, political divisions and allegiances often play a far more important role than ethnic identities” (Wahlbeck, 2002:234). Thus differences and divisions within groups are often of greater significance than the unity afforded from departing

the same nation state. This is of particular significance to populations such as the Somalis whose exile was prompted by civil war based upon clan identities (Griffiths, 1997; 2002).

As has been highlighted previously, globalisation has profoundly changed the world in which we live; including the nature and characteristics of migration and settlement. I now shift to consider the way in which these processes have influenced immigration trends within New Zealand and the local responses that have emerged. These responses are important as they directly influence the 'place' and subsequent resettlement experiences of refugee groups within New Zealand society.

## **The contexts of New Zealand immigration**

New Zealand has a long history of migration from Maori settlement (over 1,000 years ago) through to the arrival of migrants from increasingly diverse countries throughout Asia, the Middle East and Africa since the 1990s. While processes of globalisation and transnationalism have facilitated greater mobility, nation states are increasingly tightening the regulation of their borders and the flow of peoples. Immigration continues to be a popular subject for discussion within academic, media and political circles, as it touches on key issues of identity, belonging and nationhood. One indicator of the degree of interest in the topic is that between 1994 and 1998, there were over 390 New Zealand publications relating to international migration (Bedford, Spragg and Goodwin, 1998). There has also been significant 'public good' research funded on this theme including the New Settlers Programme (e.g. Trlin, 1998) and 'Strangers in Town' programme (e.g. Migration Research Group, 2006).

This section outlines key components of New Zealand's immigration history. Important trends within NZ immigration policy are considered, followed by discussion of the implications of such shifts. Particular mention is paid to changes in African migration to New Zealand. The place of refugees within NZ immigration policy is outlined followed by consideration of 'transnational Auckland' and how processes of globalisation and transnationalism have shaped the city.

A number of key trends within New Zealand's history of migration and settlement can be identified. One of the first phases of migration to New Zealand was its settlement by Maori 1,000 followed by the establishment of a British colony from the early 1800s (Belich, 1996). Although migration to NZ was dominated by those from the United Kingdom up until the mid 1970s (Ongley and Pearson, 1995), there were a number of different groups of people who arrived in NZ such as Chinese gold miners in the 1860s and 1870s (Ip, 1996). Key events such as the Second World War heralded the arrival of Jewish and Eastern European refugees as well as ex-Servicemen and 'Assisted Migrants' from Europe, most notably immigrants from Holland. Another important immigration flow was that the arrival of Pacific Islanders in the 1970s. This was facilitated by the labour shortages generated by the establishment of manufacturing activities in the 1950s and 1960s (Bedford, Ho and Lidgard, 2000). In the late 1970s and 1980s refugees arrived from the wars in South East Asia, Cambodia

and Vietnam. The Fijian coups were also key events with over 11,000 Fijian citizens being granted permanent residence in New Zealand (Ongley and Pearson, 1995). The most recent migration trend since the mid-1990s is the influx of Asian migrants and international students from countries such as China, Korea, Taiwan, Hong Kong and Malaysia (Bedford et al., 2000).

In terms of policy, one of the key milestones in New Zealand's immigration history was the introduction of a new Immigration Act in 1987. This legislation abolished the source country preference system which had effectively shaped migration policy since the 1840s (Bedford et al., 2000). Under the source country system, migrants from preferred countries such as the United Kingdom, with whom NZ had established political and economic links, were given preference over migrants from other nations. This policy shift resulted in rapid diversification of migration to New Zealand, with Asian migration being one visible change. According to Friesen et al. (2005) between 1986 and 2001, the 10 most important source countries, in terms of the issuing of permanent residence visas and permits, were the United Kingdom, China, Taiwan, South Africa, India, Hong Kong, Samoa, Fiji, South Korea and Malaysia (Friesen et al., 2005:388).

In 1991, a 'points system' was introduced. This system aimed to welcome migrants with professional skills, qualifications and capital. As a result of the introduction of the points system, New Zealand experienced its highest annual net migration gains since the 1870s with substantial increases in the numbers of migrants from North East Asia (Ip and Friesen, 2001; Bedford et al., 2002). While there were migration targets, these were exceeded during the 1990s. It is important to note however, that the United Kingdom and Australia remained important migrant sources, a fact often overlooked in sensationalist media reporting during the time. The 'newness' and visibility of migrants from Asia attracted both political and media attention, and as documented by Ip and Friesen (2001), migrants and refugees have been intermittent targets of xenophobic and racist responses.

Immigration has always generated considerable political attention (Ip and Friesen, 2001; Bedford, 2002). With the policy shifts, there was a perception that NZ was being inundated with migrants. For examples, selected headlines from this period included "Asian property buyers flock to Auckland" (New Zealand Herald, 9 September 1989) and "The Inv-Asian" (Suburban Newspapers, 16 April 1993) (Ip and Friesen, 2001:227). The topic of immigrants was also heavily debated within political discourses during this period most notably by MP Winston Peters, currently (2006) the Minister of Foreign Affairs. From the middle of 2002, Peters employed the rhetoric of 'Asian invasion' claiming that NZ was being flooded with immigrants and asylum seekers and that immigration was out of control (Bedford, 2002). Bedford points out that at the time that Peters was making these claims, the majority of permanent and long term arrivals (51%) were from non-Asian countries including returning New Zealanders and other migrants from the Pacific Islands, Europe, North America and South Africa (Bedford, 2002). There was however an overwhelming proportion of student visas (82%) issued to those of Asian origin (Bedford, 2002).

In order to address these issues, in 1995 the Immigration Act was modified by tightening the qualifying points criteria and imposing stricter English language requirements. As a result of this and other global economic changes (particularly the downturn in the Asian economy), migration decreased sharply.

### *African Migration to NZ*

While Asian migrants have received substantial attention, African migration to NZ has also increased considerably over the last two decades. Between 1991 and 1996 the numbers of African born people living in New Zealand doubled from 10,110 in 1991 to 19,000 in 1996 (Bedford, 2004:362). According to the 2001 census, there were approximately 38,000 people born in Africa living in New Zealand. South Africans comprised nearly 70% of this total. The three next largest population groups were people from Zimbabwe (2889), Somalia (1773), Egypt (1182) and Kenya (1152). These countries (including South Africa) plus the four others with populations numbering between 100-300 (Zambia, Ethiopia, Nigeria and Sudan) accounted for 92% of the total African-born population (Bedford, 2004:369). One important feature of the African-born population in NZ in 2001 was that they were relatively recent arrivals. In 2001, over half had resided in NZ for less than five years. The Office of Ethnic Affairs estimates that 47% of all African people reside in the Auckland region (Office of Ethnic Affairs, 2005).

For much of the 20th century, South African and Zimbabwean migrants have dominated migrant flows to NZ from Africa, comprising approximately 70% of permanent long term arrivals. From the early 1990s however, smaller but not insignificant flows of black African refugees from Somalia, Ethiopia, Eritrea, Sudan and Rwanda occurred due to the intensification of conflict, climatic extremes, famines and political instability. In June 1993, the first group of African quota refugees arrived at the Mangere Refugee Reception centre. Between 1 July 1992 and 30 June 2002, 1596 Somalis, 966 Ethiopians, 120 Eritreans, 140 Sudanese and 37 Rwandan refugees were admitted under the quota programme (Bedford, 2004:364).

Chile (2002) discusses resettlement outcomes for black African refugees. He documents high levels of debt, illiteracy, unemployment and discrimination experienced by black Africans living in New Zealand. Utilising the concept of social exclusion, he describes how many African refugees are prevented from participating fully in the social, economic and political life in New Zealand. He argues that:

*“Refugees are ‘imported’ into a country by the goodwill of the government and people of the country. Shelving them on the fringes of society effectively disqualifies them from social participation and consigns them to the status of underclass. This is the fate of many Black African refugees in New Zealand” (Chile, 2002:359).*

Chile continues by adding:

*“The lack of basic language skills has the effect of economic disenfranchisement and excluding refugees from political participation and engagement in civil society. Rather than integrating into the host community, refugees tend to gravitate towards areas where people from their region or country of origin live. In the majority of cases these are poor, low-income areas. In such situations the refugee community is deprived of basic community structures, cultural environment and the social infrastructure that foster independence and inter-dependence” (Chile, 2002:365).*

While I explore Chile’s ideas more fully in Chapter Six in relation to Somalis living in Auckland, his foregoing comments direct our focus towards the question of the definition and status of refugees within New Zealand immigration policy.

## **Refugees**

Since the Second World War, New Zealand has created a special place for refugees within general immigration policy. According to the estimates of the 2002 World Refugee Survey, there are some 14.9 million refugees and 22 million internally displaced persons in the world (United States Committee for Refugees, 2002). In accordance with the United Nations definition, a refugee is:

*“any person who, owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his/her nationality and is unable, or owing to such fear, is unwilling to avail himself/herself of the protection of that country” (United Nations, 1951).*

Despite the over-arching label ‘refugee’, there are diverse circumstances compelling people to flee their homes and the subsequent ‘refugee experience’. War, famine, and political, religious and ethnic persecution are just a few of the crises that force people to leave their homelands and seek refuge elsewhere. The refugee experience is more often than not associated with trauma and distress with a profound influence on health and wellbeing. Given these experiences, it is understandable that refugees would seek a better life elsewhere.

Since the arrival of nearly 1,000 Polish children and their guardians in 1944, approximately 20,000 refugees and displaced persons have been resettled in New Zealand (Department of Labour, 1994).

As Table 1 depicts, the source countries from which refugee groups have originated has changed over the years in line with international political and economic events and circumstances.

**Table 1 Major Refugee Groups Resettled in New Zealand**

<b>1944</b>	<b>Polish children and their guardians</b>
<b>1949 – 52</b>	<b>Displaced persons from Europe</b>
<b>1956 – 58</b>	<b>Hungarians</b>
<b>1959 – 94</b>	<b>“Handicapped” refugees</b>
<b>1962</b>	<b>Chinese orphans from Hong Kong</b>
<b>1965</b>	<b>Russian Christian “Old Believers” from China</b>
<b>1965 – 70</b>	<b>Chinese refugees from Hong Kong</b>
<b>1967 – 71</b>	<b>Chinese refugees from India</b>
<b>1968 – 71</b>	<b>Czechoslovaks</b>
<b>1972 – 73</b>	<b>Ugandan Asians</b>
<b>1974 – 81</b>	<b>Chileans</b>
<b>1974 – 86</b>	<b>Soviet Jews</b>
<b>1974 – 91</b>	<b>Eastern Europeans – predominantly Polish, Czechoslovak, Hungarian Bulgarian, Romanian, Yugoslav and Soviet refugees</b>
<b>1975 – 94</b>	<b>Indo-Chinese – Vietnamese, Cambodians and Laotians</b>
<b>1979 – 89</b>	<b>Iranian Baha’is</b>
<b>1985 – 94</b>	<b>Assyrian Christians from Iraq</b>
<b>1992 – 94</b>	<b>Somalis</b>
<b>1992 – 94</b>	<b>Bosnians</b>
<b>Smaller numbers of refugees have been accepted from a variety of other countries including Afghanistan, Albania, Bolivia, El Salvador, Ethiopia, Guatemala, Myanmar, Nigeria, Peru, Sri Lanka, Syria and Tunisia</b>	

Source: (Department of Labour, 1994:15)

In 1987, the refugee programme was reviewed and formalised in accordance with NZ being party to the United Nations 1951 Convention and the 1967 Protocol Relating to the Status of Refugees. Internationally, the United Nations High Commission for Refugees (UNHCR) co-ordinates refugee protection and resettlement programmes. According to UNHCR guidelines, member states are also required to admit asylum seekers at their borders and allow them to apply for refugee status, though this is not necessarily granted. New Zealand has one of the highest refugee intakes per capita in the world (Department of Labour, 1994) and is one of the nine of the 185 member states of the United Nations that have a formal refugee quota system (UNHCR, 2002).

The 1987 review of New Zealand's refugee policy resulted in the formation of an annual refugee quota of up to 750 refugees and the establishment of an induction programme for new refugees at the Mangere Refugee Reception Centre. In New Zealand there are three categories of refugees all of which are relevant to the Somali population.

## Quota Refugees

Quota refugees are given New Zealand residency on arrival and subsequently spend a six-week orientation period at the Mangere Refugee Reception Centre (MRRRC). During this time they receive comprehensive medical screening and are introduced to New Zealand life. Once this orientation is complete, quota refugees are placed in the community and are given full access to state-funded income support, education and health services.

New Zealand is unique in that it specifically allocates places in its quota for high-need groups such as women at risk and those with high medical needs. Other countries such as the United States currently refuse entry to refugees with particular medical conditions such as syphilis, leprosy, and HIV (Adams and Assefi, 2002).

The quota of 750 places each year for UNHCR-mandated refugees has been divided into three sub categories.

### Women at Risk

This category is for refugee women, without the customary protection and support of family or community members, who find themselves at risk in their country of refuge. These women are in need of protection from gender-related danger including abduction, sexual abuse and exploitation

### Medical/Disabled

This provides for those refugees with medical, physical or social disabilities which would ordinarily mean that their application for residency would fail to meet the criteria for acceptance by resettlement countries. Applicants must have a medical condition for which being resettled in New Zealand would result in profound improvements in health. Medical conditions must be documented by the UNHCR while the Ministry of Health must confirm prior to acceptance that suitable treatment is available.

### UNCHR priority protection

This applies to refugees who require urgent protection from a life-threatening situation, deportation, a situation that violates human rights, unjust detention or arrest. It may also include refugees who the international community has identified as in need of resettlement.

## Emergency resettlement

These cases are for those for whom a degree of urgency is required and who are given priority over all other refugee cases. Approximately 50 places are available under this category every year. Places are allocated on a case-by-case basis.

## Asylum Seeking Refugees

Approximately 700 asylum seekers apply for refugee status every year (New Zealand Immigration Service, 2004b). Asylum seekers or spontaneous refugees are considered separately from, and in addition to, the UNHCR mandated refugees who are accepted for resettlement in New Zealand. Claimants are usually men under the age of 40 who have left families in their countries of origin.

Asylum seekers either apply for refugee status at the border when they arrive or some time later. Once asylum seekers have had their identity officially verified they are eligible to get a work permit and are therefore entitled to state-funded health, welfare and education services. Unfortunately, some asylum seekers must wait for a considerable period of time until their identity can be verified. This is particularly relevant for those who initially travelled to New Zealand with false documentation. This therefore leaves asylum seekers in the frightening predicament of not being entitled to any official social support for the duration of the time it takes to have their identity confirmed. There are, however, a few non-governmental organisations that are increasingly providing assistance to, and lobbying for, the needs of asylum seekers. Due to the large numbers of applications, there are indications that some applications can take up to two years to be heard (Solomon, 1999). According to Solomon (1999), approximately half of those who apply for refugee status are successful. Those whose application is declined have the right of appeal. Claims for refugee status are confirmed or rejected by NZIS depending on whether their circumstances meet the criteria set out in the United Nations Convention Relating to the Status of Refugees. Those who are successful are then eligible to apply for permanent residence and later, New Zealand citizenship. Those who are unsuccessful have the right of appeal and cannot be deported until their case is heard.

## Family Reunification Refugees

The third category is family reunification which allows families of refugees to come to New Zealand under general immigration provisions that take into account humanitarian issues. The application and the air travel costs are generally met by relatives, who are themselves often struggling with their own resettlement costs and challenges. In some years, the number of family reunification refugees is roughly equivalent to the size of the refugee quota however, the average number is thought to be approximately 600 people per annum (New Zealand Immigration Service, 2004b).

While refugees from each of these three categories are different in terms of their legal status and entitlements, there are many similarities between each of the different groups. For example, there is good evidence that quota refugees, asylum seekers and family reunion refugees have similar health status as all three groups come from similar situations in similar countries (Solomon, 1999; Smith, 2000-2001). (n.b. For simplicity, the phrase 'refugee' will be used to include quota refugees, asylum seekers and family reunion refugees unless each group is explicitly discussed).

### *Refugee resettlement*

Upon arrival in New Zealand, there are a number of established policies and institutions that focus on the needs of refugees. It is important to note however that only quota refugees are generally eligible for these support services. The Refugee and Migrant Service (RMS) is funded by the government to provide resettlement support to quota refugees. In the Government's 2004 budget, the Refugee and Migrant Service received an additional \$62 million dollars to assist with refugee resettlement. After leaving the Mangere Refugee Reception Centre, refugee families are placed in a state-provided house and assisted by volunteer support workers and a social worker for six months during the initial resettlement process. Refugees are helped to negotiate their way through key social structures including, accessing income support, receiving follow-up medical care, enrolling with education providers and utilising transport networks. A number of organisations provide refugee-specific services such as Refugees as Survivors (RAS), which is contracted to provide specialist mental health services which are tailored to the needs of refugees.

In addition, reports and studies initiated by government agencies have considered the issues facing refugees (e.g. Ministry of Education, 2003b; McDermott, 2004). The 'Refugee Voices' project is one of the best examples of this and is the only longitudinal study of refugee resettlement outcomes in New Zealand (New Zealand Immigration Service, 2004b). Researchers interviewed 398 refugees who arrived in New Zealand during the last five years. Numerous issues were identified including difficulties relating to language, housing, income and employment. For instance, an average of 84% of refugees surveyed relied on government welfare assistance with only one-third of respondents participating in the labour force (New Zealand Immigration Service, 2004b). Other reports paint a rather sobering picture of the resettlement challenges faced by refugees. One study demonstrated very high levels of unemployment of up to 85 per cent (Fisk, 2003) and high levels of discrimination against refugees in the labour market (J. R. McKenzie Trust, 2004). Data from the Ministry of Education also points to low education levels amongst refugees. Eighty percent of refugees arriving in New Zealand have less than four years schooling (Ministry of Education, 2003a) while of those in the refugee quota, 40% were not literate in any language and a further 40% had some literacy skills in their first language but not in English (Ministry of Education, 2001).

Government departments are increasingly being required to respond to the needs of refugees and to conduct regular consultation exercises to fulfill such obligations. As a result, a number of refugee profiles have been commissioned by various government sectors that are essentially designed to help to explain and increase government workers' understanding of people from diverse backgrounds (Anstiss, 2001; Bell, 2001; Ministry of Health, 2001). In recent times, consultation exercises have been undertaken in the Somali community by the Ministry of Social Development (MSD), Auckland District Health Board (ADHB), Department of Labour (DOL)/New Zealand Immigration Service (NZIS). A small number of agencies have acted upon the results of such consultation exercises. One example is the Ministry of Education which has created a specialist team and resources to assist schools with responding to the needs of refugee students (Ministry of Education, 2003b). One large project that is currently being undertaken is the creation of the Auckland Settlement Strategy which is part of the wider National Settlement Strategy (New Zealand Immigration Service, 2004a). The aim of this project is to bring together different government agencies and support services and create an integrated and comprehensive plan for migrant and refugee resettlement (Manukau City Council, 2006).

The majority (65%) of refugees settle in Auckland, New Zealand's only metropolitan city (Auckland District Health Board, 2001). My discussion now shifts to outline important content for the understanding of the geographies of everyday life for Somali people living in transnational Auckland.

### *Transnational Auckland*

Much attention has been paid to the experiences of 'world cities' such as New York, London, Tokyo and Paris (e.g. Knox and Taylor, 1995). However, globalisation has also had a profound impact upon smaller urban settlements. As has been discussed, changing migration policies and processes in New Zealand since the late 1980s have resulted in the arrival of people from diverse backgrounds. This is particularly evident in Auckland, New Zealand's largest and most diverse city, which is home to over 1.2 million people (Statistics New Zealand, 2006). This section considers the way in which processes of globalisation have manifested themselves in the local scale. Focusing on place and location is seemingly contradictory given that globalisation and transnationalism emphasise ideas of movement and de-territorialised networks, yet, as has been discussed, while migrants are globally interconnected, they are situated within places which shape and are shaped by the activities of migrants.

At the time of the last census in 2006, Auckland was home to more than one-third of New Zealand's population. While New Zealand's population grew by over 10% between 1991 and 2001, Auckland's population grew by 26.6% (Johnston, Poulsen and Forrest, 2003). Yet this growth has been unevenly distributed. While the number of New Zealand Europeans grew by 4.7%, the number of Maori increased by 22.2%, Pacific Islanders by 37.8% and those of Asian ethnicity by

196% (Johnston et al., 2003). According to Friesen and colleagues, nearly half of Auckland's population growth between 1991 and 1996 was attributable to immigration (Friesen et al., 2000). In 1996 there were 25 different ethnic groups with a population of over 1000 residing in Auckland (Friesen et al., 2000). Yet ethnic groups are not uniformly distributed throughout the city. Within media and popular discourses some areas have (somewhat stereotypically) been associated with certain people groups.

One issue that inevitably arises when discussing the location of different ethnic groups within urban spaces is that of segregation or clustering. In the Auckland setting, using measures such as the Index of Dissimilarity, Friesen et al. (2000) found evidence of ethnic clustering within Auckland, although not of the same scale as documented internationally. In a review of the four main 'ethnic' groups (New Zealand European, Maori, Pacific Island and Asian) Johnston et al. (2003) found that there was no extreme spatial segregation although there was evidence of spatial concentration. While earlier debates about segregation and concentration tended to be framed in wholly negative terms, more nuanced understandings of ethnic concentration have emerged which emphasise that there are multiple explanations of clustering. As Johnston et al. (2003) write:

*"Many, too, have deeply embedded cultural practices that differ substantially from those of their host society – such as religious practices, the nature and role of formal and informal organisations, and language – which are more readily sustained, at least during an initial period of assimilation, by living as part of quasi-separate communities that are spatially as well as socially relatively isolated"* (Johnston et al., 2003:112).

It is important however not to overlook the fact that concentration of minority ethnic groups can further reinforce and exacerbate social, economic and political disadvantage, as the weighty literature on social exclusion testifies.

Despite Auckland's national and regional significance, there are relatively few accounts that analyse the economic, social and political dimensions of Auckland's globalisation experience. In an effort to address this gap Murphy, Friesen and Kearns (1999) argue that changing immigration patterns have resulted in increased transnational linkages on one hand and social polarisation on the other. Using the housing sector as an example, Murphy and colleagues demonstrate how a property boom has resulted in the creation of elite residential landscapes and reinforced social polarisation particularly within the state-provided housing sector (Murphy, Friesen and Kearns, 1999).

In one case-study which explicitly focused on the impact of globalisation and transnationalism within Auckland, derived from the same research project, the authors consider local responses to globalisation using the case study of Indian transnationalism within the suburb of Sandringham. For many years, Sandringham was the epitome of the 'kiwi suburb', however it has been

transformed due to “increasingly complex layering of transnational connections involving movements of people, goods and information” (Friesen et al., 2005:398). Changes in ethnic composition have been mirrored by changes in the built environment, particularly in terms of retail and religious spaces as exemplified by the opening of Halal butcheries, spice and Islamic clothing shops.

A study by Lawrence and Kearns (2005) in the neighbouring suburb of Mt Roskill found evidence of increasing ethnic diversity and local transformations. Analysis of the proportions of ethnic groups within 10 census area units (CAU) between the 1991 and 2001 censuses demonstrated the growing presence of diverse populations (Lawrence, 2003). An important population change in the area between 1991 and 2001 was the reduction in the proportion of New Zealand Europeans and the doubling of numbers of Chinese and Indian populations. There has also been the arrival of refugees and migrants from countries throughout the Middle-East, Africa and Asia.

Of particular interest for this study is the emergence of Somali people as the tenth largest group within the clinic catchment area according to 2001 Census figures. Many Somali who arrived in New Zealand as quota refugees were settled in the area due to the availability of large tracts of publicly-provided housing. With the establishment of various community structures and networks (which will be elaborated upon in Chapter Six), Somalis who have arrived subsequently have also clustered in the area and it has become a highly sought-after area with long waiting lists for state housing.

In 1991 there were no Somalis recorded as residing in the clinic catchment area. However, by 2001, this had grown to 381 (although the actual figure is likely to be much higher) (See Table 2 overleaf). This data highlights the recency of Somali settlement in Auckland and also the degree to which the Auckland community has clustered within a particular locality. The table also highlights that Mt Roskill is increasingly being populated by a diverse range of population groups. While the numbers of individual groups are small compared to other major ethnic groups in the area, they demonstrate that the area has experienced a profound change in terms of ethnic composition.

**Table 2 Growth in numbers of selected ethnic groups between the 1991, 1996 and 2001 censuses**

<b>Birthplace</b>	<b>1991</b>	<b>1996</b>	<b>2001</b>
Afghanistan	0	21	158
Ethiopia	0	21	159
Iran	60	153	159
Iraq	0	51	66
Kuwait	0	9	42
Somalia	0	129	381
Sudan	0	0	54

Source: (Lawrence, 2003)

In a similar vein to the findings of Friesen et al. (2005), the preliminary investigation by Lawrence (2003) revealed how the built environment has also been transformed through the arrival of people from diverse backgrounds. Particularly evident were the creation of new religious and retail spaces.

## **Summary**

As this section has demonstrated, global shifts have resulted in an increasing inter-connectedness between people and places. This has led to the emergence of new patterns of migration and settlement which has a number of implications in terms of TB. Conceptual frameworks such as transnationalism and diaspora offer great potential in considering the migration and resettlement experiences of refugee groups such as Somalis living in Auckland as they allow us to contextualise daily lived experiences within wider structural forces. As shall be more fully discussed in Chapter Six, Somali refugees living in Auckland have developed strong networks and connections not only with each other but also with fellow diasporic nationals residing abroad.

Although New Zealand is spatially isolated from the rest of the world, global economic, political, social and cultural shifts have had a profound influence on the nation at a variety of scales (national, regional and local). New Zealand's policy towards migrants and refugees is just one example of institutional responses to these global shifts and the changing face of the nation. These national-level policies have also influenced the 'local experience' of global change as highlighted in the discussion pertaining to Auckland. Yet the inherent unevenness of globalisation is especially evident when considering the experiences of various neighbourhoods within Auckland City. Mt Roskill is one such suburb with a particularly unique history and demographic composition and is one of Auckland's most ethnically diverse neighbourhoods.

Looking ahead, Chapter Three builds on the themes raised during this chapter by considering the characteristics and development of the Somali diaspora. In order to understand more fully the reasons for the establishment of the Somali diaspora in the first place, I profile the social, economic and historical contexts that have shaped Somalia's place in the world today. Understanding the background from which Somalis originate help understand subsequent migration and resettlement experiences and the impact such processes have had upon identity, culture, health and illness beliefs and experiences in the Auckland setting.

## Chapter 3: Somalia and Somalis

*“The Somali are widely dispersed around the world, they are generally poorly integrated and maintain an uneasy relationship with their host societies, and they are a community with their minds turned towards their homeland”*  
(De Montclos, 2003:38)

This section provides an overview of the socio-political context that was the precursor for the diaspora that resulted in the settlement of Somalis in New Zealand. In order to understand the everyday geographies, sense of place and resettlement experiences of Auckland Somalis (Aim Two), it is vital to consider the context from which they originate. It is impossible to analyse the settlement and health experiences of a refugee community in isolation from their wider life history.

Somalia came to the world's attention in 1992 with the circulation of shocking images of famine and violence from the protracted civil war. Peace-keeping forces were sent to Somalia in response to the crisis but withdrew after the killing of 18 US soldiers in Mogadishu. Not only was there a military withdrawal, but Somalia itself slipped off the international radar and was left alone to resolve deeply-entrenched conflict and to rebuild a shattered nation. The Somali nation today is in a state of limbo. There is no central government and political instability remains in many parts of the country. As a consequence of civil war, millions of Somalis fled to other parts of Somalia or neighbouring countries such as Kenya and Ethiopia. Subsequent migration of these refugees to other parts of the world has added to the well-established Somali diaspora that had its origins in the mid-twentieth century labour migration to Britain and the States.

Unlike the UK and Italy, with whom Somalia had long-established colonial links, Somali migration to New Zealand is a very recent phenomenon and occurred solely due to New Zealand's humanitarian commitment to refugees as outlined in Chapter Two. The first sizeable intake of Somali refugees to New Zealand occurred in 1992 and at the time I conducted fieldwork (2003-5), most Somalis had been living in New Zealand for less than 10 years. Most Somalis live in New Zealand's main urban areas (Auckland, Wellington, Christchurch and Hamilton) of which the Auckland Somali community is the largest. Due to the recency of Somali migration, there are very few studies that have considered their resettlement experiences in New Zealand, let alone in Auckland. There is also a dearth in official data held by government departments due to the tendency to group smaller population groups within the category of 'other' and to collect or report only specific ethnicity data of 'main' ethnic groups.

Literature on Somalia can be categorised into six main strands. Firstly, works considering early Somali and colonial history (Lewis, 1961; 1965; Cassanelli, 1982) and descriptive “country” studies of Somalia touch upon a broad range of topics including environment, economy, history and social structure (Kaplan et al., 1977; Nelson, 1982; Metz, 1993; Drysdale, 2000; Abdullahi, 2001). The civil war also has generated a number of articles considering the reasons behind, and possible means of resolving, conflict in Somalia (Drysdale, 1964; Ahmed and Green, 1999; Kapteijns, 2001; Spears, 2003). There are also a number of popular press journalistic accounts of the war that focused in particular on the 1992 killing of US soldiers in Mogadishu (Bowden, 1999; Peterson, 2000).

The mass flows of Somali refugees throughout the world have reinvigorated academic inquiry on Somali migration and diaspora (Farah, 2000; Griffiths, 2002; Gundel, 2002). There have been a number of accounts of the experiences of Somali immigrants in resettlement countries including Canada (Opoku-Dapaah, 1994; Berns McGown, 1999; Abdulle, 2000), the United Kingdom (El-Solh, 1991; 1993; Griffiths, 1997; 2002), Australia (McMichael, 2002; McMichael and Manderson, 2004), New Zealand (Jenkinson, 1999; Humpage and Fleras, 2000; Guerin, Abdi and Guerin, 2003b; Lilley, 2004) and Denmark (Nielsen, 2004). Research tends to focus exclusively on Western nations despite the presence of large Somali populations in the Middle East (Budiani, 2005; Al-Sharmani, 2006). Researchers in Canada and Britain in particular have published extensively on Somali resettlement, perhaps reflecting the size of the communities that have been established there.

Studies of diasporic Somalis tend to focus on the challenges experienced in resettling, particularly in terms of education (Alitolppa-Niitamo, 2002), employment (Opoku-Dapaah, 1994), housing (Murdie, 2002) and, albeit to a lesser degree, health (Adair, Nwaneri and Barnes, 1999). Key shifts in Somali social life in terms of religion (Tilikainen, 2003), gender relations (Al-Sharmani, 2006) and clanship (Griffiths, 1997) have also been documented. Considerable attention has been paid to the special issues facing Somali women during the process of resettling (Buckland, 1997; Israelite, 1999; Jenkinson, 1999; Mohamed, 1999; Halane, 2004; McMichael and Manderson, 2004), especially the increasing incidence of veiling (Berns McGown, 1999; Tilikainen, 2003) and the controversy surrounding female genital mutilation (FGM) (Shorten, 1995; Denholm and Jama, 1997; Knight et al., 1999; Allotey, Manderson and Grover, 2001; Vissandjee et al., 2003; Campbell, 2004; Morison et al., 2004; Johansen, 2006). Before delving into the characteristics and experiences of the Somali diaspora, I provide an overview of the historical, social, political and economic dimensions of Somalia and the 1992 Civil War that resulted in the displacement of millions of Somalis.

## Background

Somalia is located on the easternmost edge of the Horn of Africa, as depicted below in Figure 1.

Figure 1 Map of Somalia



(Source: [www.maps.com](http://www.maps.com))

Somalia is approximately 700,000 square kilometres in area, most of which is either arid savanna grassland or semi-desert. In the north there are mountain ranges and hills, such as the Golis mountains while the two main rivers, the Shabelle and Jubba are situated in the south (Abdulle, 2000). Somalia shares its borders with Ethiopia in the west, Kenya in the south and Djibouti in the North. Somalia has a number of large urban centres. Mogadishu in the south is the capital with over 2,000,000 residents. In total, the Somali population is estimated as approximately nine million although figures vary considerably between sources (Fishpool, 2001).

Somalia is largely a nomadic, pastoral nation with over two-thirds of the population raising livestock such as camels, goats, cattle and sheep for a living (Abdulle, 2000). The camel is at the heart of Somali pastoralism due to its hardy nature and usefulness in the harsh climatic environment. The mainstay of Somalia's economy is agriculture, employing over 65% of the population and contributing 65% of GDP (Fishpool, 2001). The main exports are livestock and bananas of which

Saudi Arabia receives 49%, United Arab Emirates 25% and Yemen 18%. Agricultural outputs are particularly vulnerable to extreme climatic events such as drought and flooding which frequently produce famine. Somalia is therefore highly dependent on food aid. The protracted civil war virtually destroyed Somalia's economy which has been broken down by warlords into localised areas. Northern Somalia (commonly referred to as Somaliland) has, however, experienced a positive up-turn in the economy due to greater stability and peace (Ahmed, 2000), yet is unable to access IMF or World Bank funding due to the lack of recognition of its statehood (Fishpool, 2001).

## *History*

### Pre colonisation

Considerable doubt and controversy exists over the early origins and history of Somalia and its peoples, in part due to the absence of a formal writing system, this was not instituted until 1973. According to Abdulle, there are two main schools of thought about the origins of the Somali people (Abdulle, 2000). Firstly, there is a view that the Somalis originate from Arab immigrants who migrated to the Horn of Africa. Proof of this theory is based on the fact that the Somalis have lighter skin than other groups in the Horn. The second theory is based on linguistic and archaeological evidence which suggests that the Somalis originated from southern Ethiopia; given that the Somali language is part of the Cushitic group of languages including Ethiopian variants, Oromo, Saho and Afar. Although there are different theories, it is generally believed that the Somalis occupied much of the Horn of Africa by 500AD. Somalia, along with Ethiopia and Djibouti, had trading relationships with North Africa and Arab nations thus facilitating the spread of Christianity into parts of Ethiopia and Islam into Somalia via Arab merchants. Until the beginning of the sixteenth century, Somali was part of the Arab-controlled Indian Ocean trading network. This situation altered however when a passage to India via the Cape of Good Hope was discovered. In the nineteenth century, Somalia's traditional borders were narrowed as Ethiopian ruler Menelik I seized the Ogaden desert, an issue that continues to be highly contentious (Gundel, 2002).

### Colonisation

According to scholars, Somalia is a classic example of the 'scramble for empire' by colonial powers during the nineteenth century (Hyndman, 1997). Between 1885 and 1898, Somalia was divided into British, Italian and French zones. Britain initially colonised northern Somalia for strategic military reasons and to provide supplies for the Aden garrison in Yemen. The French claimed Djibouti for similar reasons as the British and tried to transplant French culture and way of life. A port and railroad was developed in the port city also named Djibouti which has since become a key trading point. In 1977, French Somaliland became the Republic of Djibouti. In the 1880s, Italy settled southern Somalia with assistance from the British who preferred Italian rule to French in the south. Commentators suggest that the Italians took their Somali colony more seriously than their

British and French counterparts, establishing Italian political, economic and social institutions in preparation for the arrival of Italians (Samatar, 1991). Somalia was seen as a way to relieve population pressure in Italy and as an African getaway in the sun.

## Post colonisation

Due to both internal agitation and external forces, Somalia gained independence in 1960. The post-independence period saw enormous change internally within Somalia and changing external allegiances. The colonial partition of Somalia shaped the future path of the nation as it sought to undo colonial divisions. In 1960, northern British Somaliland joined with the southern Italian controlled United Nations Trust Territory of Somalia. The reunification of these two territories resulted in the formation of the independent Somali republic. This state however, excluded the large number of Somalis residing in the Ogaden region which had been seized by Ethiopia and the Northern Frontier District (NFD) in Kenya (an area given to Kenya by British colonial authorities). The new republic was intended to operate as a Western democratic system, however this system was ill-suited to the clan-based politics and became corrupt (Gundel, 2002). Amidst growing frustration and unhappiness, in 1969 General Mohamed Siyad Barre initiated a coup that flung the newly-formed republic into chaos. Barre's military dictatorship was influenced by socialism and supported by the Soviet Union. Between 1969 and 1989 Somali received most of its aid from the Soviet Union and other 'Eastern Bloc' states. In the first half of the 1970s, Barre improved Somalia's situation by launching large-scale literacy and development projects. Barre vowed to remove clannism, yet cleverly manipulated inter-clan rivalries and gave his own clan preferential access to the state. Barre also attempted to unite Somali people with an attack on the Ogaden region of Ethiopia in 1977. The Soviet Union however, supported Ethiopia and Somalia suffered defeat. Gundel (2002) argues that the defeat of Somalia marked the onset of a downward economic and political spiral, characterised by marginalisation and repression.

After the Ogaden war, the United States took over the Soviet Union's role as Somalia's patron and pumped large amounts of money and resources into the area. Wide-spread corruption manipulated the use of foreign aid, undermining the economy. The deteriorating situation contributed to the beginning of full-scale war in 1988 as the north-western Isaaq clans and Somali National Movement (SNM), both of which were persecuted by Barre, attacked government forces in Hargeisa and Burco. In response, the government destroyed Hargeisa, with the loss of 50,000 lives, producing a large refugee flow from the north (Gundel, 2002). Barre came under growing international scrutiny for human rights abuses (Sheikh, 2000). In January 1991, another guerrilla group, the United Somali Congress (USC) (affiliated with Hawiye clans) overthrew Barre in Mogadishu while the SNM attacked the north-west culminating in the declaration of the independent republic of Somaliland in May 1991 (Gundel, 2002). Violence and looting in the capital almost destroyed the city resulting in hundreds of thousands of Somalis fleeing to their traditional clan-controlled lands.

The first refugee camp to accommodate Somalis fleeing from the conflict was erected at Liboi on the Kenyan border. The situation became even more desperate with the onset of famine in 1991. The 1991 – 1992 civil war and famine produced a devastating loss of life of between 240,000 – 280,000 Somalis and further entrenched internal clan divisions as clans divided into warring factions (Gundel, 2002). In 1992, nearly 75% of children under five died from malnutrition related to the war as famine became widespread (Kalipeni and Oppong, 1998). By the end of 1992, nearly 500,000 people were living in 13 refugee camps in Kenya and approximately two million people had been uprooted due to the conflict (UNHCR, 2003b). The United Nations intervened in the face of a humanitarian disaster providing much-needed aid. In 1992, Operation Restore Hope was launched by the UN at an annual cost of \$1.5 billion, representing the most costly humanitarian aid programme ever carried out (Ahmed and Green, 1999). However, the UN and United States forces withdrew in 1995 after the earlier killing of Pakistani peacekeepers and the much-publicised battle between US troops and a local Mogadishu warlord, General Aideed, which resulted in the killing of 18 US soldiers and hundreds of Somalis. This conflict was the inspiration for the book and movie titled *Black Hawk Down* (Bowden, 1999). Despite the efforts of the United Nations and other international organisations to broker peace deals, fighting still persists within Somalia. Today Somalia continues to operate without a national government; in part due to the highly fragmented nature of society. Localised political structures have emerged, with a mix of local identities, clan authorities and Islamic courts.

### *Somalia and its peoples*

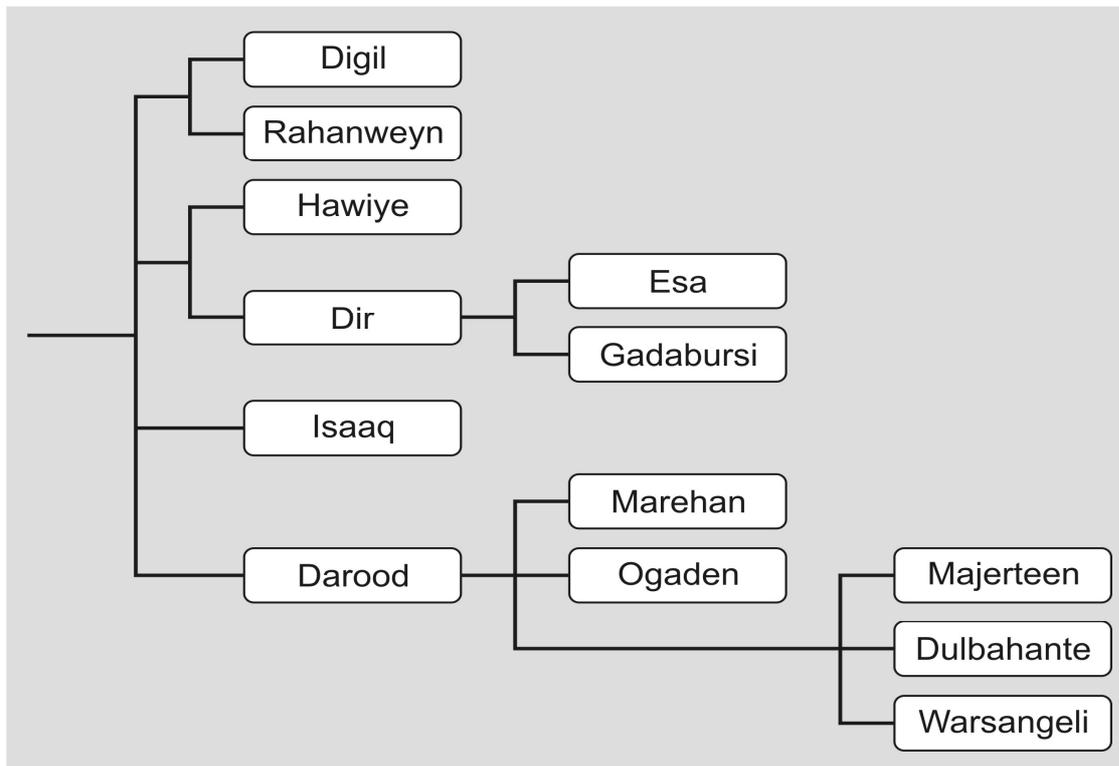
Somalia is a patriarchal society rooted in Islam. According to tradition that is still upheld today, most Somalis descend from a common ancestor, Samaale. It is estimated that around 80% of the population belong to the Samaale group in the north while 20% descend from Saab in the south. Even those who do not descend from Samaale still identify themselves as Somalis, thus accepting, in what Samatar (1991) calls “a symbolic sense” the place of Samaale as the forbearer of the Somali people. Interestingly, a feature commonly cited throughout the literature is the uniqueness of Somalia’s population composition in that, unlike other African nations, Somalia is thought to be homogenous in terms of ethnicity, culture and language (Abdulle, 2000). Yet a growing number of commentators assert that this representation fails to acknowledge the relatively large numbers of minority groups including Bantu, Bajuni and Baravani people and the large degree of cultural, linguistic and social variation between different areas in Somalia (Mukhtar, 1996; Ahmed and Green, 1999; Gundel, 2002).

The basis of Somali social structure is clan identity through patrilineal descent: a source of unity and division (Lewis, 1961). According to Lewis, “Children learn their ancestors’ names by heart back to twenty generations or more. A Somali does not ask another where he is from but whom he is from. Strangers who meet recite their genealogies until they reach a mutual ancestor - the more

closely they are related, the more readily they unite transiently against others” (Lewis, 1994:89). While clans are widely acknowledged as the foundation of Somali society, debates rage about whether clans are the dominant social structure or not (Luling, 1997; Lewis, 1998; Ahmed and Green, 1999) and the extent to which they caused the civil war (Besteman, 1996; Webersik, 2004).

There are six main clans in Somalia originating from mythical ancestors as depicted in Figure 2 below. Darood is the largest clan with over a million people who are mainly agro-pastoralists. Hawiye is the second largest clan occupying southern-central Somalia including the city of Mogadishu. The Isaaq clan predominates in northern Somalia and was the group persecuted by Siad Barre. The three smaller clans are Dir, Digil and Rahanweyn and are considered by other clan groups to be less noble due to their engagement with agriculture and inter-marriage with Bantu and other Africans who had formerly been slaves (Berns McGown, 1999; Kusow, 2006).

**Figure 2. Main Somali Clans**



(After Lewis, 2001:11)

Clans are also separated into sub-clans and ‘dia-paying’ groups. According to Ahmed and Green (1999), the dia-paying group is a collection of families who have an informal contractual agreement to help one another during hardship and also to provide compensation for wrongdoing committed by their members and in turn, receive recompense for acts against their own members. Somalis are renowned for their strong social networks and sense of familial responsibilities (Horst, 2001).

This is in contrast with Lewis' (1961) characterization of Somalis as highly individualised and independent people, answerable to no-one. In Horst's study of Somali social networks, she found that these networks are extremely strong as evidenced by the informal communication and banking networks that function well today (Horst, 2001). An example of this strong sense of connectedness amongst "urban" refugees is described by Horst, "As one of my informants stated, a Somali will not miss relatives as long as he is in Ethiopia, Djibouti or Kenya. If a problem emerges in one location, people can immediately shift to another where they relatives living" (Horst, 2002:243).

Somalia has a long history of vibrant oral traditions and is referred to by some as "a nation of poets whose poetic heritage is intimately connected with people's daily lives" (Samatar, 1991:14). Oral poetry are central to Somali life (Andrzejewski and Lewis, 1964; Doob and Hurreh, 1970-71) and serves many purposes such as regaling genealogies, preserving history and commenting on current events (AMNI, 2002). Poetic combat has also featured predominantly throughout Somali history.

One of the first accounts of Somali poetry is from British explorer Richard Burton in the 1850s who wrote:

*"The country teems with 'poets'...Every man has his recognized position in literature as accurately defined as though he had been reviewed in a century of magazines – the fine ear of this people causing them to take the greatest pleasure in harmonious sounds and poetic expressions, whereas a false quantity of or prosaic phrase excites their violent indignation...Every chief in the country must have a panegyric to be sung by his clan, and the great patronize light literature by keeping a poet" (Burton, 1856 cited in Samatar, 1991:14)*

Building on this poetic heritage, acclaimed novelist Nuruddin Farah (1970; 1980; 1998) has published numerous award winning books. He has also recently written about his own experience being part of the Somali diaspora (Farah, 2000).

With a strong linguistic tradition, many older Somalis are fluent in languages including Arabic, English, Italian and French. This is in large part due to Somalia's close affinity with Islam and the legacy of colonisation when schools were conducted in the language of the coloniser (Lewis, 1996). With the declaration of Somali independence in 1960, schools reverted to teaching Somali. However many older generations are still conversant in other languages.

Undoubtedly the dominant feature of Somali society today is that of Islam. Over 99% of all Somalis are Muslim with the remainder comprising a small number of Anglican and Catholics. Islam has five pillars: professing the faith, praying five times every day, observing and fasting during *Ramadan*, giving to the poor and making a pilgrimage to Mecca. *Ramadan* is a key component of

Islamic life. During the 30 days of *Ramadan* people pray, fast and refrain from immoral behaviour. People are only able to drink and eat before sunrise and after the sun sets. *Id al-Fitr* is a holiday that marks the end of *Ramadan*. This celebration involves large gatherings of family and friends and children receive gifts and new clothes. Another important milestone for Muslims is *Id Arafah* which is when followers make pilgrimages to Saudi Arabia. Muslims also abstain from alcohol and pork and will only eat *Halal* meat that is slaughtered according to Islamic regulations.

Samatar (1991) suggests mass Islamization of the Somalis occurred between the 11<sup>th</sup> and 13<sup>th</sup> centuries. The adoption of Islam has infused every aspect of Somali life; it provides a belief system, social structure, way of life and structure for government (Lewis, 1996). Prior to the arrival of Islam, Somalis followed a belief system that included good and evil spirits, reverence of ancestors that included various ceremonies and offerings (AMNI, 2002). Elements of this still remain in Somali culture today.

The practice of Islam was, however, adapted within the Somali setting. Somali women did not typically wear the same sort of veils as other Muslim women and participated within the agricultural workforce alongside men rather than being confined within the home (Samatar, 1991). Prior to the Civil War, many Somalis were Muslim in name only and not strict adherents to the religion. There is evidence however, that since migrating overseas, Somali women have become more religiously conservative and devout, marked by an increase in veiling and censorship of women's behaviour (Ahmed, 1999; Berns McGown, 1999; Madjar and Humpage, 2000; Tilikainen, 2003).

Somali social customs, traditions and gender roles are largely based on Islam. Under Islamic custom, those who can afford to may have up to four wives. However not all wealthy men choose to do so. In urban areas, a man will provide separate homes for his wives however in rural areas, multiple wives tend to live in the same household (Lewis, 1996). Marriages are typically arranged although some are created through personal choice. There are conflicting accounts about the prevalence of divorce (Ahmed, 1995; Mohamed, 2004).

Much attention has been paid to Somali gender relations both historically (Ahmed, 1995; Kapteijns, 1995) and in recent times (Ahmed, 1999; Al-Sharmani, 2006). These debates are largely in response to the feminist movement and heightening sensitivity to Islamic practices and beliefs. Traditionally, there were strictly prescribed gender roles with men serving as the bread-winner while women were in charge of caring for children and domestic affairs within the household. In the late 20<sup>th</sup> century, urban Somali women were receiving higher education and obtaining jobs. This was only possible due to the tradition of living with extended families where female relatives took over the responsibility of caring for children and the household.

## *Somalia today*

Despite ongoing hardship and conflict in Somalia, in many ways it has slipped off the international radar. While there are numerous accounts of Somalia diasporic communities being published in recent times, there are far fewer accounts of the situation of Somalis living in Somalia. This situation probably reflects the 'politics of publishing' whereby academics in developed countries (which tend to be the same countries where refugees are resettled) have greater access and ability to undertake and publish research.

This sense of invisibility is evident in the dearth of data on Somalia's social, economic and political situation (Gundel, 2002; UNDP, 2002). According to a report published by the UNDP, there has been limited statistical data on Somali for over 15 years (UNDP, 2002). For example, there is very little information about Somalia in the rankings and statistics of the United Nations Human Development Report, World Development Report published by the World Bank and the UNFPA State of World Population report (UNDP, 2005; UNFPA, 2006; World Bank, 2006). Somalia is included in a comparison of basic indicators for "other economies" and only contains limited variables, summarised overleaf in Table 3.

In order to overcome this lack of data, since 1995 the UNDP supported a data collection programme in the form of a household survey of 3600 households. The survey conducted in 2001 and 2002 estimated population size at 6.8 million of which one third are located in urban areas (UNDP, 2002). High fertility and mortality rates were documented. Of particular interest, the report surveyed literacy and education rates, a characteristic excluded from the indicators provided by the World Bank and UNFPA reports. Adult literacy rates varied from 34.9% in urban areas to as low as 6.7% for females in rural areas. As expected in a population who has experienced war, there are an increasing number of widows and female headed households.

Another UNDP report on the state of Somalia's level of development further emphasises the struggles Somalia faces (UNDP, 2001). The continuation of violence, presence of climatic extremes and shortages of food has had a great toll on the wellbeing of Somalis. According to the report, chronic malnutrition persists in southern Somalia along with an increase in infant mortality. The economy remains in recession and the education system is very limited with one of the lowest education enrolment rates in the world (UNDP, 2001).

**Table 3 Selected indicators for Somalia**

	Human Development Report 2005 (UNDP)	World Development Report 2006 (World Bank)	State of World Population 2006 (UNFPA)
Population	8 million	9.9 million	8.5 million
Life expectancy	46.2	48	46.8-49.8
Literacy			
Under 5 mortality (per 1,000 live births)	225		117
Total fertility rate (per woman)	6.4		
Undernourished people (% of total population)			
Education ratio (combined primary, secondary, tertiary gross enrolment rate)			
Adults living with HIV/AIDS (% age 15-49)			0.7-1.0%
Average annual population growth (%)		3.3	3.1
Density people per square km		16	

Source: Data compiled from (UNDP, 2005; UNFPA, 2006; World Bank, 2006)

Somalia's future remains unclear. In August 2000, a peace conference was held in Djibouti in an effort to restore order and government in war-torn Somalia. A transitional national government was formed, though some suggest this has failed to overcome deeply seated clan politics (UNDP, 2001; Gundel, 2002). North western Somaliland has enjoyed greater stability and order than the south and has an elected government, government institutions and currency, though it is not recognised as an independent state by the international community (Fishpool, 2001). This stability in the North has resulted in the return of hundreds of thousands of refugees from neighbouring countries. By the end of 2001, UNHCR assisted 176,000 people to return to Somaliland (UNHCR Somalia, 2003). In a 2001 referendum, the majority of Somalis living in northern Somalia voted in favour of breaking away from southern Somalia and forming an independent state although there are opponents to this quest for independence and self-determination. In October 2002, warring factions signed a ceasefire in Kenya in the quest to establish a sound government in the rest of Somalia however violence and unrest continues (United Nations Security Council, 2003). The

killing of humanitarian and NGO workers threatens the existence of the few organisations who remained in Somalia following the withdrawal of UN peace-keeping forces (UNHCR, 2000; Temple, 2003).

Somalia continues to suffer from ongoing conflict and climatic extremes. In 2001, the United Nations Food and Agriculture Organisation (FAO) estimated that 800,000 Somalis were at risk of serious food shortages due to drought and lower earnings. In 2001, a UNDP report on Somalia noted that Somali's Human Development Index (HDI) score of 0.284 puts it near the bottom of world rankings on development (UNDP, 2001:37). Somalia's problems were further compounded by the closure of remittance agency *Barakaat* who had been suspected of channeling money to terrorist networks (Horst and Van Hear, 2002). Commentators have demonstrated how remittances are a vital life-link for a large proportion of Somalis. Somalia's uneasy relationship with the United States has been further strained since the aftermath of the September 11 attacks on the World Trade Centre. Somalia has been linked with terrorist networks and potentially being sympathetic to the cause of Osama bin Laden.

Somalia has a long and rich history that in recent centuries has been characterised by increasing violence and conflict. Ongoing disputes over borders inflamed by colonial partitions and gifting of Somali lands to neighbouring Kenya and Ethiopia, puts Somalia on a collision course with the prospect of further conflict in the future as it seeks to reclaim its territories. Somalia faces considerable challenges ahead, particularly as it is now alone and without substantive aid and support from developed countries since the 1992 Mogadishu massacre – a turning point both for Somalia and US foreign policy in Africa.

This review has provided an overview of the history, social structure and contemporary situation of Somalia. It is important to understand these aspects of Somali life as they have a profound influence on the characteristics of the Somali diaspora that resulted from the emergence of Civil War in 1992.

# The Somali Diaspora

## *Introduction*

While many people think of the Somali diaspora as comprising solely of refugees, migration and movement has long been at the heart of Somali culture and identity. For many years, most Somalis were nomadic pastoralists whose livelihood depended on moving in order to adapt to climatic cycles and to search for water and green pastures.

With time however, the reasons and characteristics of Somali movement have altered in response to shifts within Somali social and economic organisation. The outbreak of civil war in 1988 produced significant migratory flows of refugees within Somalia and also to neighbouring countries. Although impossible to accurately pin-point, some estimates number the Somali diaspora at around one million. This means that, “the Somali ‘nation’ is no longer confined within territorial borders, but has been globalised, and the diaspora links Somalia into global economic networks” (Gundel, 2002:275).

This section describes key phases within Somali migration history before moving on to consider recent accounts of the Somali diaspora. Key characteristics of the Somali diaspora are discussed including the literature outlining resettlement outcomes.

## *Diaspora and resettlement*

Gundel (2002) identifies four main phases of Somali migratory movement which have contributed to the Somali diaspora. The first occurred during the period of British colonisation when Somali men who worked in the merchant navy settled in ports such as Cardiff and London. Members of the north-western Isaaq clan also migrated post-independence in 1960. The second wave of migration occurred in the 1970s when Somalis migrated to Arab countries in order to work on oilfields. It is estimated that by 1987, the number of migrant workers to Gulf states were around 375,000 with a large number originating from the north-western Isaaq clan (Gundel, 2002:264; Horst and Van Hear, 2002). The third migration wave occurred during the Ogaden war when Somalia attacked Ethiopia. As a result of the conflict, large numbers of Somalis living in the Ogaden region returned to Somalia, with one commentator suggesting they constituted between 20-40 percent of the Somali population (Gundel, 2002:264). Before the civil war, Somalia was home to one of the largest refugee populations in Africa. This led to tension as these refugees were considered as non-residents and marginalised within Somali society.

The onset of conflict in 1988 prompted the fourth major wave of migration with approximately 600,000 people fleeing Somalia for Ethiopia. The initial out-migration occurred when Hargeisa was

bombed in 1988, while in 1991 more than one million Somalis fled the conflict in southern Somalia. The UNDP Somalia suggested that in 1992, there were an estimated 636,000 visibly displaced Somalis in camps although this is a conservative estimate as many others had fled to other parts of Somalia (Gundel, 2002:264). Gundel notes that since 1992 there have been smaller scale displacements, notably in 1997 and 1998 when flooding displaced people from central and southern Somalia. In 2001, fighting in the Gedo region displaced people into Kenya. Despite the reduction in refugee flows, large numbers of Somali refugees remain in camps in neighbouring Kenya, Ethiopia and Djibouti. It is important to note however that the majority of Somali refugees were 'internally displaced persons' – people who have relocated away from the conflict to other parts of Somalia. The next largest group of refugees was those who fled to neighbouring countries such as Kenya and Ethiopia while only a small proportion of Somali refugees were able to be resettled overseas. This is in keeping with UNHCR figures which suggest that only one percent of the world's refugees are resettled in another country (UNHCR, 2002).

The distribution of people within each of these categories of refugees is not uniform. When trouble arose, the most affluent and highly-educated were the first to flee as they had the resources to seek safe-haven in western countries. These western countries tended to be ones with whom Somalia had historical relationships with such as colonial links with Italy, France and the United Kingdom and labour migrant destinations in the Gulf. As a result, these countries have well-established Somali communities (Gundel, 2002). Subsequent refugee flows included the full spectrum of social classes as the UNHCR began resettling refugees in recipient countries with no previously established Somali community such as Holland, Sweden, Denmark, Australia and New Zealand (Koser, 2003). The difference with these later refugee flows was that they were reliant on the UNHCR for assistance and were not able to choose where they were sent.

With the worldwide tightening of asylum processes in the early 1990s, Somalis have explored different ways to obtain asylum. With ever-increasing refusal rates for asylum, Somalis have employed other means including moving from country to country to avoid deportation and entering through alternative borders such as accessing European countries via Italy. According to de Montclos, nearly 90% of recent Somalis arriving in Europe have been assisted through smuggling networks (De Montclos, 2003:47). As a result, both asylum seekers, and those who have been assisted by smugglers, live with the risk of being found out and ultimately deported. This insecurity has contributed to poor settlement outcomes for some Somalis as will be discussed later.

One of the few attempts to quantify the extent of the global Somali diaspora is found in the work of Marc-Antoine Perouse de Montclos who describes the characteristics and patterns of the Somali diaspora throughout the world (De Montclos, 2003). Table 4 overleaf summarises his estimates of community size and remittance flows of Somali communities. De Montclos notes that many of these figures are very rough approximations due to the difficulties in obtaining accurate data. Population figures are based on official estimates which significantly under-represent true

population numbers. For example, the number of Somalis in Toronto according to the 2001 Census was 17,380 although other estimates range between 40,000 – 100,000 (Israelite et al., 1999; Simich et al., 2003).

**Table 4 Estimated size and remittance flows of diasporic Somali populations throughout the world**

<b>Country</b>	<b>Somali population size</b>	<b>Annual remittance flows \$US (millions)</b>
Sweden	12,000	24
Finland	5,000	6
Norway	4,000	4.8
Denmark	14,000	16.8
The Netherlands	25,000	10.4
Britain	20,000	10.8
Italy	20,000	10
Germany	8,400	4.7
Switzerland	5,400	3
Canada	30,000	22.8
United States	25,000	N/A
Australia	2,000	1.2
Saudi Arabia	20,000	12
United Arab Emirates	25,000	15

After De Montclos (2003:40-43)

One of the features of Somali settlement in the diaspora is that there is a strong urban focus. This is in part because early Somali migrants were city-dwellers themselves, but there has also been an overall trend to agglomerate with pre-existing Somali communities established in main urban areas. In 1991, 91% of Somalis living in Australia lived in Sydney, Canberra or Melbourne. In Canada two thirds of Somalis live in Toronto while one quarter live in Ottawa (De Montclos, 2003).

Somali resettlement is also strongly patterned between and within countries according to clan identities. Early refugee flows in the 1990s were Darood clans fleeing Hawiye opposition. Members of the Majerteen sub-clan settled in the Netherlands while members of the overthrown dictator’s clan (Marehan) were resettled in Sweden. Resettlement within cities is also strongly patterned. In London, clans are highly segregated with Hawiye settling in Streatham south London, Isaaq in Tower Hamlets and Newham and Darood in Kilburn, Paddington and Acton (Griffiths, 2002:104).

These clan identities are important as they have resulted in the importation of tension based on the politics of their homeland. De Montclos notes that community associations tend to be dominated by various clan factions e.g. the Anglo-Somali Society is considered an Isaaq lobby group while the Somali Community Association is Darood dominated. De Montclos notes that the Somali diaspora have not developed a unified political force and that Somali support organisations tend to be focused around short term settlement needs. Hopkins' (2006) research on Somali community organisations in London and Toronto also demonstrated a high degree of inter-clan conflict, although in Toronto, different Somali associations are increasingly co-operating with one another in order to attract the necessary resources and political visibility to sustain operations.

In Griffiths' (1997) work on Somalis living in Tower Hamlets, London, he points out how clan identities remain the foundation of Somali society. However these identities have come to be modified and reinterpreted within the new context of England. In particular, he notes how there is a gap in the perceptions of clan identities between the generations with younger generations starting to question the value and legitimacy of "old ways of doing things" (Griffiths, 1997:13). The identification of young Somali men with Afro-Caribbean culture and music is seen by older Somalis as a threat to Somali identity (Griffiths, 1997). This is interesting given that Hopkins (2006) found that many Somalis resented being aligned with other African/Caribbean population groups and identified more strongly with Arabic identity.

Somali social structure has also come under pressure operating within a new socio-political environment. For example, parenting 'between two cultures' is a complex and conflict-laden process. Somali mothers interviewed by Mohamed (2004) lamented the speed at which their children were adopting Finnish cultural norms and values with the concomitant abandonment of Somali customs. This process of cultural adaptation has also transformed gender relations. Horst (2001) documents the circulation of information about changing gender relations for Somalis who resettle abroad. There is a perception that Somali women become liberal thus departing from 'culture' and 'religion' once they have moved. According to Horst this idea is circulated through BBC Somali news service, plays and songs (Horst, 2001). Often, refugee men experience loss of status within the family as the breadwinner with most families relying on social welfare (Tilikainen, 2003). On the other hand, women often come to gain greater independence often through performing important economic functions (Al-Sharmani, 2006). Al-Sharmani's (2006) study of Somali women in Cairo, found that more women than men are able to generate income through finding jobs as maids and child-carers or engaging in trading activities such as selling homemade food. Fangen (2006) attributes the high rate of domestic violence amongst Norwegian Somalis to the heightened independence of women compared to men whose role as the breadwinner had been subsumed.

El-Solh's (1993) research into the gendered dimensions of Somalis living in London's East End considers the tension between the need to adapt to a new socio-political environment (such as the importance placed on 'women's rights') and the desire to remain 'true to your culture'. Salmela (2004) explores gendered behavioural norms between Somali and Finnish girls. She found that Somali girls' use of space is governed by prevailing notions of morality and the desire to maintain a credible social status. Women who venture outside of appropriate gendered spaces (i.e. the home), became targets of gossip and allegation regarding their sexual purity.

Not only have relationships between men and women been transformed, but the place of religion within the lives of diasporic Somalis has increased. A number of commentators have observed that diasporic Somalis have become more religiously devout since leaving Somalia (Buckland, 1997; McMichael, 2002; Fangen, 2006). According to Tilikainen:

*"For Somali women, Islam features as a practical and moral guideline, which helps them to manage in a new religious and cultural environment, but which may also heal the sufferings of the Civil War, whereby Somali mothers appear as religious and moral agents who, in an active way, follow Islam in their daily life and construct their identities as Muslims" (Tilikainen, 2003:67)*

This intensification of Islam involves both inner changes, such as a greater commitment to prayer and religious learning, and outward displays of faith such as veiling (Tilikainen, 2003; Salmela, 2004). While this clearly makes Somalis more visibly different and targets of racist taunts, it is suggested that these changes are a coping strategy used to help Somalis adjust to their new reality and reconciling themselves with the past. One of Bern McGown's participants related that she began veiling as a means to cope with the hostility and lack of acceptance she experienced living in London (Berns McGown, 1999:84).

Tilikainen (2003) explores how Islam permeates the daily lives of diasporic Somali women. She argues that Islam allows women to maintain a sense of control in an often foreign and overwhelming situation. She describes how women's days are structured by prayer times and that the home is the primary religious space. In a similar vein, McMichael (2002) found that Islam provided continuity and support during the traumatic processes of displacement and resettlement. She describes how women draw upon Islam in their everyday life and also in the way they use and conceptualise space.

## Mobility

While much literature on diasporic populations tends to focus on movement between homeland and country of settlement, one key characteristic of the Somali diaspora is high levels of mobility between and within diasporic populations (Griffiths, 1997; 2002). High levels of mobility were

documented in Horst's research on Somalis living in Minneapolis (Horst, 2004) while Griffiths' (1997) study of London Somalis found high levels of mobility within the city and the within the rest of the country. Nielsen (2004) explored the phenomenon of secondary migration amongst Danish Somalis once Danish citizenship had been obtained. Nielsen argues that many Somalis migrated from Denmark to Britain in order to search for better opportunities based upon information gained via transnational networks. Fangen (2006) noted a similar trend with Norwegian Somalis relocating to Britain.

Many commentators attribute these high mobility levels to Somalis' nomadic heritage where people would move in search of greener pastures. Lewis (1961) even goes as far as to state that Somalis nomadic tendencies preclude the development of ties to the locality in which they live. Rousseau et al. (1998) note that migration is a culturally accepted facet of Somali life and is valued as a way of promoting personal growth and development. Accordingly, Somalis migrate for three reasons. Firstly, their nomadic background provides a foundation for further migration. Secondly, because of peer pressure and thirdly, the way in which migration is constructed as an adventure (Rousseau et al., 1998). Yet an important point to note is that this nomadism is often a necessity and not 'an unambiguous expression of freedom' (Nielsen, 2004). As Nielsen states:

*"It is important to stress that the decision to move to a place (in this case secondary movement to Britain) is never a final decision. Some have returned to Denmark, some have moved on to the United States or Canada, and some are staying, at least for the time being, 'checking out the conditions', as they put it themselves. Thus the migration of the respondents is not a predictable unilinear movement from their country of origin to a country or exile as the migration process is often portrayed but can be characterised as back-forth-and-onwards movements where the next place is constantly considered and reconsidered, Britain is just one stop" (Nielsen, 2004:16)*

Within some political and popular press circles, high mobility is interpreted as a lack of 'commitment' to the country of origin. Yet it is important to remember that traumatic experiences fleeing civil war and the difficulties in resettling in a new country are not forgotten because individuals move on (Nielsen, 2004).

Warfa et al. (2006) contribute to the debate by considering the implications of high mobility. Of the 34 Somalis residing in England who were surveyed, individuals moved an average of four times within a five year period. Participants cited reasons such as housing shortages, poor housing conditions, overcrowding, discrimination and employment opportunities for such mobility. Participants perceived that mobility has a negative impact on mental health due to instability, erosion of support networks and difficulties accessing health services. High levels of mobility present additional challenges in developing long-term and sustained relationships with health care providers, particularly for conditions that require long-term care and follow-up.

## Networks

The high mobility documented above is made possible through the strong links and networks between diasporic Somalis. Although Somalis are scattered throughout the world, family members stay in close contact and know what is happening in each other's lives. This is captured well by one of the respondents in Nielsen's (2004) study who commented:

*"The Somalis know each other even though they live everywhere. We have a big family with many branches spread all over the world. There are cousins in America and almost all countries...Africa, Australia, New Zealand and Europe" (Nielsen, 2004:8).*

Strong family networks have always been a dominant element of Somali social life. For nomadic pastoralists, dispersal of the larger family into smaller units is an important strategy to ensure survival and maximization of resources.

Somalis also maintain strong links with their homeland via telecommunication networks. The development of email, internet and mobile phone technologies has enabled Somalis at home and in the diaspora to establish and maintain strong social connections. Horst's (2001) research in three Kenyan refugee camps found that Somalis maintained strong networks through flows of money via Somali remittance agencies (*hawilaad*), proliferation of telephones, radio transmitters (*taars*), fax and email. *Taars* are used by refugees in camps to contact relatives in Somalia to request assistance, maintain personal contact, share and receive news or send money. In many parts of Somalia, *taars* are the only reliable form of communication.

Within the diaspora, the telephone has come to be the dominant means of communication. In Germany, because they use the telephone so much, Somali are required to make a sizeable deposit because they often fail to settle their telephone account before moving (Utteh, 1997). Partly fuelled by increasing flows of remittances, within Somalia there has been a proliferation of telecommunication companies established in joint ventures between local residents and Somalis in the diaspora (UNHCR, 2003b). Somalis returning from the diaspora have brought with them new businesses, ideas and technology (Gundel, 2002).

Diasporic Somalis have also tapped into developing information technologies as a means to maintain strong networks. One remittance organisation provides a website for people to replay Somali language news reports by the BBC (UNHCR, 2003b:257). Horst (2005) notes how there are over eighty Somali websites which provide information on developments on Somalia, calls for tracing people and business news. They provide Somalis with a space to discuss pertinent issues, share views, maintain contact with each other and be involved in each other's lives.

The development of information and communication technologies has also facilitated humanitarian and political mobilisation of Somalis. In Britain, Somalis have formed Som-scan and UK

Cooperative Association (Jama, 2004). Som-scan is an umbrella organisation bringing together nine Somali associations and 330 Somali families residing in Scandinavia and the UK. Collectively, the organisation has purchased land in Burao, Somaliland, with the express intent of creating a collective settlement for association members hoping to return to their country.

## Remittances

Facilitated by developments in communication technology, remittances have become one of the most important features of the Somali diaspora. Remittances typically involve the transfer of money but can also include goods in kind such as cars, jewellery, clothing, electrical goods (Ahmed, 2000).

The source of remittances has changed as the reasons behind migration have changed. In the 1980s it was primarily the migrant workers in the Arab countries whose earnings comprised 60 percent of total remittances. During this phase, remittances were used for investment or establishment of businesses. After the onset of civil war, the growing international Somali diaspora became the primary source of remittances and money is now used for crucial household spending.

There is a worldwide system of Somali remittance agencies known as *Hawilaad* which have been facilitated by the development of communication and information technologies. Under this system a Somali person brings the amount of money to be transferred to a remittance agency. The broker contacts the Nairobi or Mogadishu office that then contacts the person to whom the money is being sent. Fax machines are frequently used to transfer remittances however email is now becoming more commonly used. The recipient visits the *hawilaad* office and provides the full details of the sender and their own identity. Providing all information is correct, the money is received a few days after it is sent (UNHCR, 2003b). According to Horst and van Hear (2002), accounts between the different *hawilaad* offices are later reconciled through sending cash or by trading commodity items.

Remittances from the Somali diaspora have become the mainstay of the Somali economy and provide a vital lifeline for many Somalis struggling to survive in refugee camps (Koser, 2003). There is enormous variation in estimates of total remittances due to the lack of formal regulation of the sector. The UNDP estimates remittances of US\$500 million per annum or constituting on average between 20 – 40% of household income (Gundel, 2002:271; Horst and Van Hear, 2002). In Ahmed's (2000) study in Somaliland (Northern Somalia), the average household remittances received were US\$4,170 and represent two-thirds of household income. Somalis living in the USA and Europe send home approximately US\$120 million per year, doubling the average household income in some parts of Somalia (Koser, 2003). De Montclos calculates remittances at over US\$140 million per year – twice the amount invested in Somalia by the UN or other European development agencies (De Montclos, 2003:51). Yet these figures should be treated with caution as

it is extremely difficult to estimate accurately the total amount of remittances as many are made by informal arrangements thus avoiding documentation. *Hawilaad* are reluctant to reveal their business activities to avoid taxation or to jeopardise the welfare payments of recipients.

According to research undertaken by Ahmed (2000), remittances have contributed to economic recovery and growth in Somaliland through the establishment of businesses and the acquisition of assets. Remittances have also contributed to growth of telecommunication networks and airlines linking Somaliland to outside world (Ahmed, 2000). When telephone services first became widely available in Hergeysa, remittances tripled (Ahmed, 2000). In recognition of this, money transfer organisations began investing in telephone networks. Remote villages are now able to link into telephone networks using high-frequency radio.

Not only have remittances boosted Somalia's economy at the macro-level but they also play a profound role in the livelihood of individuals. For example, commenting on the situation of refugees living in Dadaab refugee camp in Kenya, Horst and van Hear (2002) note that food rations are handed out every 15 days but only last about 10 days. In this case, remittances from relatives overseas make the difference between life and death. In Horst's research with Somalis in Kenya, while remittances are sent to one person, they are spread throughout the family, benefiting a wide group of people (Horst, 2004). In the absence of accurate data, UNDP Somalia estimates remittances range between US\$50-200 per month per household which increase in times of economic hardship, drought or inter-clan conflict (UNDP, 2001). Remittances are also used for funding further migration, pilgrimages to Mecca and paying for family occasions such as weddings (Ahmed, 2000). In discussing the closure of Somali remittance agency *Al Barakaat* as part of the United States' war on terrorism, Horst and Van Hear (2002) pose the question:

*“Could there be a better way to create more hardship, more instability and more potential refugees, while increasing the appeal of extremism, than to cut off the money transfer lifeline to Somalia by shutting down remittance agencies?” (Horst and Van Hear, 2002:14)*

While remittances play an important role in the survival of many Somali families they are unevenly distributed and reinforce existing income inequality as higher-class families tend to be those who receive regular remittances. Thus the families and clans of higher social status are the ones who are benefiting the most as they have a higher proportion of members in the diaspora than poorer and weaker clans/families. There is also spatial patterning of remittances. For example, in Hergeisa while the majority of urban households received remittances only five percent of rural households did (Ahmed, 2000).

Yet it is also important to consider the circumstances of diasporic Somalis who are sending remittances. De Montclos suggests that Somali remittance levels are astounding in their frequency

and size, particularly as many of those who are sending money are in tenuous legal and financial situations themselves (De Montclos, 2003). These remittance levels are possible because:

*“Somali in exile have an impressive capacity to save. They save money in every possible way, complementing their social allowances with black market jobs, eating cheaply and buying clothes in charity shops. Occupation rates in houses where Somali live are at least twice the usual average’ (De Montclos, 2003:47).*

Many of those who are remitting are themselves dependent on welfare payments. De Montclos notes that remittances represent between 20 to 30 percent of diasporic Somali household income and that some individuals are pressured by elders to remit (De Montclos, 2003). The sense of responsibility can be a heavy burden for some diasporic Somalis. Horst (2004) describes how the need to send remittances influences the decisions they make about their own lives. One research participant stated that they were reluctant to get married because it might compromise their ability to send home remittances to their relatives in Somali who depended on them. Some felt that relatives did not understand the pressures faced by diasporic Somalis in sending remittances, particularly as many find it difficult to obtain employment in the first place. Women interviewed by Buckland (1997) felt that remittances are one way in which they can help overcome feelings of guilt for leaving family behind (Buckland, 1997).

## Settlement outcomes

Despite strong personal communication networks, Somalis leaving refugee camps for abroad have very high hopes for their new lives. This is in part fuelled by media portrayals of Western countries which in combination with the large amounts of money that are sent from abroad, give the impression that resettlement countries offer an easy and prosperous life (Horst, 2004). Life in fact proves to be very difficult with many Somali refugees being forced to rely on welfare support, having limited access to employment or education opportunities and being subjected to discrimination and racism.

There have been a considerable number of research projects undertaken amongst the various Somali communities throughout the world, particularly those living in Canada and London (e.g. El-Solh, 1991; 1993; Griffiths, 1997; Berns McGown, 1999; Gwynne-Vaughan, 1999; Abdulle, 2000; Farah, 2000; Griffiths, 2002). These have tended to focus on resettlement issues and the challenges faced by Somali refugees settling into a new society. These challenges include difficulties with employment and income, education and social integration and support.

## Employment and Income

Research suggests that unemployment rates amongst Somalis are very high. According to De Montclos unemployment rates for Somalis are 60% in Canada, 85% in London and 90% in Sweden

and Finland (De Montclos, 2003:50). In the early 1990s, Opoku-Dapaah (1994) surveyed 385 Somali men and women living in Toronto. Survey respondents reported a number of settlement problems including high levels of unemployment (only 29% had a job) despite 50% possessing high school or college qualifications.

In Fangen's (2006) study in Norway, Somali refugees had the lowest levels of living standards compared to other migrants groups in terms of employment, accommodation and health status. Given the difficulties faced by Somalis in accessing employment opportunities, a large proportion relies on social welfare support to provide for themselves and their families. According to De Montclos (2003) nearly half of all Somalis in Canada rely on government income support while 80% of Somalis in Scott's study in Toronto were on income support (Scott, 2001). This trend has not escaped media and political figures who blame Somalis for relying heavily upon government welfare (De Montclos, 2003).

This dependency on government support means that household income levels are very low. According to Opoku-Dapaah (1994) nearly 41% of Somalis living in Canada survive on less than \$10,000 per year. Due to the large size of Somali families and numbers of dependent children, many live beneath the poverty line. There are a number of flow-on effects from poverty including difficulties accessing housing opportunities. In London, El Solh (1991) noted that many continue to live in sub-standard housing with little hope of improvement. As will be discussed in more detail later, poverty also increases social isolation. Some Somali refugees are so impoverished they are unable to afford transportation or telephone calls to maintain contact with fellow Somalis. This has contributed to the increasing burden of mental illness amongst Somalis (El-Solh, 1991).

## Education

Numerous language and education difficulties have also been well-documented. According to El Solh (1991) Somalis are often caught in a vicious cycle whereby their qualifications are not recognised in Britain requiring lengthy periods of retraining and English language education. In many cases the costs of doing so are prohibitive. Those whose qualifications are compatible often struggle in obtaining appropriate employment (El-Solh, 1991). Danso (2001) suggests 69% of Somalis who have obtained a job are 'underemployed' in an ill-fitting occupation compared to their qualifications and experience.

While some Somalis are university-educated, a significant proportion of adult refugees have a limited education and struggle to communicate in their country of resettlement. Most Somalis in Scott's study had only basic primary-level education and felt uncomfortable using and understanding English (Scott, 2001). This is similar to the findings of Opoku-Dapaah (1994) who found that 60% of women and 38% of men either speak English with difficulty or not at all. According to El Solh (1991) there are high rates of adult illiteracy amongst the Somali population in

London. While there is some evidence of educational progress by British-born Somalis, parents' hopes for academic attainment by their children have not always eventuated.

Children also face a number of challenges within the education system. Somali parents reported that their children have difficulties at school resulting in behavioural problems leading to suspension (Scott, 2001). Somali mothers interviewed by Israelite (1999) spoke about how children are placed in classes with children their same age, even though refugee children may not have the same sort of abilities due to being in a refugee camp for many years and thus missing out on schooling. In research with Somali children in Finland, Alitolppa-Niitamo (2002) found that Somali young people experience difficulties in navigating and adjusting to the Finnish education system. Students suffered 'cognitive overload' due to the quantity and foreignness of the material they are required to learn. Many experience difficulty trying to 'fit in' to a curriculum based on ideologies of the mainstream population. Because of the limited language and educational backgrounds of adult Somalis, many parents also struggle to support their children's education at home (Israelite et al., 1999; Scott, 2001).

### Social Integration and support

One issue that is often raised within the literature is that of integration. This is a topic that has received considerable attention with regard to migrant groups in general. In the context of Somali migration, de Montclos states, "The Somali are widely dispersed around the world, they are generally poorly integrated and maintain an uneasy relationship with their host societies, and they are a community with their minds turned towards their homeland" (De Montclos, 2003:38). Somali communities are often portrayed as existing in isolation from wider societal structures. Research by Opoku-Dapaah confirms that most Somalis limit interaction to members of their own community with only 7% of respondents indicating that they have any native Canadian friends (Opoku-Dapaah, 1994:62).

Researchers indicate that social isolation is common amongst many Somali refugees due to reduced social networks and interaction (Simich et al., 2003). Respondents suggested this was because of the:

*"harsh weather, the busy lifestyle, and the less-integrated structure of society. In Somalia, the tropical climate, communal living, and that society's "open door policy" facilitated frequent visiting" (Simich et al., 2003:49).*

In Somalia when problems arose, there was plenty of help available in the form of family, friends and neighbours. In Canada however, the existence of stress and pressure to survive meant that there were fewer opportunities to provide social support to one another. Participants linked this lack of social support with poor health.

Another explanation for social separation is that it has been adopted by Somalis as a mechanism to overcome discrimination. A number of studies have highlighted how Somalis (particularly Somali women) are the targets of racism and discrimination (Buckland, 1997; Kusow, 1998; Berns McGown, 1999; Kusow, 2006). Over half of the participants in Danso's (2001) study cited racial discrimination as the cause of their initial settlement problems. Kusow (1998) suggests that Somalis limit their social interactions to the Somali community to overcome racism and the racialised identities afforded to them in Canada. This claim is contested by Israelite (1999) who believes that social isolation has resulted from structural factors which have limited Somalis ability to participate in wider society. Kusow's (2006) research is nonetheless valuable as it provides insight into the issues of ethnicity and identity. In Somalia, political relations are largely determined by clan affiliation rather than colour/ethnicity. Kusow documents the ways in which some Somalis react to skin-based social stratification in the United States – firstly by ignoring the issue, secondly by reinscribing social boundaries between themselves and the dominant population and by identifying more strongly with nationality/culture than skin colour.

Critiquing the assumption that strong networks and social capital 'travel with' migrants, McMichael and Manderson (2004) contend that migrant groups can just as equally be ridden with conflict, exclusionary practices and social control. In many cases with refugee groups, the resettlement process brings together people who are strangers at best and enemies at worst. Furthermore these people are from diverse backgrounds – some are nomads, elite traders or professionals. The refugee process also means that social networks are torn apart through war and mistrust of other clan groups. They suggest that the successful resettlement of Somalis in Melbourne is hampered due to the reduction in social capital and networks.

### Resisting marginality

All in all, studies exploring Somali resettlement paint a grim picture of the overwhelming struggles faced by Somali refugees in addressing the trauma of the past and challenges of the present. Very few accounts address the ways in which Somalis have exerted agency and sought to resist and overcome their circumstances. While McMichael and Manderson (2004) document the erosion of social capital and networks amongst Somali refugees in Melbourne, they also discuss how women have forged new social relationships in order to provide support and stability to one another. Furthermore, "Social events, religious gatherings, and celebrations play an important role in women's lives, promoting interaction, shared time, and a sense of well-being" (McMichael and Manderson, 2004:96). Food is an important unifying commonality that brings people together, facilitates interaction and creates a sense of belonging based on shared recollections of the past. Buckland (1997) also found that women created new systems of support by using the telephone as a key mechanism to develop social support. Instead of visiting a neighbour for assistance, people now ring others for advice and support.

Al-Sharmani (2006) documents the experiences of Somali families living in Cairo. Many of these refugees have obtained citizenship in Western countries and have moved to Cairo to overcome the marginalisation they had experienced in the West. She suggests that Somali families dwell in multiple nations to resist:

*“...legal, economic, and/or cultural forms of marginalisation in host societies. Whether it is related to their inability to work and make a living, to live legally in a host society, to secure good education and opportunities for social mobility for their children or to be racially and culturally accepted in the host society, resisting marginalisation involves renegotiating the nature as well as the varying levels of integration that diasporic Somalis can find or strive for in different nation-states” (Al-Sharmani, 2006-72).*

Many Somalis living in Cairo are women who have relocated with some of their children, typically leaving their husband and other children behind. These women establish businesses and trading connections and attempt to achieve a higher quality of life.

As has been discussed in this section, Somali refugees face numerous challenges during the process of resettlement. This is in part due to the dual challenge of dealing with the trauma and loss caused by the Civil War and also having to adapt to new socio-political environments in the West. Building on this review of international literature, the following section considers literature on the experience of Somali refugees in New Zealand. The Somali population in New Zealand is smaller than many other diasporic Somali populations but bears many similarities to the experiences documented overseas.

## **Somali refugees in New Zealand**

This section aims to survey published research on Somali refugees in New Zealand. Unlike other Somali communities scattered throughout the world with a long history of migration (e.g. Britain and Italy), New Zealand's Somali community is relatively recent. Somali refugees began arriving in New Zealand from 1992, as quota refugees, asylum seekers and as family reunion refugees. By the 2001 census there were over 1,770 people born in Somalia living in New Zealand (though it is highly likely that this figure is much higher in reality due to census undercounting, as will be elaborated upon in Chapter Six). Most Somalis have settled in Auckland, Hamilton, Wellington and Christchurch. Many have faced enormous challenges settling into New Zealand life especially given the violent and distressing circumstances which forced them to leave their homes. A small number of researchers have documented the resettlement challenges faced by Somalis with a special focus on the experiences of Somali women and the practice of Female Genital Mutilation

(FGM). There have been a small number of projects researching the localized experiences of the Somali community in Hamilton and Christchurch, but nothing in Auckland.

Although the Somali community is small compared to other ethnic groups, it is becoming the focus of increased attention from a number of different sources, for example popular press articles which address the arrival and settlement of Somali refugees (Bowron, 1996; Schaer, 2002; Rapson, 2003; Watson, 2005). In addition a growing number of academics have considered the resettlement experiences of Somalis. Researchers who are part of the Foundation for Research Science and Technology (FRST) funded 'Strangers in Town' research group at the University of Waikato have made a number of contributions to understanding the resettlement experiences of Somali people living in Hamilton, writing on a diverse range of topics including discrimination (Guerin, 2003), physical activity (Guerin et al., 2003c), health (Guerin, Abdi and Guerin, 2003a; Guerin, Diiriye and Guerin, 2004c), employment (Guerin, Diiriye and Guerin, 2004b) and Female Genital Mutilation (Diiriye, Guerin and Guerin, 2004), resettlement issues (Guerin et al., 2003b) and poverty (Guerin and Guerin, 2002).

Two studies document Somali resettlement experiences within Christchurch. Lilley (2004) considers the housing experiences of Somalis and suggests that Somalis experience numerous challenges in accessing affordable and appropriate housing. Humpage and Fleras (2000) examine the experiences of Christchurch Somali students within the school system. They found that while schools are endeavouring to become more aware of, and encouraging of, diversity, the system remains embedded with 'eurocentric' ideologies and discourses. Somali students continue to experience poor educational outcomes and struggle to adapt to a Western teaching and learning system resulting in frustration and tension with teachers and fellow students. Teachers report a high-rate of behavioural issues with a number of Somali students dropping-out of school.

One of the topics that has received attention is the practice of female 'circumcision', more commonly known as Female Genital Mutilation (FGM). While this practice is illegal in New Zealand, between 90-98% of Somali women have been affected by FGM (Denholm and Jama, 1998). This presents unique challenges for New Zealand health professionals working with circumcised women. Denholm and Jama (1996; 1997; 1998) have published extensively on this topic. In 1997 they interviewed 81 Somali women in Auckland regarding their views on FGM and its management. While there were varying levels of support for the practice, significant numbers had experienced problems including recurrent urinary tract infections, vaginal infections and pain during menstruation and intercourse. Diiriye et al. (2004) present somewhat different views based on their research amongst Somali women throughout New Zealand. Surprisingly, of the 54 women who were interviewed, 83% felt that being cut/circumcised had been a positive experience for them while only 4% felt it had been negative. Most women favoured the practice as it was perceived to be an important cultural expression.

The plight of Somali women has also been documented. A project funded by the Ministry of Social Development highlights the special challenges faced by Somali women (Auckland Somali Community Association, 2006). This research project is unique in that it was largely conducted by a Somali elder with the assistance of an advisory committee. As a high proportion of Somali families were resettled in New Zealand through the women-at-risk selection category, many have additional resettlement support needs. Many women in this category have low education and literacy skills, are without family support and find it difficult to access existing support services. These women have children with high and complex health and social needs that require intensive support. Jenkinson (1999) similarly explores Somali women's experiences and traces their journey from Somalia to New Zealand. Based on in-depth interviews with six Somali women, the main difficulties that emerged were accessing English language and lack of employment opportunities. Jenkinson seeks to refute the construction of refugees as passive victims through emphasising the way in which women actively recreate and fashion their culture in New Zealand's socio-political environment. I similarly address such ideas in subsequent chapters outlining Somali resettlement experiences (Chapter Six).

## *Summary*

Although there have been a small number of studies focusing on Somalis living in New Zealand, there remains great scope to consider the 'lived experience' of resettlement. This is particularly so for the Auckland Somali community whose settlement experiences have not yet been comprehensively documented. Prefaced by international literature surveyed in this section, numerous questions on the characteristics and resettlement experiences of the Auckland Somali community remain unanswered. To what extent can the Auckland Somali community be thought of as a transnational population and to what degree do their resettlement experiences conform to those of other diasporic Somali communities throughout the world? How has the Auckland Somali community responded to the challenge of settling in New Zealand and what are the implications for Somali identity, culture and health? This research attempts to address this gap in the literature in Chapter Six which draws on fieldwork data to outline the resettlement experiences of the Auckland Somali community. In the meantime, Chapter Four shifts to introduce tuberculosis (TB) and the way in which medical/health geographers have researched infectious disease including TB.

## **Chapter 4: Medical/Health Geography and TB – from dots on maps to DOTS in neighbourhoods**

*“The populations most at risk of tuberculosis are those which are frequently disadvantaged and socially excluded. Responses by society to the disease often reflect the social relations between, on the one hand, these groups at risk and, on the other hand, the more affluent and powerful social groups with greater control over the collective resources of society that might be used to combat the disease”  
(Curtis, 2004:241)*

With the unrelenting influences of globalisation, people and places have become increasingly connected leading to new geographies of health and disease. While many developed nations face unprecedented levels of chronic diseases (McMurray and Smith, 2001; Lee, 2003), developing nations still experience a high burden of infectious disease (Gatrell, 2002). Tuberculosis (TB) is one infectious disease that remains a leading cause of death in developing nations (1.4 million deaths in 2004) (World Health Organisation, 2006f). While this global patterning appears to support the concept of the ‘epidemiological transition’ (Smallman-Raynor and Phillips, 1999), small pockets of high TB rates have persisted within developed nations and are the focus of intense study (Gandy and Zumla, 2002a).

Medical geographers have long been interested in the spatial distribution of disease yet in recent times, health geographers have sought to understand the lived experience of illness beyond plotting ‘dots on maps’. This section describes the disciplinary evolution of medical/health geography and the way in which it has addressed the topic of infectious disease and TB in particular. I then move on to survey the wider literature on the topic of TB including biological, historical and important socio-cultural developments. This chapter is particularly important as it sets the scene for the subsequent findings chapters that endeavour to bridge the gap between health and medical traditions.

### **Disciplinary evolution of health/medical geography**

There are two main research traditions within medical geography - disease ecology and the spatial location of medical services although these ‘twin-streams’ have become increasingly inter-twined in recent years (Kearns and Moon, 2002). The first approach focuses on the spatial distribution of disease through mapping, modelling and geographically representing epidemiological models of infectious disease (Meade, Florin and Gesler, 1988; Meade and Earickson, 2000). A classic

example of this is the work of Cliff et al. (1981) who modelled the spread of measles epidemics in Iceland. According to Meade and Earickson (2000) the focus of medical geographers has since expanded from mapping the diffusion of 'traditional' infectious diseases such as cholera, measles and influenza to the study of a variety of factors within social and physical environments such as the distribution of bronchitis, suicide and teenage pregnancy (Meade and Earickson, 2000).

The second strand within traditional medical geography focuses on the provision of medical services (Joseph and Phillips, 1984). This too is characterised by cartographic representations of location of service provision based on frameworks, such as central-place theory, to determine the efficiency and equity of such services. Researchers have attempted to determine why medical services are located in particular places and to understand the relationships between different service providers. In recent times, geographers have considered the spatial dimensions of health services on various scales e.g. global (Phillips and Rosenberg, 2000), national (Kümpers et al., 2006) and local (Cloutier-Fisher and Skinner, 2006), including a variety of health care facilities such as primary care clinics (Barnett, 2001), hospitals (Joseph and Kearns, 1996), health screening (Perkins et al., 1999) and prevention services (Gesler et al., 2006).

While medical geography has greatly contributed to our understanding of health and disease it has been criticised for failing to engage with wider socio-cultural shifts within the social sciences, inadequately theorising the importance of 'place' and focusing narrowly on disease and biomedicine rather than wider issues of health and wellness (Kearns, 1993; Dorn, 1994; Kearns, 1994; Dyck, 1995). In response to these critiques, a new field of research titled 'health geography' has emerged although this shift has not been universally embraced (Mayer and Meade, 1994). Nonetheless, health geography has emerged as more than a re-branding through increased theoretical and methodological rigour and diversity. With a wider scope than medical geography, it focuses on the inter-connections between people, places and health. This growth is evident in the appearance of 'Health Geography' within the Dictionary of Human Geography and the establishment of the journal *Health and Place* in 1995 (Kearns and Moon, 2002).

One characteristic of health geography is an increased sensitivity to, and nuanced understanding of, 'place' - defined as "bounded settings in which social relations and identity are constituted" (Duncan, 2000:582). Health geographers are interested in the meanings and significance of place and the way in which places shape and are shaped by those who reside in them. This interest draws on wider shifts within cultural geography, particularly the development of the notion of landscape as a 'text', which can be 'read' and deconstructed. According to Duncan, landscape is at the very core of social processes and "acts as a signifying system through which a social system is communicated, reproduced, experienced and explored." (Duncan, 1990:17). The renewed emphasis on the significance of 'place' has also been extended beyond individuals' experiences of actual places to a notion of 'sense of place' or 'place-in-the-world' (Eyles, 1985). This notion links

identity with place and suggests that individuals gain a sense of place through experiences of particular sites and the feelings that are evoked from such experiences (Gesler and Kearns, 2002).

This re-conceptualisation of the significance of place has yielded a number of different research directions such as, but not limited to, studies focusing on particular sites such as the home (Kearns et al., 2000), neighbourhoods (Sooman and Macintyre, 1995) and health care facilities (Kearns and Barnett, 1999; Warin et al., 2000). There has also been considerable investigation into the concept of therapeutic landscapes (Gesler, 1992; Kearns and Collins, 2000; Williams, 2002; Gastaldo, Andrews and Khanlou, 2004), area effects on health (Macintyre, Maciver and Sooman, 1993; Macintyre and Ellaway, 1998; Macintyre et al., 1998; Macintyre et al., 2000; Macintyre, Ellaway and Cummins, 2002) and health inequalities (Curtis and Jones, 1998; Hayes, 1999; Dunn, 2002; Curtis, 2004). There is evidence of a concerted effort to give 'voice' to and delineate, the experiences of groups often marginalised within society and by earlier medical geographical scholarship. Examples of this include research on those with disabilities (Valentine, 2003), children (Kearns and Collins, 2000) and the elderly (Andrews, 2002; Andrews and Phillips, 2002a).

### *Medical/Health geography and infectious disease*

Although infectious diseases only account for a small proportion of deaths in developed countries, they remain on the agenda particularly in an era of heightened anxiety, and concerns of bio-terrorism and outbreaks of new and emerging diseases such as Severe Acute Respiratory Syndrome (SARS) as well as the recent avian influenza threat (Oppong et al., 2004). Despite this, the study of infectious disease by medical/health geographers has tended to be within the setting of developing nations focusing on diseases such as leishmaniasis, malaria and Lyme disease (Phillips and Rosenberg, 2000). Within these countries, there has also been recognition of the relationship between socio-economic disadvantage, economic and political upheavals and the incidence of infectious disease (Kalipeni and Oppong, 1998; Oppong, 1998).

In terms of the 'twin-streams' of medical geography, there appear to be a number of studies outlining the spatial distribution of infectious disease but very few focusing on the location and provision of medical services (Kearns, 1996; Meade and Earickson, 2000). The disease ecology tradition, as discussed in the preceding section, has a well-established history of investigating the spatial distribution and diffusion of infectious disease (Gatrell, 2002). In 1950, Jacques May attempted to explain infectious disease by delineating the differing ecologies that contributed towards its incidence. Infectious diseases according to May's typology could be reduced to the following components:

Host – who gets the disease

Agent – direct cause of the disease e.g. bacteria, virus

Vector – organisms that transmit diseases e.g. insects, water

Intermediate host – in which the agent reproduces

Reservoir – Maintains the agent as well as the human host

(Jones and Moon, 1987:150)

This tradition was furthered in the 1960s when geographers attempted to use quantitative methods to study infectious disease in order to illuminate spatial processes and structures at work (Jones and Moon, 1987). Different taxonomies were created to depict the different mechanisms facilitating the spread of infectious disease. For instance, according to the work of Cliff et al. (1981) there are three types of diffusion. *Spatial diffusion* refers to the spread of a disease from an epicentre, *network diffusion* is where diseases travel along pre-existing personal and business networks while *hierarchical diffusion* refers to the way in which diseases spread from higher-order to lower-order settlements (Cliff et al., 1981). Researchers also attempted to model the spatial diffusion of disease such as measles in Cornwall (Haggett, 1976) and Iceland (Cliff et al., 1981). Yet these models were problematic, given that they assumed that individuals had the same likelihood of developing disease thus ignoring social, economic, psychological and environmental conditions (Jones and Moon, 1987). As Kearns (2002) notes with respect to HIV/AIDS, by focusing exclusively on the distribution and diffusion of disease, incidence is reduced to dots on a map rather than considering the experiences of the person living with the illness. Kearns notes:

*“...in its traditional forms, medical geography reduced the body to little more than a container of disease, whereas health has increasingly spoken to geographers of the larger reality of people’s experiences of place and identity” (Kearns, 2002:141)*

Although TB has been well documented within wider biomedical literature, there are few medical and health geographers who have researched the disease although there are a number of contributors who would not consider themselves as medical/health geographers per se (e.g. Gandy, 2001). This paucity of TB-focused research is potentially due to the fact that health geography espouses a focus on ‘health’ as opposed to ‘disease’ and that TB rates in much of the developed world (where most health geographers operate) are very low, although there are pockets of high TB incidence that have been researched e.g. New York City (Wallace, 1994). With the decline in mortality due to infectious disease, researchers are increasingly focusing more upon chronic diseases such as cancer (Pearce and Boyle, 2005; Kravdal, 2006), diabetes (Rytönen et al., 2003; Gesler et al., 2006) and obesity (Reidpath et al., 2002; Lopez-Zetina, Lee and Friis, 2006). Of those researching infectious disease, HIV/AIDS receives most attention and considerable effort has been devoted to understanding and chronicling the characteristics and

impacts of the illness (Wilton, 1996; Asthana, 1998; Oppong, 1998; Kearns, 2002; Law, 2003; Elmore, 2006).

Of the geographic research on TB, the dominant emphasis is the depiction of the spatial distribution of the disease, often aided by Geographic Information Systems (GIS) (Dawson, 2000; Donkor, 2001; Kistemann et al., 2002; Wanyeki, 2003). Oppong et al. (2004) use GIS to depict the dynamic processes of transmission of TB within enclosed spaces. Using new computational epidemiological tools they model the diffusion of TB within a homeless shelter and factory in Tarrant County, Texas. According to the authors, medical geographers have not previously had the necessary tools to map diffusion on such a micro-scale – dealing with inches and feet as opposed to regions and kilometres. In a similar vein, Moonan et al. (2006) use GIS to assist with screening endeavours designed to identify those at high-risk of developing TB.

Deborah and Rodrick Wallace have utilised quantitative methods in their work on the geography of TB in New York and the resurgence that has occurred there since the 1980s (Wallace and Wallace, 1993; Wallace, 1994; Wallace et al., 1995; Wallace and Wallace, 1997; 1999). They examine the ecology of the disease using disease diffusion models in the context of wider social, political and economic shifts. Using epidemiological data between 1978 and 1990, the authors demonstrate that new cases of TB in New York City demonstrated characteristics of spatial and hierarchical diffusion (Wallace, 1994). In Britain, Elender (1998) examined the association of TB mortality with ethnicity, poverty and AIDS and found a strong positive association between TB mortality and overcrowding at the household level rather than at district level.

A number of geographers have also considered historical dimensions of TB particularly during times when rates were very high (e.g. Craddock, 1994; Moorhead, 2000). Grineski et al's (2006) research on TB seeks to understand the social dimensions of the disease, specifically the way in which class and 'race' shaped historical TB experiences in Phoenix, Arizona. Furthermore, despite the promotion of Phoenix's health-promoting properties, many of the poor were spatially isolated and stigmatised.

Although there are relatively few medical/health geographers who have undertaken research on TB, it has been used as a case study within two leading textbooks. In both cases, the authors advocate a distinctly social approach to considering the disease. Curtis (2004) uses the concept of 'landscapes' to structure her discussion on the variety of dimensions that form geographies of TB – including epidemiological, socio-economic inequality, health care use, power and therapeutic landscapes. Another textbook published by Jones and Moon (1987) considers the social causes of TB, seeking to counter biomedical notions that understanding the biology of the disease will result in control of the illness. The authors contend that a social explanation of TB, such as one including rapid social change, financial inequality and low income explains why TB is endemic in many developing nations and not in more developed nations. These 'social' factors contribute to low

resistance to infection which influences who is more likely to develop TB disease upon being infected. They suggest that TB "...may not harm a well-nourished and otherwise healthy person" (Jones and Moon, 1987:184). The authors also highlight that high TB rates among immigrants are not due to biological reasons but because of the conditions in which they live.

Although not writing explicitly within the rubric of health geography, Matthew Gandy echoes the sentiments expressed by Jones and Moon in urging that TB research needs to be re-situated within broader social, political and historical contexts (Gandy, 2001; Grange et al., 2001; Gandy and Zumla, 2002a; 2002b; Gandy, 2003). For instance, much of the literature on the resurgence of TB and Multi Drug Resistant TB (MDR TB) focuses on behavioural and biological aspects such as patient non-compliance neglecting social and historical contexts. Gandy and Zumla argue that, "the principal motor behind the resurgence of tuberculosis has been the sharp rise in global poverty which has undermined many of the public health advances of the twentieth century" (Gandy and Zumla, 2002a:393). In a similar vein, Mayer (2000) includes TB as one of the 'emerging infectious diseases' in his paper on how a 'political ecology' approach that includes political economic perspectives can be effectively integrated with disease ecology.

Of particular relevance to this thesis, Ng Shiu (2006) uses a health geography approach to examine the social determinants of TB amongst Pacific peoples living in Auckland and Samoa. Ng Shiu contends that cultural identity, migration history and socio-economic status greatly impact upon Pacific people's health status, health seeking behaviour and subsequent disease experience. Furthermore, she discusses how Pacific peoples 'place' and experience of 'place' are an important context for health, disease and TB.

I now broaden the focus of this chapter by reviewing key aspects of the wider literature on TB. Although this literature is largely biomedical in nature, there are a growing number of calls to analyse the social and cultural dimensions of TB, grounded in an understanding of the wider structural forces that have had a profound influence on the lives of all.

## **The characteristics of TB**

The literature on TB is vast and highly diverse although the intensity of interest in the disease has waxed and waned over time, paralleling trends in TB's incidence. Yet the interest in TB, and lack thereof, reveals an important insight into the way in which knowledge and academic enquiry is influenced by social, political and economic forces. This section will introduce and review important topics and themes within the body of literature on TB, identifying key trends and areas requiring additional research.

Research on TB can be roughly organised into three main groupings. Firstly, research on the extent and incidence of TB. Key issues of concern are mainly quantitative - the trends in

notification, mortality and morbidity rates. The second grouping is research seeking to understand the reasons behind the resurgence of TB rates since the 1980s; three factors that are frequently implicated include TB/HIV co-infection, MDR TB and immigration. A smaller group of researchers has also suggested that socio-economic factors are also behind the resurgence in TB. The third strand of research tackles the issue of compliance with treatment regimens, or more specifically, the reasons why patients fail to comply with Directly Observed Therapy Short-Course (DOTS). Included within this last category is research conducted among specific people groups (either ethnically or socio-economically bounded) with high non-compliance rates, seeking to understand their cultural perceptions and knowledge about TB with the (usually) explicit purpose of reforming and educating them. Critiques of the literature on non-compliance will be presented. The final section overviews the TB situation in New Zealand.

## **Biology of TB**

TB is an infectious disease usually caused by *Mycobacterium tuberculosis*. When healthy people are infected with TB, 90-95% of people's bodies are able to control the infection so it remains dormant or latent (abbreviated as TBI) (Klovdahl et al., 2001). Those with TBI are unable to transmit the infection. The other 5-10% of individuals who become infected with TB go on to develop active disease (TBD). Those with the active disease in their lungs and respiratory tract are infectious and can transmit it through activities whereby bacteria in the respiratory passages are aerosolized and expelled as moisture droplets into the air. Such activities include sneezing, talking, coughing and singing. After the droplets have evaporated, they become 'droplet nuclei' which circulate and can subsequently be inhaled by others resulting in infection. The disease usually resides within the respiratory tract (lungs/larynx) however it can occur within other parts of the body (extra-pulmonary TB).

There is debate over the extent to which TB is contagious. It is thought that close contact over an extended period of time with an infectious person within a confined space is required for transmission (De Zoysa et al., 2001), however there is some evidence that the disease can be transmitted during relatively brief encounters (Klovdahl et al., 2001). TB can usually be treated successfully if detected early.

## **Extent and incidence of TB worldwide**

According to current estimates, approximately two billion people equal to one-third of the world's population are infected with TB (World Health Organisation, 2006g). In 2004, there were an estimated nine million new cases of TB and two million deaths due to TB (World Health Organisation, 2006c). Yet the incidence of TB is not evenly distributed but is strongly patterned with the vast majority of TB occurring in developing nations. In 2004, more than 80% of new TB patients originated from Africa, South-East Asia and the Western Pacific Region (World Health

Organisation, 2006c). Although incidence rates are stable or decreasing in most developed nations, TB incidence continues to rise in Africa due to the HIV/AIDS epidemic.

There are also disparities in the treatment outcomes between the developed and developing world (World Health Organisation, 2006c). Although the World Health Organization (WHO) is endeavouring to expand the coverage of TB programmes, many developing countries still lack adequate detection, reporting and treatment services. Furthermore, less than half of existing TB patients have access to health services in developing countries (Kochi, 1991).

When investigating the developing/developed world divide another difference can be observed. In developed nations, 80% of infected individuals are over 50 while in developing countries, 75% are under 50 (Kochi, 1991). This indicates two quite different patterns of TB. In developed countries, most TB cases are reactivations of dormant infections amongst the elderly while the majority of infections in younger populations in developing countries signal new cases. Raviglione et al. (1993) found that TB deaths decreased between 1980 and 1990 in most Western European countries with the majority of deaths occurring in the over 65 category. Similar patterns can also be observed when considering the development of the disease over time.

## **History and resurgence of TB**

Before discussing the resurgence of TB, or what some have named the 'new' TB, it is important to be aware of key historical developments. TB has long been the focus of historical inquiry dating back to Hippocrates (460-370 BCE) through to more recent commentators including Rene Dubos, Paul Farmer, Linda Bryder and Barbara Rosenkrantz (Dubos and Dubos, 1987; Bryder, 1988; Rosenkrantz, 1994; Rothman, 1994; Farmer, 1996; 1997; 2000). It is difficult to accurately date the origins of TB, however archaeological and historical evidence points to TB being prevalent in early Hindu, Greek and Roman societies over 2000 years ago (Gandy, 2003). For much of its history, TB has been difficult to classify due to confusion over its symptoms and various sites of manifestation in the body (Gandy, 2003). There were many different explanations of the causes of TB including hereditary, constitutional, lifestyle and environmental factors.

The discovery of the TB bacterium by Robert Koch in 1882 was a watershed moment in the history of TB, although it took many years to develop effective treatment. This discovery occurred in tandem with increasing rates of TB, linked with the processes of urbanisation, industrialisation and marginalisation of the poor. Atrocious urban living conditions were quickly blamed and individuals with TB were advised to seek more favourable climates to obtain relief. The sanatoria movement beginning in the 1850s catered to this demand and rapidly spread internationally (Dubos and Dubos, 1987; Bryder, 1996). Although 'consumptives' migrated to the colonies to seek a cure for TB, they unwittingly spread the disease to the local populations, often with devastating consequences (Gatrell, 2002).

In conjunction with the establishment of sanatoria, the social construction of TB was transformed by the romantic literary movement in the early nineteenth century. TB became known as an affliction associated with those of creative tendencies and was romanticized as a tragic yet dignified death. This was reinforced by the deaths from consumption of literary greats such as John Keats, the Bronte sisters and Ralph Waldo Emerson (Dubos and Dubos, 1987). Nevertheless, towards the end of the 19th century, the disease had lost its romantic connotations and was once more an affliction of poverty and moral deficiency (Farmer, 2000; Gandy, 2003).

Evidence from the early 20th century suggests that TB began to decline well before the medical interventions that were to follow. This formed the heart of the 'McKeown thesis' which argued that wider social and economic improvements had resulted in improved TB rates rather than direct medical intervention (McKeown, 1976). McKeown suggested that the declines in rates of TB, cholera, whooping cough and scarlet fever preceded the development of medical interventions. This assertion has been widely contested and debated by commentators who suggest that social reform needs to be considered in conjunction with medical advances and public health reform rather than relying on one explanation or another (Colgrove, 2002; Link and Phelan, 2002).

Another important advance in the battle against TB was the development of the Bacille Calmette-Guerin (BCG) vaccine in 1922. This vaccine was not universally adopted and had variable rates of effectiveness. Treatment of TB progressed with the development of streptomycin in 1944 and isoniazid in 1951. These two drugs transformed the treatment of TB and within 30 years, TB mortality in the developed world had reduced by over 90% (Gandy, 2003). This success buoyed commentators who predicted the disease would be quickly eradicated. Ogden et al. (2003) argue that TB slipped off the WHO priority list during the 1970s as support and funding for TB control waned. A decrease in the publication of scientific papers on TB and diminished frequency of the International Tuberculosis conference are illustrations of this trend (Raviglione and Pio, 2002). The WHO cut back on TB staff and emphasised primary health care initiatives such as immunisation and population control. Attention also shifted to the emerging HIV epidemic. Compared with other diseases, TB is low on the international aid expenditure agenda. For every person who dies from TB, \$8 of external aid is spent compared with \$137 for malaria, \$925 for AIDS and over \$38,000 for leprosy (World Health Organisation, 1994). It is important to remember however that although TB was largely eradicated from developed countries, it remained a leading cause of death for developing nations who were unable to access new medication and technology and were increasingly marginalised by accelerating global social, economic and political change.

Despite predictions of success, TB returned with vigour in the mid-1980s with a sharp increase in TB rates in developed nations. This resulted in the WHO declaring TB to be a global emergency in 1993, an unusual step for a disease that is completely treatable if diagnosed early. Predictably, this resurgence has attracted considerable attention and a plethora of studies have considered the

variables that may have contributed to the rise. As Grange et al. (2001) state, "We are now witnessing an emerging pandemic of a 'new tuberculosis' with quite different characteristics resulting from an equally, or perhaps more, complex interplay of the old and new factors" (Grange et al., 2001:211). In a similar vein, Farmer (1997) suggests that TB was never conquered but retreated within certain populations removed from the attention of many researchers and policy-makers. He states, "One of the implications, clearly, is that one place for diseases to 'hide' is among poor people, especially when the poor are socially and medically segregated from those whose deaths might be considered more significant" (Farmer, 1997:355).

The three main factors that are cited throughout the literature as the main 'drivers' behind the 'new' tuberculosis are the emergence of TB/HIV co-infection, increase in MDR TB and immigration. Each of these will be discussed in turn. There are also commentators who argue that any understanding of the resurgence of TB must be situated within economic, social and political contexts. This group of researchers links the growth in the disease to poverty and widening disadvantage as opposed to behavioural factors. The last section will consider these socio-economic factors.

## *HIV*

One factor that has been linked with the rise in TB incidence is co-infection with Human Immunodeficiency Virus (HIV). TB kills more HIV-infected people than any other cause (Johansson et al., 2000:35; World Health Organisation, 2006g) and in 2004, approximately 250,000 TB deaths were associated with HIV. TB/HIV co-infection is particularly evident in Africa which accounts for 81% of the estimated 741,000 cases of TB among HIV-positive people in the world (World Health Organisation, 2006c).

Those with HIV frequently experience atypical pulmonary TB with a high rate of extra pulmonary TB (Raviglione, Narain and Kochi, 1992). Normally, people have a 5-10% chance of developing active disease after becoming infected with TB, while people with HIV have an 8% chance of developing TB disease each year which rises to a 50% chance over the remainder of their life span. Antunes and Waldman (2001) document the resurgence in TB rates in Sao Paulo since 1985 and found a strong association between TB and AIDS mortality. They argue that the increase in TB mortality from the mid 1980s can be partially attributed to the growth of AIDS.

Although TB/HIV co-infection constitutes over 10% of new TB cases in some countries, there is evidence that it does not completely explain why TB rates have increased so much since the 1980s. Elender et al. (1998) examined standardised annual TB mortality rates in England and Wales between 1982-1992 and found no evidence to support the proposition that the resurgence in TB is due to HIV/TB co-infection except amongst younger men, the group most likely to have AIDS. The authors conclude that AIDS has little influence on TB mortality amongst the wider population.

This is because there is only a small overlap between HIV and TB populations as the majority of TB sufferers are elderly, while HIV mainly tends to be found in young white men. This points to two types of TB – new infections (mainly in the young) and reactivation of old, dormant infections (mainly in the older population). Heath et al. (1998) comment upon how HIV/TB co-infection has not played a major role in the resurgence of TB in Australia with only 2% of notifications due to co-infection. The authors speculate that possible reasons for this could be: the low number of AIDS cases altogether, and that high risk populations for TB and AIDS do not coincide either socially or geographically. For instance, while those with AIDS tend to comprise homosexual men, TB rates for men in general are actually decreasing. In a study undertaken by Lillebaek et al. (2002) of TB in Somali immigrants in Denmark, it is suggested that HIV co-infection with TB is virtually non-existent with perhaps only one or two Somali TB patients found to be HIV positive every year (Lillebaek et al., 2002:682).

### *Multi Drug Resistant TB*

Another factor that has been thought to contribute to the rise in TB rates is the emergence of Multi Drug Resistant TB (MDR TB). Gandy and Zumla (2002a) suggest that MDR TB may be responsible for 10% of new TB cases. MDR TB is believed to occur due to poor supervision of therapy, incomplete treatment regimens, use of badly prepared/combined preparations, inconsistent prescribing, erratic drug supplies and unregulated over-the-counter prescription use (Gandy and Zumla, 2002a). Some commentators have even suggested that MDR TB is partially attributable to the degradation of health services (Wallace, 1994; Wallace and Wallace, 1999; Wallace et al., 1999). For example, in New York, public health expenditure on TB steadily decreased from the 1960s. In 1979 TB rates began to climb and by 1992 a third of New York's TB cases were resistant to at least one first line drug and almost 20% were resistant to both isoniazid and rifampicin (Farmer, 1997; Gandy and Zumla, 2002a). The MDR TB outbreak ended up costing the city 10 times more to bring under control than the savings made through reducing TB expenditure (Boseley (1999) cited in Gandy and Zumla, 2002a:387). Yet, as is the case with TB/HIV co-infection, not all countries are facing widespread MDR TB. In Australia, Heath et al. (1998) document low levels of MDR TB with only five instances of MDR TB reported between 1992 and 1995. In New Zealand, there are fewer than four MDR TB cases per annum (Forde, 2003).

Paul Farmer has extensively documented a number of MDR TB outbreaks in Peru, Haiti and Russia (Farmer, 1997; 2000; 2001). According to Farmer, TB is the leading cause of death for Russian prisoners with 20-25% having MDR TB at rates reaching 7,000 per 100,000 (Grange et al., 2001), with only 46% being cured with standard treatment regimens (Farmer, 2001). This is due to the fact that DOTS, though being the standard control strategy, is not an effective response to MDR TB as many patients are already resistant to the drugs used in DOTS regimens. Yet there is, Farmer suggests, a reluctance to treat TB with anything apart from DOTS. This has implications for furtherance of existing drug resistance and increasing toxicity. Drawing on an example from

Peru, Farmer suggests that DOTS needs to be modified to combat MDR TB. Despite Peru having an excellent DOTS programme, there were a number of patients who repeatedly failed to complete therapy. Through laboratory analysis, it was discovered that 90% of Peruvian patients who failed to complete their DOTS treatment had MDR TB. Furthermore, of those with MDR TB, most were resistant to all four first-line drugs with many being resistant to between 8-12 types of TB drugs (Farmer, 2001:170). Clinicians began a programme for these 'problem' patients by establishing individual treatment plans and training members of the community as health workers. Despite predictions the programme would fail, 85% were cured in spite of the considerable side-effects.

## *Immigration*

The third main factor commonly associated with the resurgence in TB is immigration. A number of researchers have documented how people from countries with a high TB incidence rate have immigrated to low incidence countries and are responsible for a significant proportion of the disease burden despite making up only a small percentage of the total population. For instance, immigrants constitute 64% of TB cases in Canada (Health Canada, 2000), 79% in Australia (Gilroy and National TB Advisory Group, 1999) 56% in the Netherlands (Bwire et al., 2000), over 50% in six of the 13 US states (Talbot et al., 2000b) and over half of TB cases in European countries such as Denmark, Israel, the Netherlands, Norway, Sweden and Switzerland (Schwoebel et al., 1999). In many cases TB rates amongst those born overseas are 10 to 20 times greater than for the host population (Littleton et al., 2007). It is important to note however that the proportion of overseas-born TB notifications varies between different areas, largely reflecting the distribution of migrants. For instance, in Australia in 2002, 86% of TB cases in New South Wales were overseas-born compared with only 30% in the Northern Territory (Samaan et al., 2003).

Cowie and Sharpe (1998) found that of the 351 cases of TB during the five year study period, 70.6% were immigrants to Canada despite immigrants constituting only 16% of the population. The annual incidence of disease in Southern Alberta is 25.8 per 100,000 amongst the immigrant population but only 5.8 per 100,000 amongst the Canadian born population. Lillebaek et al. (2002) consider the way in which immigration from high incidence countries to low-incidence countries can increase TB rates, focusing particularly upon the Somali population in Denmark. They posit that the doubling in TB cases over the last 15 years is largely attributable to the number of Somali immigrants, as is the case in other European countries. For example, between 1991 and 1999, 57.5% of reported TB cases were foreign-born, of whom 37.8% were Somali (Lillebaek et al., 2002:681). Lillebaek et al. conducted a retrospective cohort analysis of surveillance data for 901 Somalis with TB out of a total of the 13,535 Somalis who arrived in Denmark during the 1990's. They found that the overall annual incidence rate for Somalis was between 1.1% and 2.0%.

TB rates amongst Somali immigrants in Minnesota were the focus of the study by Kempainen et al. (2001) who found that Somalis account for less than 0.4% of the Minnesota's population but

comprise 17% of Minnesota TB cases and 23% of all foreign born cases. The researchers found 82 cases of TB amongst the Somali population between 1993 and 1998, resulting in an incidence rate of 170 per 100,000. A study done by Heath et al. (1998) in Australia investigated the influence of immigration from high-incidence countries on the TB levels of a low-incidence country. They suggest that immigration has greatly contributed to Australia's rising notification rate. Although TB rates are generally quite low in New South Wales, notification numbers have increased by around 50% over the last ten years. This has placed TB services under considerable pressure given that resources have been directed away from them in recent years. By 1995, the TB notification rate was 13 times higher for the overseas-born population than for Australian-born residents (26.8:100,000 compared to 2.1:100,000).

Given the association between immigrants and TB, one of the main public health responses is to screen migrants for a wide range of diseases and health problems either prior to, or shortly after, arrival. Yet there is some research that challenges the assumption that screening upon arrival will necessarily identify and resolve infectious disease and thus provide the degree of protection desired. Although Farah et al. (2005) found that TB rates were the highest in the first two years following migration, rates remained much higher amongst immigrants than the Norwegian-born population even after seven years post-migration. Cowie and Sharpe (1998) discovered that the mean period between arrival in Canada and diagnosis of TB was 11.2 years with a median of seven years. The interval between arrival and diagnosis depended on the type of TB contracted with pulmonary TB having the longest interval and TB in the lymph node the shortest. The authors state that:

*"The risk of TB for immigrants is the same as prevails in their countries of origin, but there may be little general awareness among physicians that foreign-born residents remain at significant risk for many years after their arrival in Canada" (Cowie and Sharpe, 1998:601)*

This finding is supported by the work of Lillebaek et al. (2002) who established that the TB incidence rate decreased only slightly when taking into account years of residence. For example, the incidence rate for Somalis who had lived in Denmark for five years was 1.2% compared with rates of 2.0% during year of arrival. Lillebaek et al's (2002) research shows that TB rates declined only gradually over the first seven years of residence, which raises questions about the effectiveness of only screening migrants prior to, or upon, arrival in the resettlement country which is premised on the notion that TB will decline sharply within the first few years of residence. The authors propose solutions to this quandary including multiple health checks, preventative therapy and sub-group specific interventions. An implication of the findings presented by Lillebaek et al is that the main mechanism by which TB can be stopped is to prevent the transition from latent to active disease.

One of the reasons why public health authorities screen immigrants upon arrival is to protect the host population from disease and infection. However there is evidence that challenges this assumption by suggesting that transmission of TB from immigrants to the host population is very rare (DeRiemer et al., 1998). Using DNA fingerprinting, Lillebaek et al. (2001) found very little transmission of TB occurring between migrant and host populations. Of the 391 Somali patients with culture-positive TB between 1996 and 1998, three-quarters were reactivations of old TB infections as they had unique DNA sequences. The remaining 23.3% were likely to have been infected by other Somali immigrants because they belonged to clusters largely made up of other Somalis. Only 1.8% of Somalis were likely to be infected by Danes. The authors speculate that this is due to Somalis' limited social contact with the Danish population. Using DNA fingerprinting technology, a number of different researchers have documented that most TB cases amongst migrant populations are unique strains of TB and are a result of imported TB infections which subsequently reactivate into active disease (Chin et al., 1998; DeRiemer et al., 1998; Heath et al., 1998; Kempainen et al., 2001; Lillebaek et al., 2002).

One particularly interesting finding in the study conducted by Lillebaek and colleagues was that TB rates amongst Somalis living in Denmark may in fact be the same or higher than rates in Somalia (Lillebaek et al., 2002:682). While this finding is not universally supported (Watkins, Plant and Gushulak, 2002) it does raise interesting questions about whether the social, economic and political environment in which migrants live, facilitates the development of TB. While the comparison of TB rates between countries is problematic due to differences in detection and data collection, it shifts the focus from the 'diseased migrant' to the quality of living conditions of the host country.

Yet some have argued it is simplistic to equate rising TB incidence to immigration. Elender et al. (1998) discuss how, although ethnic minorities tend to experience much higher rates of TB than the host population, the recent increase in TB does not correspond with the increase in immigration from high-incidence countries. They describe the debate over whether ethnicity or poverty is the main determinant of TB and cite studies that found that TB rates amongst the white population and immigrants from the Indian subcontinent were very similar in deprived areas (Cundall and Pearson, 1988; Goldman, 1994). Thus it can be argued that poverty can be the main causal mechanism in certain settings. In the study conducted by Elender et al. into the relationship of TB mortality with poverty, ethnicity and AIDS, they found no relationship between ethnicity and mortality. The strongest association with mortality was overcrowding. The authors critique other studies which tend to assume that the variable 'ethnicity' can be easily compared with other variables such as 'overcrowding' or 'unemployment'. They state, "Within such groupings [ethnicity] are a wide variety of genetic backgrounds, cultures, lifestyles and health-related behaviours, any of which may contribute to tuberculosis levels" (Elender et al., 1998:679). Furthermore, the label 'ethnicity' masks the high degree of variation between populations.

Antunes and Waldman (2001) support the idea that rising TB rates cannot solely be explained by immigration from high incidence areas, but that the multiple needs and deprivation of immigrants increase the risk of transmission and reactivation of TB. Kistemann et al. (2002) used statistical analysis to consider risk factors for TB in Cologne, Germany. They found that although there was a strong positive association between TB incidence and immigration, there was evidence for a correlation between TB incidence and deprivation indicators, particularly between ethnicity and economic indicators. They conclude by suggesting that it may be wider deprivation that is associated with higher rates of TB rather than immigration. In a similar vein Kempainen et al. (2001) suggest that the large TB burden in the Somali population in Minnesota is due to multiple factors such as poverty, overcrowding and limited medical resources.

While immigration has been repeatedly linked with the re-emergence of TB a variety of authors have engaged with it in a limited, almost binary way. Many studies are restricted to discussing whether or not immigration has caused the resurgence in TB, whether TB is imported or not, and the length of time between arrival and notification. While these questions are important, they fail to adequately explain what it is about the process of immigration and being a migrant that is resulting in high TB rates. Although there is a wealth of literature on the health impacts of being a migrant (e.g. Ingleby, 2005; Jatrana, Toyota and Yeoh, 2005), this avenue of investigation has not been well-explored in respect to TB. Furthermore, many of the studies on immigration only focus on a singular major migratory journey - from 'there' to 'here' when in fact, mobility is an ongoing process in the lives of migrants. The broad implication of this mobility is not well understood in relation to TB (c.f. Warfa et al., 2006 who consider the connection between mobility and mental health), a disease for which long-term care and relationships with health-providers are required.

Although immigrants clearly have far higher rates of TB than local populations, many studies have failed to disentangle the different types and characteristics of immigration flows. One could argue that there is a vast difference in circumstances, and thus health status between an immigrant who moves to another country to take up a professional position compared with a refugee. An exception to this shortcoming is a report by Kelly et al. (2002) that considers the relationship between the refugee experience and high rates of TB amongst East Timorese refugees evacuated to Darwin, Australia during 1999. In addition, the process of classifying people as 'immigrants' and 'host population' when discussing TB rates is a somewhat artificial duality given that many migrant families have children born in the country of resettlement and would thus fall under the 'locally-born' category.

The main shortcoming of the literature on the effect of immigration on TB rates is that many commentators fail to engage with the lifeworlds and realities of 'migrants' in order to understand why migrants experience such rates of disease. While we know that immigrants have high TB levels there are few studies that seek to understand what it is about being a migrant that leads to this experience. Littleton et al. (2007) suggest that focusing on the experiences of migrants can

help explain why reactivation occurs. Such factors include the nature of the migratory journey itself and the process of resettlement where migrants may face discrimination, language barriers, lack of social support, difficulty obtaining employment and limited financial resources. These experiences can damage health and wellbeing, lower immunological resistance thus rendering migrants vulnerable to health problems including TB (Jones and Moon, 1987).

### *Socio-economic status*

With the increase in TB rates since the mid 1980s, many researchers have focused on analysing epidemiological data to understand and explain the resurgence of TB. There has been a tendency to attribute this problem to groups typically 'othered' in mainstream society – immigrants, people with HIV and those who do not take their medication 'properly'. A smaller but not insignificant group of researchers argue that the resurgence in TB needs to be situated within social, political and economic contexts. Calls for such an approach are not new. Rene and Jean Dubos emphasised the social nature of TB in 1953 when they described it as, "...a social disease, and presents problems that transcend the conventional medical approach ... its understanding demands that the impact of social and economic factors on the individual be considered as much as the mechanisms by which tubercle bacilli cause damage to the human body" (Dubos and Dubos, 1953:vii).

Writing some fifty years later, Gandy and Zumla (2002a) argue that the resurgence of TB has been examined mainly in behavioural and biological terms with an overwhelming emphasis on patient non-compliance as the main barrier to TB control. They suggest that this focus neglects social and historical contexts. Furthermore, many commentators have employed 'bio-medical individualism', failing to take into consideration broader disease epidemiology or social processes. Gandy and Zumla argue that the most decisive factor in the 'new' TB is not MDR TB or TB/HIV co-infection but wider structural issues - "Issues of poverty, gender inequality, disease stigmatisation and the adequacy of medical services are central elements in any full explanation of the contemporary resurgence of this disease" (Gandy and Zumla, 2002a:391). In other words, TB is as much a social phenomenon as it is biological.

Gandy and Zumla (2002a) underpin their argument by stating that the issue of TB is not one that can simply be explained from a bio-medical perspective; rather that there is a complex web of interconnected social, economic, cultural, political and biological factors at work. One such example is the way that the rise in TB can be linked with global restructuring. They state, "An emerging theme is the extent to which the resurgence of TB can be related to contemporary processes of social and economic restructuring in response to changes within the global economy since the late 1960's and early 1970's associated with a shift towards neo-liberal patterns of policy making" (Gandy and Zumla, 2002a:388).

These claims resonate strongly with the views of Paul Farmer who has been published extensively on TB. Farmer critiques the way in which social scientists have approached TB and their “immodest claims of causality” (Farmer, 1997) and focus on ‘culture’ and ‘patient agency’ to the detriment of wider structural forces such as poverty. He continues by advocating that social scientists devote attention to illuminating, and subsequently addressing, the social forces that contribute to the prevalence of TB.

Overcrowding is one socio-economic factor and measure of poverty that has been frequently mentioned throughout the literature as being important to TB. It is also pertinent given that TB is an infectious disease generally transmitted through close contact. Antunes and Waldman (2001) found evidence for a link between TB mortality and socio-economic factors. Interestingly, there was a relationship between mean number of dwellers per bedroom of the home and TB/AIDS mortality while, the smaller the mean size of the household, the greater the mortality. They found that although there was no relationship between mortality and population density at a district level, there was a relationship at the household level where crowding could lead to greater transmission. This is because of the lack of ultra-violet light (which is known to kill the bacteria) and airflow. Thus inhabitants have a greater chance of breathing in the germs. Yet, while household crowding increases the risk of becoming infected with TB if a household member has the disease, it does not necessarily lead to disease. This outcome depends on the individual’s immune system status. This evidence suggests that prolonged contact is required for transmission to occur. Yet it is impossible to ignore the extent to which TB is strongly associated with material deprivation. Overcrowding can therefore be seen as both a measure of material deprivation and as a transmission route.

Tocque et al. (1998) considered the effects of deprivation, immigration and the elderly in explaining differences in TB notifications in England. Regression models showed that the immigrant index had the strongest statistical power in explaining TB rate variations, though there was an observed relationship between immigration and deprivation indices. Interestingly they observed spatial patterns between London and other metropolitan districts. In London, measures of deprivation, immigration and the elderly were inter-correlated. Areas with a high proportion of immigrants had high levels of deprivation and low proportions of elderly. In surrounding districts however, only immigration and deprivation were significantly related, although removing the immigration component out of the deprivation index eliminated the statistical significance. No relationship between the proportion of elderly and TB notifications was observed in the metropolitan districts.

The authors make an important statement in the conclusion of their paper, saying that “differences in TB levels across metropolitan districts and boroughs of London can be more accurately predicted by both the immigrant component and deprivation indices of the area than by each factor alone” (Tocque et al., 1998:217). This conclusion is particularly useful as it highlights one of the limitations of the body of research on TB in that causal factors and variables tend to be examined

in an either/or fashion thus atomising highly related and interdependent variables i.e. ethnicity and socio-economic status. Taking each variable in isolation can lead to inconsistent, and at times conflicting, relationships between variables. Although it is undoubtedly important to understand the degree of influence of individual variables, it is crucial to remember the people who are being described do not experience their 'ethnicity' and 'socio-economic status' atomistically, but in unison. One could argue that the whole is greater than the sum of its parts.

## **TB Control, treatment and compliance**

One topic that has received an enormous amount of attention is the success and failure of TB treatment regimens. In order to consider this topic, the current TB treatment regimen, DOTS will be described followed by a discussion of issues around compliance. I argue that adherence, and non-adherence in particular, has become the focus of debates about why TB treatment fails. Feeding into this debate is what I have termed 'culture' studies. By this I mean research that seeks to gauge the knowledge and perceptions of different cultural groups (with previous or current high rates of non-adherence) about various aspects of tuberculosis, usually with the desire to educate and reform the group in question and thus to improve treatment success outcomes.

### *Directly Observed Therapy Short-course (DOTS)*

In response to TB being declared a global emergency by the WHO in 1993, a new TB strategy called DOTS was implemented. WHO set goals of achieving cure rates of 85% in developing countries and 95% in developed nations. DOTS consists of five elements: case-finding through bacteriological examinations of those with symptoms, administration of short-course treatment primarily via direct observation, creating greater political support to generate resources for TB control, regular supply of anti-TB drugs, and reliable systems to monitor and provide data for case finding and treatment activities. It is important to note that there are many variations of DOTS in practice and it is not always clear within the literature what form of health service is being discussed or compared.

Since inception, DOTS has been controversial due to concerns with the 'directly observed' component for operational and ethical reasons. Some programme designers denied that DOTS was ever the focus it was simply a catchy acronym used to sell the programme (Ogden et al., 2003). Nevertheless, the WHO became subject to allegations of ignoring the human rights aspects of TB control (Bayer and Wilkinson, 1995). By 2000, WHO relaxed its strict enforcement of the DOTS model by acknowledging it was just part of a wider approach to combat TB that needed to be country-specific. This is in response to critics questioning whether one approach (DOTS), developed by industrialised nations should be universally applied. Farmer (2001) similarly argues that DOTS should not be an 'one size fits all' universal solution to TB. He points out that, although DOTS is the best way to combat TB, MDR TB is not responsive to DOTS. Beyond the human

rights dimension, some researchers began to question whether DOTS improved treatment outcomes (Volmink, Matchaba and Garner, 2000). A trial was conducted in South Africa of DOTS vs. non-DOTS (Zwarenstein et al., 1998). They found DOTS to be of no benefit to treatment outcomes, however the study was dismissed by the WHO.

Hurtig et al. (1999) similarly critique the DOTS strategy from a human rights perspective. They argue that DOTS is ethically problematic due to the imbalance of power between the 'observer' and 'the observed'. This places undue burden on patients, "...the strategy focuses on the individual patient, who is treated without reference to the social conditions that frame his or her life" (Hurtig et al., 1999:555). Hurtig et al. continue by suggesting that DOTS is exclusively biomedically focused and fails to address the non-medical determinants of health such as environment, socio-economic status and wellbeing. In other words, DOTS falls short of embracing the social, economic and cultural dimensions of TB as "Public health strategies for the control of infections concentrate on disease rather than 'well-being'" (Hurtig et al., 1999:555). Johansson et al. (2000) contend that DOTS is very insensitive for some sectors of the Vietnamese population, particularly low income women (Johansson et al., 2000). In summary, DOTS has been criticised from a number of standpoints including human rights and the exclusive focus on biomedical disease. Feeding into this discussion is a large number of studies which have sought to investigate the reasons why people fail to comply with treatment regimens.

## *Compliance*

One of the main issues being addressed by TB researchers is that of non-compliance. Although compliance has been intensively researched since the early 1980s, it has been the focus of attention since the early 20th century (Lerner, 1997). While tuberculosis is a treatable disease, treatment regimens can be complicated, entailing taking multiple medications for six months or more often with unpleasant side effects. Evidence suggests that significant proportions of patients fail to complete treatment (between 20-40% on average) although estimates vary between studies (Sumartojo, 1993; Liam et al., 1999; Calder et al., 2001). Compliance and non-compliance is important both in terms of health outcomes for the individual but also at the macro level in terms of preventing widespread outbreaks, particularly in an age of MDR TB.

Within the literature on compliance, a wide range of variables are implicated including demographic, socio-economic, health services, educational and cultural factors. Unfortunately, however, the predictive strength of these factors is variable between different studies (Sumartojo, 1993) such as, whether men are more likely to be compliant (Johansson et al., 2000) than women (van der Werf, Dade and van der Mark, 1990). Furthermore there is great inconsistency in the definition and methodologies used to research compliance (Homedes and Ugalde, 1993). Frequently, education is cited as the means to overcome non-compliance, in addition to calls for in-depth studies of particular cultural groups' attitudes and perceptions of TB. Such efforts are

premised on the notion that by understanding cultural beliefs about TB, erroneous views can be remedied and compliance improved. There have been a number of critics of the literature on compliance whose arguments will also be outlined.

Baarnhorn and Adriaanse (1992) considered the factors responsible for non-compliance amongst TB patients in India and found that socio-economic variables such as monthly income per capita, house type and total monthly family income were the most significant variables in explaining the difference between adherent versus non-adherent patients. Others have established that demographic or personal characteristics are important predictors of compliance. Van der Werf et al. (1990) found that gender and younger age were linked with higher compliance, while Cummings et al., (1998) discovered that personal characteristics such as, moving frequently were connected with default from treatment.

While treatment failure tends to be blamed on the non-compliance of patients, some have increasingly blamed health services (Rubel and Garro, 1992; Braun and Wiesner, 1994). A number of studies suggest that the lack of availability, affordability and acceptability of health services is strongly linked to low compliance levels (Juvekar et al., 1995; Thomas, 2002; Greene, 2004). LoBue et al. (2001) administered a survey to 384 physicians in San Diego to assess their knowledge, attitudes and practices regarding TB. Despite clearly established guidelines on the treatment and management of TB, a number of physicians did not comply, made errors in TB treatment and/or demonstrated poor TB knowledge. Jaramillo (1998) documents cases of erroneous beliefs and practices of health care workers involved in treating those with TB. He provides the example of how some health workers exhibit poor knowledge of TB treatment guidelines, modes of transmission and wrongly attribute poor adherence to the laziness of patients. Interestingly, while Calder et al. (2001) recommend further “surveillance” and multiple methods of monitoring patients to ensure adherence MacIntyre et al. (2005) found that patient self-reporting of adherence was more accurate than clinician assessments of adherence.

Another key explanation for compliance is that of education or knowledge. Despite evidence that high levels of TB knowledge and understanding do not improve treatment adherence (Goyal, Mathur and Pamra, 1978; Purohit et al., 1988; Ramachandran et al., 1995) a number of researchers have called for greater education to improve adherence (Barnhoorn and Adriaanse, 1992). Liefoghe et al. (1995) sought to understand the reasons behind high default rates at a TB hospital in Pakistan. They conclude with a call for greater health education stating that, “Education is an integral part of the whole programme. The education of both staff and patients should begin with an assessment of their knowledge so that old erroneous beliefs can be corrected and current knowledge imparted” (Liefoghe et al., 1995:1686).

Against this backdrop of high non-compliance rates, a number of studies report on initiatives to improve compliance. While some predictors of non-compliance, such as gender and ethnicity

cannot be changed, other social, cognitive and behavioural variables are being addressed. One such example is research by Demissie et al. (2003) and Getahun (1998) who report on a project to improve TB treatment compliance through the establishment of TB clubs in Ethiopia which were established with patients from the same neighbourhood to provide mutual support. During meetings, club members would talk about TB and the side effects of their medication. The elected leader would monitor drug intake and follow up on defaulters. The authors found that those in the TB club had a greater completion rate and lower default rate compared to the control group. Other initiatives to improve compliance described in Volmink et al's (2000) review of 32 international DOTS programmes include offering participants free food, transport, additional social support, medical services and celebrations of accomplishments (Volmink et al., 2000).

### *Culture studies*

Within studies on non compliance, a number of commentators have called for research that elucidates the cultural beliefs particular groups have about TB. The goal of such research is to improve adherence by ensuring that health education is culturally specific (e.g. Carey et al., 1997; Tulskey et al., 1999). As stated by Kocs et al. (1995) "one critical barrier to controlling this pandemic (TB) is still our relative ignorance of how different cultural structures and beliefs shape patterns of non compliance" (Kocs et al., 1995:1).

One important contribution is the work of Rubel and Garro (1992) who lament the failure of TB researchers to engage with socio-cultural determinants of TB arguing that that most TB researchers have focused on discovering a 'magic bullet' to the TB problem rather than exploring the social nature of TB. There are relatively few researchers who have considered the experiences of those with TB and how they cope with their situation (see Wilton (1996) for a similar discussion in respect to HIV AIDS). Furthermore, research has also tended to focus on single barriers to successful TB treatment in isolation rather than exploring the interconnections between multiple factors. They argue that an integrated approach is required to consider the multiple dimensions and complexity of TB.

Following the arguments put forward by Rubel and Garro about the importance of understanding socio-cultural factors, a number of studies have been conducted investigating different cultural groups' knowledge and perceptions of TB. Most often the groups chosen are marginalised, either ethnically or socio-economically, and have high levels of TB. The topics that have been investigated include knowledge of TB and beliefs about causation, transmission, prevention, treatment and impacts. Each of these topics will be considered in turn with a special focus on TB research conducted with Somali people.

## TB knowledge

A number of studies have examined the way in which particular groups perceive and conceptualise TB within a range of settings including South Africa (Westaway, 1989; de Villiers, 1991; Edginton, Sekatane and Goldstein, 2002), Vietnam (Carey et al., 1997; Long et al., 1999a), Philippines (Navio, Yuste and Pasicatan, 2002), Malaysia (Liam et al., 1999), India (Nair, George and Chacko, 1997), Pakistan (Liefoghe et al., 1995) and Mexican farm workers and homeless adults in the US (Poss, 1998; Tulsy et al., 1999).

Mexican farm workers interviewed by Poss (1998) perceived TB as a serious and dangerous disease. When asked about the social significance of TB, most said that people do not like to talk about it and are afraid of it. In Vietnam, Johansson et al. (2000) document how TB is seen as incurable and particularly affecting the poor. The authors argue that attitudes and behaviour towards TB are influenced by socio-economic status, family structures and gender roles. In Liefoghe et al's (1995) work in Pakistan, patients saw TB as dangerous and contagious with patients hoping for, but not being convinced about, the prospects of being cured. Rural South Africans interviewed by Edginton et al. (2002) also viewed TB as a disease of 'bad' people associated with heavy drinking, poverty and the infringement of cultural norms. Rubel and Garro (1992) contribute to this discussion in their research into how different ethnic groups perceive TB in different ways. For example, a study in Florida with three different ethnic groups found that Latinos and Anglos saw TB as a mild, slow-moving disease while African Americans perceived TB as fast-moving, powerful, mysterious, and not well understood by science. African Americans believed TB is a dirty disease that tends to attack 'bad people'.

De Villiers (1991) explored perceptions of TB among the Xhosa in South Africa and found that it continues to be perceived as a highly serious, shameful disease associated with being dirty or unhygienic. He begins by suggesting, "Xhosa-speaking patients' perceptions of tuberculosis are often shaped by both Xhosa tradition and a diversity of socio-cultural factors that arise from the acculturation process" (de Villiers, 1991:69). Xhosa perceptions of TB have changed over the last 30 years due to westernisation among other factors, such as the discovery that patients are no longer infectious almost as soon as they start treatment, and that most TB patients can be treated at home. Nevertheless ideas about TB are still informed by Xhosa traditions such as the belief that TB is a disease caused by witchcraft. In line with this tradition, patients' main concern is to find out *who* has caused their affliction (TB) although some are reluctant to disclose this to others. This type of TB is thought to be untreatable and not understood by Western doctors due to its supernatural origin. Therefore a patient may utilise the services of a biomedical doctor and also a diviner, with different expectations of each and the results that are hoped for. For instance, a doctor might provide symptom relief while a diviner provides diagnosis. Generally these two modes co-exist but sometimes they come into conflict with patients holding different views on the effectiveness of diviners.

Other researchers have also documented multiple models of TB. Johansson et al. (2000) and Long et al. (1999a) describes the four types of TB in the Vietnamese conceptualisation of the disease: 'Lao tam' caused by too much thinking and worrying, 'Lao luc' caused by too much hard work without enough food or rest; 'lao truyen' a hereditary disease in the blood, and 'lao phoi' a contagious type of TB. Those with hereditary TB and their families experienced social isolation. Interestingly, this traditional four-dimensional conceptualisation of TB tended to be employed by those who had experienced the disease themselves while participants who had not experienced it tended to ascribe to a more western scientific way of viewing TB. Participants identified a number of risk factors which were highly gendered reflecting the different roles of men and women in Vietnamese society. Participants believed that male risk factors (eating out, smoking, drinking, wider social contacts, heavy work) were stronger than female risk factors (too much thinking, poorer health status, dependence on in-laws, pregnancy and delivery) thus explaining the higher proportion of men with TB.

Rural South Africans interviewed by Edginton et al. (2002) also spoke of two types of TB: 'western TB' and 'tindzaka'. Tindzaka is indistinguishable from 'western' TB but is thought to be caused by breaking traditional protocols such as the requirement to abstain from sex for those mourning the death of a loved one and for women who have recently miscarried. According to the authors, "There is considerable secrecy and stigmatisation attached to this disease" (Edginton et al., 2002:1078). Western style medicine is thought to be ineffective for this type of TB. The second type of TB is what is known as 'western' tuberculosis. This type of TB is thought to be spread by contact with infectious patients, sharing food, drinks, utensils, cigarettes with infected persons. It is believed that it can only be treated by doctors.

Kwan-Gett (1998) established a Somali TB cultural profile following focus groups with eight members of Seattle's Somali community. According to participants, TB is identified when individuals begin to cough blood or lose weight. It is known to be contagious and it is believed that climatic and other factors such as overwork can contribute to illness. Some believe it is hereditary, up to six generations. In southern Somalia, TB is called *tibisho* (derived phonetically from Italian) while in the north, the word '*qaaxo*' or '*urug*' is sometimes used. According to Kwan-Gett, "*Qaaxo* and *Urug* are historical Somali words for the entity of TB with cough and haemoptysis. Both words bring to mind a powerful dark image of an isolated ill person who is close to death. *Qaaxo* may be even be used as a curse" (Kwan-Gett, 1998:2).

Nichter (1994) argues that there is a need to move away from considering discrete illnesses, such as TB, to focusing on sets of inter-related illnesses. He states that, "Most health social science research on TB in the Third World has studied TB in isolation from other lung diseases. As a result, little is known about how TB is conceptualised by laypersons in relation to other types of sickness, the extent to which these disease are recognised as predisposing one to TB, and how perceptions of causality influence illness treatment practices" (Nichter, 1994:649). Nichter

considers illness semantics including "...how this illness is and is not spoken about, by whom, in what contexts and for what reasons" (Nichter, 1994:649). He argues that illness semantics such as the language used to market TB drugs and speak about TB are important but have been under-researched. Interviews conducted by Nichter revealed that 76% believed that weak lungs developed into TB if not cured, 12% said the illnesses were identical while 12% said there was no connection. TB was not openly spoken about in the community and informants denied having much knowledge of the disease. The researcher found that, in order to gain information about people's TB beliefs, it was more productive to focus on general health problems in the community and to ask open ended questions rather than directly ask questions about TB.

A number of studies have also sought to evaluate the extent and accuracy of TB knowledge amongst particular groups, and what factors influence this knowledge. Research suggests that in most situations, at-risk groups tend to have a fairly good level of understanding and knowledge of TB, though a number of studies also point out erroneous beliefs. Carey et al's (1997) research amongst Vietnamese found that nearly two thirds thought it was possible to carry TB infection without experiencing symptoms through having a strong immune system, while just under one third thought that those infected would automatically experience symptoms. Over half of the sample thought that the disease could be prevented by taking medicines. This is in contrast with Long et al. (1999a) who found that participants had a good biomedical understanding of the characteristics of TB. No differences were observed between men and women, or between those in the north and south in terms of their beliefs and understanding of TB.

A number of researchers suggest that TB knowledge is related to overall education levels. Navio et al. (2002) found that in their sample of Filipinos, TB knowledge scores were highest amongst those with college education and family incomes over 10,000 pesos per month. Overall, low TB knowledge was determined by individuals' level of education rather than age, sex, income, occupation or place of residence. Westaway (1989) assessed the extent of TB knowledge amongst black South Africans and found that those with greater levels of schooling had better knowledge. Liam et al. (1999) found that most patients had a limited understanding of TB, with those of older age and with higher education levels having greater knowledge. Homeless adults interviewed by Tulskey et al. (1999) had a fairly good knowledge of TB. Over 40% reported they were not worried about catching TB while around half said they were actively trying to avoid getting TB.

In line with the widespread impetus to improve TB education programmes, some researchers are beginning to examine where people get their information about the disease. Poss (1998) found that two-thirds of participants had attended a TB education programme while others gained information from other sources such as fellow workers, friends, family, nurses and doctors. Navio et al. (2002) suggested that respondents gained knowledge about TB from the radio or family/friends while participants interviewed by Tulskey et al. (1999) learnt the disease from health

care providers, medical clinics and printed material. According to Liam et al. (1999) the most common source of information about TB was friends/relatives (71 out of 135 patients) followed by mass media. Discussing their results, the authors state, "More than half of the patients had gathered information on TB through conversation with friends or relatives. However, such information was from people who themselves were likely to be misinformed and was therefore inaccurate" (Liam et al., 1999:305).

## Causes and risk factors

Socio-cultural research has also illuminated differing lay explanations of the causes and risk factors associated with TB. These can be divided into medical, behavioural and environmental categories with most population groups identifying with a range of factors from each category.

When surveying lay people about the causes of TB, exposure to germs was often mentioned (Carey et al., 1997; Nair et al., 1997; Poss, 1998). Nichter (1994) however found that very few people associated TB with germs but this association increased over time potentially due to the cumulative effect of health messages. Only one-quarter of participants in Navio et al's., (2002) study agreed that TB was caused by a germ compared with 29% of people in Westaway's study (1989). Other lay explanations for TB include pregnancy (Long et al., 1999a; Johansson et al., 2000), weak lungs (Nichter, 1994), lung injury (Liefoghe et al., 1995; Jaramillo, 1998), exposure to other people with TB (Carey et al., 1997; Edginton et al., 2002) or inadequate previous treatment of TB (Edginton et al., 2002). Interestingly, TB was associated with being hereditary in only three studies (Nichter, 1994; Long et al., 1999a; Johansson et al., 2000).

A variety of other behavioural factors were also mentioned including worry (Nair et al., 1997; Long et al., 1999a; Johansson et al., 2000), smoking and alcohol (Westaway, 1989; Nichter, 1994; Edginton et al., 2002), weakness (Poss, 1998), hard work (Carey et al., 1997; Long et al., 1999b; Johansson et al., 2000), socialising outside the home (Long et al., 1999a; Johansson et al., 2000), careless sexual behaviour and bad luck (Banerjee et al., 2000). Some participants in Demissie's study (2003) thought that TB could be caused by eating certain foods such as sorghum, maize and potatoes.

Cultural factors are frequently cited as the cause of TB. Studies conducted in Africa confirm that sexual contact is thought to cause TB (Brouwer et al., 1998; Banerjee et al., 2000) along with bewitchment (Liefoghe et al., 1997). This is confirmed by Jaramillo (1998) who writes that witchcraft features in people's explanations of the causes of TB in Africa, India and Haiti (de Villiers, 1991; Banerjee et al., 2000; Demissie et al., 2003). The explanation of witchcraft is often used in a similar way to the concept of 'bad luck' or 'coincidence' to explain why a particular person, at a particular time and place, got sick or had an accident. As an explanation, witchcraft does not preclude other explanations such as germs or poverty. In some places TB is also thought

to occur due to folk illnesses such as 'piang' in the Philippines (Lieban, 1976) or 'susto' in Mexico (Rubel and Garro, 1992).

Environmental factors are often cited as one of the causes of TB. These include exposure to dust or fumes (Edginton et al., 2002), sudden climatic change (Jaramillo, 1998) and pollution (Long et al., 1999a; Johansson et al., 2000). Structural and socio-economic factors appear less frequently than might be expected. This includes poverty and lack of good food (Westaway, 1989; Nichter, 1994). It is important to note however, that a significant proportion of those interviewed did not know the cause of TB. According to Edginton et al. (2002) 30% did not know what causes the disease while Talbot et al. (2000a) stated that only 20% could identify the cause of TB.

## Transmission and Prevention

A number of studies have explored the way in which people think TB can be spread. A variety of different transmission modes have been highlighted including actions such as coughing and spitting (Westaway, 1989; Nichter, 1994; Nair et al., 1997; Jaramillo, 1998; Liam et al., 1999; Tulskey et al., 1999; Navio et al., 2002; Demissie et al., 2003) and through interpersonal contact with infected people (Nair et al., 1997; Poss, 1998; Long et al., 1999a; Edginton et al., 2002; Navio et al., 2002). Interestingly, a number of studies identified that TB could be transmitted through sharing food and drink and sharing the same eating utensils (Westaway, 1989; Nichter, 1994; Jaramillo, 1998; Poss, 1998; Navio et al., 2002), sexual transmission (Jaramillo, 1998; Poss, 1998; Tulskey et al., 1999; Edginton et al., 2002; Navio et al., 2002; Demissie et al., 2003), blood transfusion (Navio et al., 2002) and mine work (Edginton et al., 2002). Understanding beliefs about transmission is important as demonstrated in research conducted by Long et al. (1999a) which showed that because participants thought some types of TB were not contagious (TB caused by hard thinking and hard work) no precautions were taken to prevent the disease from spreading.

Surprisingly there has been little work done on the beliefs and strategies of people in high incidence areas to prevent TB. Possible reasons for this may be due to the demise in the BCG as an effective preventative of TB, attention has since turned to controlling the disease through medication and to health personnel undertaking prevention activities such as contact tracing. Yet an interesting line of enquiry would be to consider the everyday strategies used by people in their lives to avoid TB. Although more relevant in communities where TB is prevalent, this is also pertinent amongst communities where rates may be minimal. In one of the few studies that considers TB prevention measures, participants endeavoured to eat nutritious food, maintain a clean home and have the BCG vaccine (Westaway, 1989). In Poss' (1998), work with Mexican migrant farm workers participants employed prevention measures such as avoiding contact with contagious people, taking good care of oneself, eating well and making sure your lungs were not weakened. Some however felt there was no way to prevent TB.

## Impacts of TB

Given the large number of studies that have been undertaken on cultural perceptions and beliefs about TB, it was somewhat surprising to find far less work that has addressed the actual experience of TB and consequences of the disease beyond the physical symptoms of the disease including coughing, weight loss, appetite loss, weakness, chest/back pain, haemoptysis and fever (Westaway, 1989; Nichter, 1994; Carey et al., 1997; Poss, 1998). Nevertheless, a small number of papers highlight the impact of TB although the voices of individuals with the illness are not prominently featured. Edginton et al. (2002) document how participants feared contracting TB due to social disruption within the family. This is particularly true for those who are married, due to the belief that those with the disease must abstain from sex. TB can be particularly stigmatising as sufferers cannot share food or drinks from the same platter as other family members. Edginton and colleagues argue that the stigma attached to the disease is because “those with TB are perceived as having infringed cultural rules and because it is known locally as a disease of ‘bad’ people (associated with heavy drinking and poverty)” (Edginton et al., 2002:1079). Carey et al. (1997) reports that 94% of respondents in their research anticipated TB would negatively impact their work and 90% expected family related effects. Over three-quarters expected that community members would be afraid of and would avoid someone with TB in their community. Research in Mexico found that 15% of patients hospitalised with TB expected to be rejected by their families; however this ended up increasing to 52% (Rubel and Garro, 1992).

In Somali culture, children are taught that TB is a horrible disease resulting in social isolation. The stigma experienced by those with TB is profound. In a nomadic context, other families might move their huts away from a family with TB. Sufferers may have to use their own utensils and drinking cup as opposed to sharing the communal family plate. This proclaims their diseased status and reinforces their stigmatised identity. According to Kwan-Gett, “the social isolation is so profound that the stigma of TB in Somali culture can be as severe as that of AIDS in Western culture” (Kwan-Gett, 1998).

TB can also have a profound impact on the family unit. Liefoghe et al. (1995) documents the distress experienced by families when an individual is diagnosed with the disease. This distress is due to the perpetual stigma associated with TB and the ensuing social costs of being associated with the disease. They state, “TB is a problem not only for the person affected, the diagnosis has implications for the whole (extended) family as well. The relatives often both bear the financial burden of the treatment and suffer from social stigmatisation” (Liefoghe et al., 1995:1690). Nair et al. (1997) document the financial costs of TB. Many individuals with TB were concerned about their ability to maintain a job. Of the respondents, 10 cited a dramatic drop in income due to the disease.

Some commentators have described how the experience of stigma is highly gendered. Nair et al. (1997) found that the level of family support received by individuals with TB depended on gender

and marital status with married men and unmarried women reporting family support and provision of rest, however many married women reported marital desertion and isolation. The authors comment, "Being female, and married, appears to lead to neglect of tuberculosis and untimely care. TB is a disease of poverty; among the poor and underprivileged, poor women are at greatest risk, and they face the greatest obstacles to seeking complete cure" (Nair et al., 1997:83).

Johansson et al. (2000) similarly found that fear of TB was most common among women, the elderly and farmers with low education levels. Stigma and social isolation were important contributors to denial in women, while for men, denial stemmed from the fear of losing income and the ability to support one's family. This explains why some people deny having the disease thus delaying the health seeking process due to stigma. For instance one person stated, "In my hamlet, I had not seen anybody saying that they had TB. So when I went to the TB clinic, I thought that I was the only one with TB, but it was so crowded – there was not even a place to stand" (Johansson et al., 2000:45). The authors comment that, "Stigma seemed to be a summary effect of contextual factors mediated via denial and concealment of disease; both phenomena more common among women than men and leading to delay" (Johansson et al., 2000:48). In a similar vein, Jaramillo (1998) contends that stigma particularly affects women. This raises important questions as many argue that education is the way to overcome stigma, however he argues, "lay beliefs and stigma do not occur in a vacuum. They are social constructions intended to aid understanding and to help deal more easily with daily life" (Jaramillo, 1998:198).

Demissie et al. (2003) elicited views on TB through holding focus group discussions with TB patients. One theme that emerged was the shock patients experienced when diagnosed with TB. It was a very frightening time with some people thinking it was incurable and that they would soon die. Significant economic and social impacts upon being diagnosed were cited. Instead of being treated, the patient was isolated and kept at home so they would not be identified. Wealthier patients sought private treatment in alternative locations so as to not be tainted with the TB label in their neighbourhood. Many marriages were dissolved based on the belief the disease could be transmitted sexually.

Yet not all studies agree. Nichter (1994) found that interactions with family members did not change much after being diagnosed with TB despite the stigma of the disease. Although 44.4% of participants in Liam et al's paper (1999) would not eat with family members, only a small number of patients in this study expressed concern about stigma. Not surprisingly in Westaway's (1989) research, those who had a family history of TB attached less stigma to the disease than those with no immediate experience with the illness.

One theme that has not been well addressed in the literature is investigation of the coping strategies employed by TB sufferers. One exception is the work done by Fuller-Thomson et al. (2000) who investigated the life histories of Chinese and Caribbean immigrants to determine the

coping strategies employed to manage respiratory illness. Participants' strategies included use of Western and traditional medicine, managing their environment, diet, exercise and educating themselves about the disease.

## Health seeking behaviours

Researchers have begun to consider the health seeking behaviours of TB patients. Johansson et al. (2000) provide one of the few gender focused investigations into the way in which TB health seeking behaviours differ between men and women. This is prefaced by a discussion of the growing awareness of the way that sex and gender influence patterns and treatment of disease. Research shows that women tend to wait longer than men to seek treatment and are less likely to utilise medical services. Johansson et al. selected TB as a 'tracer disease', a lens through which to study gender and health seeking in part because of its association with stigma. Different health seeking behaviours were observed for men and women. Men tended to ignore symptoms until the disease was in latter stages, going straight to public health services rather than visit a private practitioner. Women on the other hand tended to visit a private practitioner and/or self-medicate before seeking public health care services.

While the worldwide male-to-female ratio for TB is two males to every female, more females die from the disease than men do (Johansson et al., 2000). Yet it is not known at present whether the rates of notification and incidence by sex reflect differences in health-seeking behaviour and/or access to health services. A recent trial from South Africa found that compliance levels for those receiving hospital based DOTS and self-supervised patients, were the same for men however, DOTS was less successful for women. The researchers undertook focus groups in order to understand how social context, education, socio-economic status, stigma, and characteristics of health facilities influence health-seeking behaviour, and hence delayed access to health care (Johansson et al. 2000).

Nair (1997) provides an interesting insight into the timeframes around health seeking behaviours according to symptoms. Most respondents did nothing for symptoms of cough, fever and weakness, over a timeframe of fifteen days to two months, however perception of the severity of the illness increased upon the onset of haemoptysis (coughing of blood). In that situation most people visited some sort of health provider, initially a private doctor. As the disease progressed however, patients shifted to municipal and NGO health providers. It is argued that this shift was due to cost.

In Vietnam, Long et al. (1999a) documented the delay in patients accessing health services. Patients' delay between onset of first disease symptoms until first visit to health services was 7.7 weeks on average while doctors' delay was 4.2 weeks, although doctors' delay was much longer for women than men, 5.4 versus 3.8 weeks (Long et al., 1999b). Edginton et al. (2002) describe

how 39% of adults in their sample had visited a traditional healer. They found that adults who lived more than 10km away from the hospital were more likely to first visit traditional healers. Women were more likely to attend a clinic first and children more likely to be taken to the district hospital.

Yet many TB patients experience barriers in accessing health care services. Edginton et al. (2002) found that patients experienced a number of problems with accessing TB services and treatment due to travelling distance and lack of transport. Regularly attending clinics for treatment was difficult for those who worked or attended school. Other problems at health facilities included queues, long waiting times, disrespectful treatment by health providers and receiving poor explanations about their treatment.

Johansson et al. (2000) and Jaramillo (1998) outline the hidden costs of TB in terms of time commitments for medical consultations, drugs, time off work, travel time and lost wages. Although TB drugs were possibly free of charge, other diagnosis and treatment costs had to be met by the individual and were often beyond their financial capabilities. Spending time in hospital was also seen as costly. Participants expressed both support and criticism for health services and practitioners. The condition of health facilities, especially rural ones was criticised. Furthermore, gender roles also influenced access to TB treatment. The conceptualisation of men as the pillar of the family meant that their treatment for TB was given priority above other family members. Research suggests that men have better access to TB services, are more likely to start treatment and have bacteriologically confirmed disease.

Needham et al. (2004) produced one of the few studies that consider the barriers in accessing TB care from the perspective of individuals with the disease. The authors argue that patients' perspectives are often not considered yet cultural factors can influence treatment. Three barriers were identified through semi-structured interviews – health encounters, cost and distance. Zambian patients had on average 6.7 health encounters prior to diagnosis of TB, resulting in costs and delays in receiving treatment. Many of these encounters failed to diagnose TB. Cost was a critical barrier as seeking health care was often an added and unmanageable cost where there is already not enough money to feed the family. Among patients there was also a belief that special food is required for recovery from TB, sometimes costing up to 66% of average income. Patients must also bear the cost of missed days at work or even job loss. Cost was an even more pressing issue in a resource-poor setting such as Zambia, where at times there may not be enough money to buy sputum pots. The third crucial barrier is that of distance. In urban Zambia, 16% of monthly income is spent on transportation. Some patients walked up to two hours each way to get to the chest clinic. Decentralisation of TB treatment services has been suggested as one strategy to deal with the ever increasing numbers of the sick. One possible solution is to put traditional healers in charge of administering DOTS since that is the health provider that many people turn to first.

## Treatment beliefs

Another interesting avenue of enquiry is into the beliefs and perceptions of TB patients about treatment. As has been documented, beliefs about treatment are culturally specific (Edginton et al., 2002). According to Kwan-Gett (1998) a traditional Somali treatment for TB is a mixture of eggs, butter and honey. Those from rural areas may use herbal treatments such as *Tiire* or *Khabayere* which are consumed as a soup. When TB is detected, the family may provide a very nourishing diet including liver, milk, sheep fat, eggs, dried meat and butter to aid recovery. Those who ordinarily chew *khat* (a plant with amphetamine like properties) will stop, as it is thought to be harmful for TB, however helpful for asthma and malaria. Traditional healers may be sought to administer short round burns with a hot stick. Interestingly, skin testing is a confusing issue for many Somali people, in part due to the variety of results between refugee camps and country of resettlement. Some believe the skin test is an immunisation while others see the injection as a source of infection. Poss (1998) highlights the way in which TB testing can lead to confusion. While most patients understood that the purpose of the test was to see if they had been exposed to tuberculosis bacteria, some said that if the test area becomes swollen then it indicates a positive result while others said that a positive test indicates he was on the brink of getting the disease. There was also confusion about the BCG vaccine. Some thought the BCG vaccine protects you from many illnesses or was a life-long protection against TB.

A number of researchers have found that Western medicine is frequently used alongside more traditional remedies (Jaramillo, 1998; Navio et al., 2002). In the Philippines, the main treatments for TB that were identified include local remedies (39.5%) and herbal products (38.6%) Only 21.9% of respondents identified the use of antibiotics as the cure for TB. Interestingly, many participants thought of Isoniazid as a local remedy. There was also a wide variety in beliefs on the length of time required to treat TB. One third thought that TB had no cure. People with family income below 2,000 pesos were twice as likely to use local or herbal remedies and twice more likely than others to think of TB as an incurable disease. Yet Carey et al. (1997) disagrees as in his research with Vietnamese refugees in the state of New York, few participants mentioned traditional cures. The authors state "The majority appeared very receptive to biomedical health care, and several specifically stated that traditional medicines do not work for TB" (Carey et al., 1997:69).

Self medication and the way that people can purchase over-the-counter remedies is an important issue. Nichter (1994) describes how weak lung/TB medication is marketed as 'vitamins for the lungs'. This type of medicine is taken for short courses and can easily be procured over counter and shared amongst family members. Other important issues relating to treatment include the way that medicines are not taken during pregnancy due to the belief that they do not work. This was also found in Liefoghe et al's (1995) work in Pakistan where it was reported that pregnant women do not like taking TB medicines because they think they fail to work due to pregnancy and the belief that pregnancy reactivates TB. Other treatment issues include the way that children are sometimes given TB prevention medicine for weak lungs but carers/parents will not seek medical

advice for other conditions such as pneumonia. This is because of the cost of the medication and the belief that TB drugs supplied by the government are inferior to private sector medicines. Nichter tells the story of one person who did not trust the result of their sputum tests and bought preventative drugs and took them secretly, fearful of relapse.

Banerjee et al. (2000) sought to explore local perceptions of TB in a rural area in Malawi, focusing specifically upon usage and experiences TB patients have with traditional healers. A total of 276 healers who saw a total of 4600 patients per week completed the questionnaire. Most patients would present with chronic conditions including diarrhoea, headaches and cough. In Malawi it has been documented that nearly 40% of patients with smear-positive pulmonary TB attend a traditional healer before TB is diagnosed and treated within a western medical institution (Brouwer et al., 1998). Yet there is little existing data on usage of traditional healers and their perceptions of TB. Healers identified four main causes of disease, illnesses caused by spirits, bewitchment, careless sexual behaviour or due to bad luck. Healers use a medium for diagnosing patients and then make a preparation to treat the patient. Healers treat the cause of the disease rather than the symptoms. There was an overriding belief that western drugs will not work for TB that is caused by bewitchment or spirits. The authors conclude by suggesting that traditional healers need to be incorporated within TB treatment and control processes.

### *'Culture studies' critique*

While the culture studies discussed above have illuminated the different ways in which people think about TB, an exclusive focus on 'culture' has been critiqued from a number of different angles (Mitchell, 1995). In Sumartojo's (1993) review of the literature on adherence she postulates that there are many factors involved, demographic, cultural and practical concerns. She makes an important point in her conclusion:

*"It may be helpful to acknowledge that adherence requires behaviour change, and most people find it difficult to remain motivated to make even minor changes in daily habits for long periods. This is particularly true for those whose lives are severely stressed by competing difficulties such as poverty, substance abuse, or homelessness" (Sumartojo, 1993).*

Jaramillo (1998) argues that 'culture' is over-emphasised and that economic and structural factors are more pertinent. Jaramillo highlights the prevailing idea that patient beliefs are an important cause of TB non compliance yet in his review of relevant studies, he found that beliefs and stigma are not consistent predictors of adherence. He draws on the tensions between structure/agency and argues that too much emphasis has been placed on 'agency', thus resulting in victim blaming for unsuccessful treatment outcomes. Yet Jaramillo makes a very good point in that patients and practitioners cannot be held accountable for failing to achieve standards if they are unable to

achieve the standard, or face insurmountable obstacles in so doing. On the other hand, by over-emphasising structural factors, health care workers and patients are rendered as passive victims subjected to forces beyond their control. This idea is supported by Edginton et al. (2002) who state, "Patient adherence to treatment regimens is a complex phenomenon dependent on a number of factors, which include the social and cultural context of patients".

Paul Farmer (1997) critiques the notion of compliance, even arguing at a semantic level that the word 'compliant', "has the unfortunate connotation that the patient is docile and subservient to the provider" (Sumartojo, 1993:13). At the heart of Farmer's argument is that most studies tend to attribute blame and responsibility for non-compliance to the patient without taking into account the contextual forces that the patient operates within. He argues, "In most settings where TB is prevalent, the degree to which patients are able to comply is significantly limited by forces quite beyond their control" (Farmer, 1997:351).

Farmer reviews social scientific research into TB that aims to explain non-compliance and persistence of TB. He argues that in many of these case studies, wider structural forces such as that of poverty and racism are obscured while blame is placed on cultural factors. In India, Baarnhorn and Adriaanse (1992) found that economic factors, monthly income per capita, type of house and household per capita income were the main determinants of compliance, yet in their conclusion, they advocated the need for greater education with no mention of the economic predictors of compliance. In South Africa, de Villiers (1991) identified Xhosa beliefs in witchcraft among other factors as the reason behind high default rates but failed to mention the poverty experienced by black South Africans and the effects of apartheid and health service delivery. Farmer states, "even here, more rigorous social analysis is necessary, for TB is closely linked to a "racial capitalism" far older than apartheid itself" (Farmer, 1997:352). He quotes other examples in Honduras, Haiti and Philippines where researchers have emphasised health beliefs and cultural perceptions as influencing adherence, yet ignore how practical interventions such as making medications free and more accessible can have a dramatic influence on adherence levels. Farmer states:

*"Such research tends to be conducted in settings-called 'cultures' in many of these studies-characterized by high rates of tuberculosis and by extreme poverty, which a priori calls into question conclusions regarding the impact, on treatment failures, of the cultures of the patients in question. These patients do not share culture or language. What they share is tuberculosis and poverty. They also share, often enough, spectacularly bad TB services..." (Farmer, 1997:353).*

In Farmer's view, social scientists are guilty of conflating structural violence with cultural difference, minimising the role of poverty, exaggerating patient agency (to the detriment of the structures that constrain their agency), romanticising folk healing and becoming insulated within their own

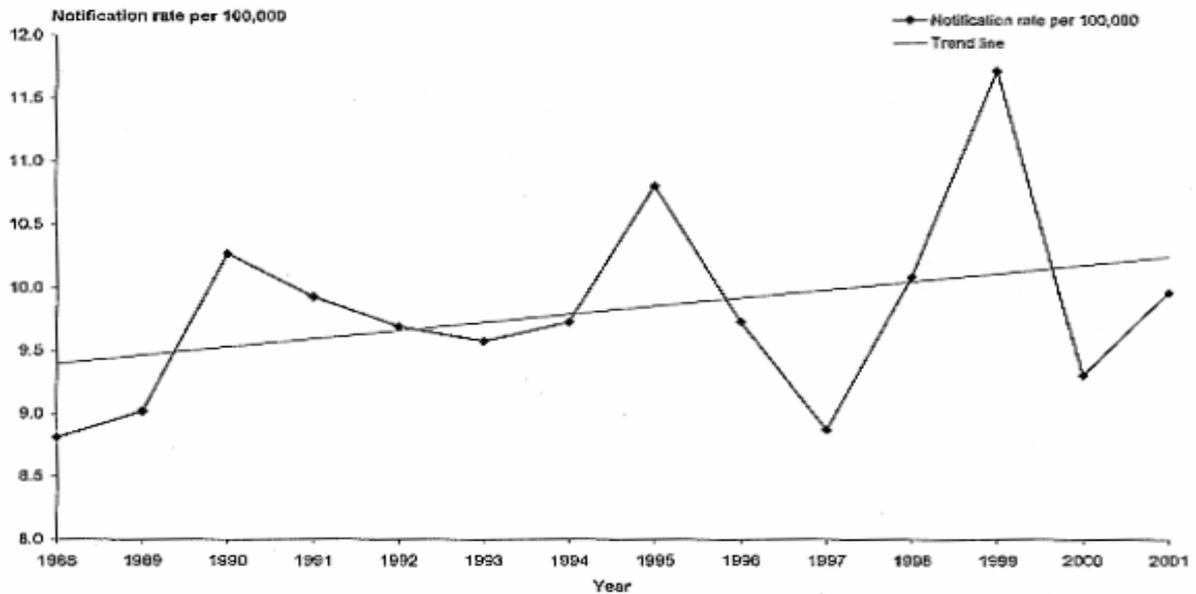
disciplinary confines. Many of the above studies assume educational interventions will improve outcomes, but Farmer suggests this is not the case and has never been true. He advocates for a more fine-grained analysis of barriers and research informed by a sound understanding of the influence of social inequality and disadvantage.

I now shift from considering international concerns with TB to focus on the New Zealand experience. New Zealand shares many similarities with TB trends documented internationally, particularly in terms of an overwhelming focus on TB amongst migrants. I argue that this topic requires further investigation in order to elucidate the reasons why migrants are disproportionately affected by TB.

## **TB in NZ**

Like many Western nations, TB rates in NZ peaked in the 1940s and then steadily declined, due to improvements in living conditions and medical advances. Since the 1980s, the global resurgence in TB has been mirrored in New Zealand with the general trend of rising TB incidence is depicted in Figure 3 overleaf although rates have since plateaued at between 9 and 10 cases per 100,000. In 2005, TB rates in New Zealand were 9.3 per 100,000 population (Institute of Environmental Science and Research Limited, 2006). This rate is nearly double that of Australia, Canada and the US (5:100.000) (Ministry of Health, 2003a; Das, Baker and Calder, 2006a). Approximately 10% of all notified cases are part of TB outbreaks (Hill and Calder, 2000; De Zoysa et al., 2001; Whitlock, Calder and Perry, 2001; McElnay, Thornley and Armstrong, 2004) of which 87% comprise of Maori or Pacific Island people (Das et al., 2006a). Unlike some other Western countries, MDR TB and HIV/TB co-infection do not significantly contribute to TB rates in New Zealand however migration is repeatedly cited as the dominant factor fuelling the incidence of TB (Ministry of Health, 2003a; Das et al., 2006b).

**Figure 3 Trends in TB incidence 1988-2001**



Source: (Ministry of Health, 2003a)

While overall rates of TB are valuable indicators, they mask the way in which TB is unevenly distributed in terms of ethnicity, socio-economic status, age and location. I will survey each of these themes in turn.

One important axis of difference is that of ethnicity. In 2005 the TB rates per 100,000 population were: Pakeha 1.7, Maori 8.9, Pacific Islands 23.5, and 'other ethnicities' 81.7% (Institute of Environmental Science and Research Limited, 2006). The last two rates are very high compared to other groups and have been increasing. It is important however to recognise that ethnicity data is not entirely complete. Das et al. (2006a) found that country of birth data was recorded for only 89.3% of notifications between 1995 and 2004.

While the numbers of New Zealand born TB cases decreased between 1995 and 2004, overseas-born notifications increased in number (Das et al., 2006a). In 2005, of the 348 new TB cases 225 occurred in those born outside of New Zealand (76.3%). This is significant given that foreign-born residents constitute a relatively small percentage of New Zealand's total population. Furthermore, between 1995 and 2002, the percentage of foreign-born TB cases as a percentage of the total number of all cases increased from 47.5% to 71.1% (Ministry of Health, 2003a; 2003b). Das et al. (2006) found that most overseas-born notifications originate from Asia, Africa and the Pacific Islands. Particularly high rates were noted amongst people born in Ethiopia (3,209.9 per 100,000 and Somalia (1,924.4 per 100,000). For overseas-born notifications in Auckland between 1995 and 2002, 33% originated from East Asia, 20% from Africa, 18% from the Indian subcontinent, 15%

from the Pacific and the remaining 14% comprised people from Europe, the Americas and the Middle East (Thornley, 2006).

Although New Zealand's TB burden is attributed to migrants from high-incidence countries, there is evidence that relatively few arrive with active TB disease. Although there is no widespread genetic fingerprinting analysis available for TB cases in NZ, using notification data, Das et al. (2006b) surmise that most overseas-born notifications have been infected overseas, as opposed to acquiring TB via local transmission. The differing epidemiology of TB in overseas-born populations compared with New Zealand-born populations provides:

*“considerable reassurance that migrant populations are not acting as an important source of TB transmission to most New Zealand born populations...This observation is consistent with the experience of other countries which have also found that TB transmission tends to occur within defined population groups” (Das et al., 2006a:10)*

Yet in a review of cases of TB found at autopsy in Auckland, Lum and Koelmeyer (2005) found a high proportion of missed diagnoses, potentially suggesting that rates of disease may in fact be higher than official rates suggest. Of 30 cases that were identified between 1994 and 2004, 21 were not diagnosed while the patient was alive. Over two-thirds of these occurred in individuals born overseas. The authors suggest a number of possible reasons for this occurrence including the varied presentation and symptoms of the disease and concurrent illnesses with similarities to TB.

While there tends to be a general belief that New Zealand's TB rates can be explained by the presence of migrants from countries with high TB incidence, this does not explain why many overseas-born people develop the disease some years after arrival. In 2001, the interval between arrival in NZ and notification of TB in foreign-born cases was less than one year for approximately 20% of cases, between one and five years for 30%, greater than five years for 32% and for an unknown interval 18% (Ministry of Health, 2003a) (Table 5 overleaf). Given that many immigrants are screened for TB prior to, or upon, arrival these figures indicate that TB disease develops during the process of resettlement, with nearly one-third of cases occurring after residence in the country for five years or more. This suggests that there are other factors at work that are resulting in the development of TB among migrants.

**Table 5 Interval between arrival in NZ and notification of TB in foreign-born cases (2001)**

• < 1 year	20%
• 1-5 years	30%
• > 5 years	32%
• Unknown	18%

Source: (Ministry of Health, 2003a)

Das et al. (2006b) found that overseas-born notifications were highest within the first year of arrival with one quarter of those notified within the first year occurring in the first two months. The authors suggest this reflects health screening of refugees at the Mangere Refugee Reception Centre (MRRC). Screening data from the MRRC found that of the 1405 refugees screened between July 1995 and July 1998, 2% had active disease (Reeve, 2004). It is important to note that screening for asylum seekers and family reunion refugees, many of whom originate from the same situations as quota refugees, is ad hoc and not compulsory.

The increasing association of TB and migrants has led researchers to conclude that the main consideration in terms of TB control in New Zealand is the high prevalence of infection in developing countries. Das et al. (2006a) state that, "This global disease burden manifests itself in a high prevalence of infection in migrants from these countries and is a further reminder of the urgent need to increase TB prevention and control at a global level" (Das et al., 2006a:14). Some have suggested that the solution to this problem is to strengthen border screening processes (Harrison et al., 1999). A number of initiatives have been introduced, such as the requirement for chest x-rays for short term migrants, visitors and international students (New Zealand Immigration Service, 2005). In addition, there have been efforts to ensure that New Zealand-bound refugees are screened and treated for diseases such as TB within refugee camps (Mortensen, 2006). While such initiatives are important, their effectiveness in preventing TB incidence in New Zealand is questionable due to the fact that most overseas-born notifications have latent TB upon arrival in New Zealand which may not be detected by chest x-rays.

Littleton et al. (2007) consider the wider context of immigration by suggesting that border control is only part of the equation in controlling TB. Of equal, if not greater importance are:

*"the circumstances that promote the reactivation of latent TB infection in migrant communities, including migrants' experiences in-transit and after arrival, structural conditions and personal characteristics" (Littleton et al., 2007:2).*

The authors argue for a more holistic and comprehensive perspective beyond a singular focus on place of birth. They state:

*“Obviously, screening and treating people who come to New Zealand for appreciable periods is an important component of TB control, but ameliorating the conditions that contribute to reactivation, or that place those born overseas in high-risk situations for new infection, need to be real foci for effort” (Littleton et al., 2007:11)*

While the relationship between inherently ‘diseased migrants’ and TB in New Zealand is widely accepted, far less attention has been given to the reasons why migrants with latent TB infection subsequently develop active disease. This observation provides an important justification for the present research amongst Somali refugees living in Auckland. Little is known about the experiences of migrant groups which fall into the category of ‘Other’ ethnicity when analysing the epidemiology of TB. Yet it is this group which shoulders the heaviest burden of TB with rates over 50 times higher than the New Zealand European population (Thornley, 2006).

Internationally, commentators have begun to reflect on what it is about being a migrant that contributes to TB incidence. Tocque et al. (1998) suggest that migration and deprivation have a compounding effect while Kistemann et al (2002) contend that the deprivation of particular ethnic groups rather than their country of origin is significant in explaining disparities in TB in Cologne, Germany. Littleton et al. (2007) suggest that focusing on the experiences of migrants can help explain why reactivation occurs. Such factors include the nature of the migratory journey itself and the process of resettlement where migrants may face discrimination, language barriers, lack of social support, difficulty in obtaining employment and limited financial resources. This can damage health and wellbeing and lower immunological resistance, thus rendering migrants vulnerable to health problems including TB.

In a recent study of TB within Samoan people living in Auckland, Ng Shiu (2006) found that migration history and socio-economic status greatly impact upon Pacific Peoples’ health status, health seeking behaviour and subsequent TB experience. Das et al. (2006a) suggest that socio-economic status explains the disparity between the TB rates between different ethnic groups and explain that Maori and Pacific people are disproportionately affected by outbreaks of TB due to poor access to health care and overcrowding. Given that two-thirds of TB cases are diagnosed as a result of presentation at a general practitioner, Littleton et al. underscore the importance of ensuring that migrant groups have good access to wider health services (Littleton et al., 2007).

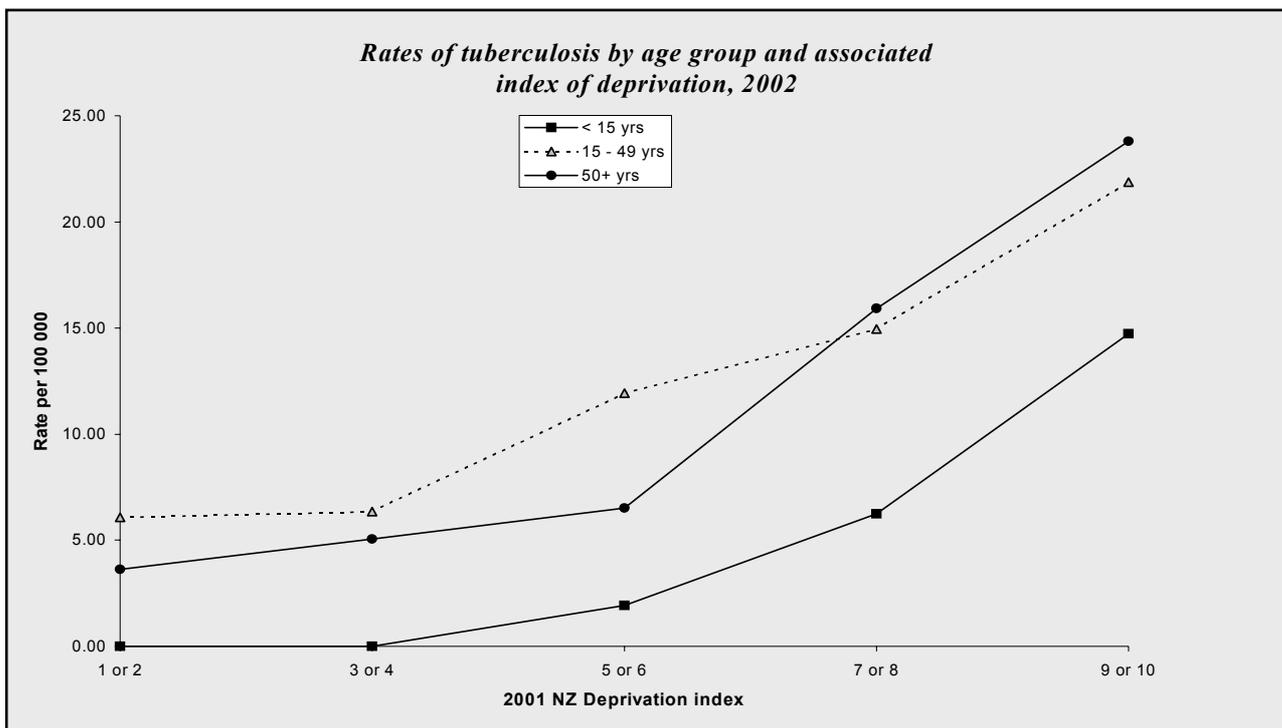
Access to health services was one of the foci of van der Oest et al’s (2005) exploration of TB views amongst migrant groups (including the Somali community) living in Hamilton. Participants stated that migrants experience a number of barriers in accessing health services including cost, cultural sensitivity and communication issues which contribute to TB treatment outcomes and health in general. Health education was cited as one mechanism to reduce the stigma associated with TB.

Socio-economic inequality is another important dimension of TB that has not been well explored within the New Zealand context in comparison with other variables such as ethnicity. This was also noted in an analysis of the representation of TB within New Zealand print media (Lawrence et al., 2007). According to Martin (2000) "Historically, TB has been strongly linked to poverty. Studies from the UK show that it still is. In New Zealand we lack information about the relationship between poor living conditions and many diseases of disadvantage" (Martin, 2000:69). Elsewhere, in the UK researchers have demonstrated that the resurgence in TB is greatest amongst the poorest sector in society. Bhatti et al. (1995) document a 35% increase in TB amongst the poorest 10%, 13% increase in the next poorest 20% and no increase in the other 70%. In Brazil, the estimated TB rate ranges between 50 and 100 per 100,000 inhabitants, however poorer regions of Brazil account for more than half of new cases despite constituting 35.7% of the population (Antunes and Waldman, 2001).

Similar trends have also been documented within New Zealand. Thomas and Ellis-Pegler (2006) suggest that TB control in New Zealand would be improved with widespread poverty reduction (coupled with strengthened screening amongst immigrants). Data from the Ministry of Health illustrates that TB rates in three different age groups increase as deprivation scores increase (Figure 4 overleaf). Furthermore, TB rates in least deprived areas (NZDep1) vary between 0 and 6:100,000 while in most deprived areas (NZDep10), the rates range between 14 and 23:100,000 (Ministry of Health, 2003b). A study within Auckland found that the effect of poverty appears to be independent of ethnicity with TB notification rates among NZ born individuals 60 times higher in NZDep10 areas compared to NZDep1 areas (Auckland Healthcare, 2000).

The third important axis of TB is age. International research has shown that in developed nations, 80% of infected individuals are over 50 while in developing countries, 75% are under 50 (Kochi, 1991). This indicates two quite different patterns of TB. In developed countries, most TB cases are reactivations of dormant infections amongst the elderly while the majority of infections in younger age groups in developing countries signal new cases. Available data suggests that this is also the case *within* New Zealand. For example, in 2002 most notifications in the European ethnicity category occurred in the 70+ age group. Within the 'other' ethnicity category, nearly half of the TB cases occurred in the 20-39 age group (Ministry of Health, 2003b). This concentration tends to indicate a greater presence of new infections as opposed to the reactivation of TBI caught during historical times of high rates of infection, such as the World War Two period. When considering notifications by age in conjunction with ethnicity an interesting pattern emerges. Within European, Maori and Pacific people incidence rates are highest in people aged 70 years and over (Das et al., 2006a).

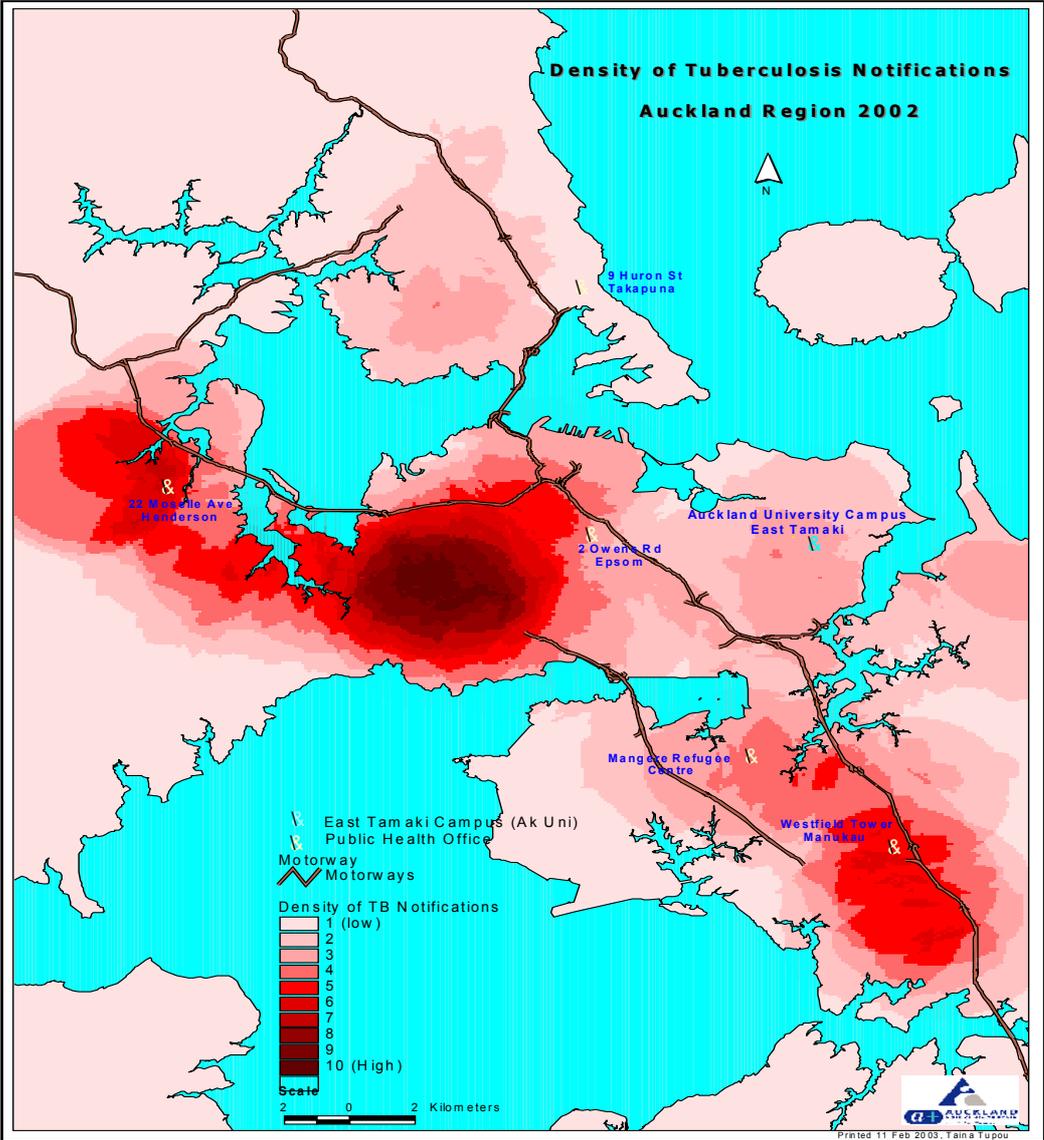
**Figure 4 Rates of TB by age group and deprivation**



(Source (Ministry of Health, 2003b))

TB rates are also spatially patterned within New Zealand. In data categorised by health district, notification rates varied considerably. For example, the highest average annual notification rate per 100,000 between 1995 and 2001 was in Auckland (23.0), South Auckland (19.0) and Wellington (15.1) health districts. These rates are considerably higher than the average national rate. The lowest notification rates were in Taranaki (2.0), Nelson-Marlborough (2.2) and the West Coast (3.1) health districts. There are a number of possible reasons for this spatial variation. In many ways it is expected that large cities such as Auckland and Wellington will have higher rates of TB due to the greater numbers of migrant peoples who originate from high TB incidence countries. Mapping work (Figure 5 overleaf) has also revealed variation within the Auckland Region with three clusters in West, South and Central-Western Auckland (Auckland Healthcare, 2000).

Figure 5 TB notifications within the Auckland Region (2002)



(Auckland Healthcare, 2000)

As Figure 5 depicts, TB notifications are not evenly distributed throughout the Auckland Region but are clustered in particular parts of the city. Such patterning also reflects socio-economic disadvantage and the location of high-risk groups (Somalis, for instance tend to reside in the Central-Western suburbs of Auckland which have the highest density of TB notifications on the map).

**Summary**

While medical/health geographers have made valuable contributions to our understanding of the spatial dimensions of infectious disease, there remains great scope to consider the more nuanced

experience of illness situated within broader structural constraints. Although health geographers seek to consider health, wellness and healing as opposed to disease, Parr argues that:

*“geographers of health do not need to ‘do away with’ the medical, but can continue to engage with it, albeit in a more critical capacity than has been the case previously within the sub discipline” (Parr, 2002:241).*

As noted within the literature on HIV/AIDS (Kearns, 2002), there remains considerable opportunity to flesh out the way in which individuals with TB experience the world around them rather than reducing disease to a dot on a map. Wider disciplinary shifts in the late 1980s and early 1990s resulted in the development of health geography which seeks to understand health and illness within the context of broader social theory and a more sensitive approach to the concept of ‘place’. Drawing upon Isabel Dyck’s call for geographers to move beyond conceptualising spaces and places as ‘backdrops’, Smyth (2005) goes further to argue that health geographers need to consider the way in which understandings of disease and health change over time and are not “fixed realities but are situated and socially produced in particular historical, social, economic, cultural and political contexts” (Smyth, 2005:490). Such an approach has been utilised within this thesis as it offers a means to bridge the gulf between biomedical and social scientific traditions.

As has been discussed above, TB is a major public health problem that disproportionately impacts particular ethnic groups and the poor. While the resurgence and incidence of TB has been extensively studied from an epidemiological viewpoint, there remains considerable scope to explore the wider social, economic and political determinants of TB amongst smaller migrant groups who are frequently implicated as the ‘cause’ of the TB burden in Western nations.

With this in mind, I now shift to consider the methodological underpinnings of this study and issues related to the process of conducting cross-cultural research with Somali people living in Auckland, New Zealand.

## Chapter 5: Methodology and the research context

*“Caring-in-practice involves a profound sensitivity to everyone with whom the practitioner comes in contact, and what can only be described as a kind of “love” for others and for one’s work...As a social researcher I try to practice such caring. To do so, one must be committed to one’s work and to the truth: to discovering, understanding, and then communicating just what is going on amidst the confusion and “noise” of human motives, behaviour, and emotions” (Cassell, 2002:184).*

Much TB research, and to some degree, health research, focuses on the biological with the individual ‘host’ merely being an anonymous vessel of infection. Qualitative research drawing on people’s narratives, ideas and values offers enormous potential to better understand health issues, yet remains somewhat marginalised within the medical world.

While the previous chapter outlined the way in which health and medical geographers have engaged with issues of health, disease and TB, this chapter documents the research process and methods used in this study. Methodology is defined in its broadest sense, including both the philosophical and practical aspects of conducting research. The highly personal and contextual nature of the topic lends itself to the deploying of qualitative methods to understand the way in which health and disease is experienced by the Auckland Somali population. This study is largely ethnographic in nature and draws upon three years of fieldwork amongst the Somali community.

Throughout this study, I actively and consciously endeavoured to create a place for people’s own accounts of their views and experiences. This is especially important given the marginalisation and discrimination faced by Somali refugees living in New Zealand (Chapter Six). I also reflect on how my role as researcher influenced the research process by drawing upon ideas of reflexivity, positionality and power relations (e.g. Rose, 1997; Valentine, 1997; Butler, 2001).

## Research Methods

In order to address the research questions raised in Chapter One, I used a range of research techniques including interviews, participant observation and focus groups:

**In depth interviews** with members of the Somali refugee and migrant group (both with and without TB)

**Participant observation** where appropriate

**Focus Group discussions** with community members to explore ideas about health and TB

**Stakeholder interviews** with agencies involved, (e.g. health care providers and community workers involved with the Somali community).

## Early encounters

After a process of consultation with key advisors, the TB Project Team invited the Auckland Somali Community to participate in the research. There were a number of reasons for this. Firstly, due to the stigmatised nature of TB, it would be beneficial to work with a community in which individuals interviewed would not be easily identified. As many of the refugee populations in Auckland are very small, preserving participant anonymity would be particularly problematic. Secondly, of the larger refugee communities, the Somali Community is well-established and has community structures in place. The first group of Somali refugees arrived in 1992-1993, thus representing a 10 year time period up to the date of commencing the research. The Auckland Somali Community Association (ASCA) was established in 1996 with particular individuals responsible for key portfolios including health, education and employment. In addition, members of the Somali community have worked closely with a number of health professionals on a variety of programmes within the community. The final reason for choosing the Somali community is that there have been a number of TB notifications amongst this group, thus potentially providing opportunities for interviews.

After this process of consultation with key advisors, I met with key community members together with the Project Team. This meeting on the 23<sup>rd</sup> June 2003 was attended by six members from the research team, six Somali community representatives and an additional advisor who chaired the meeting. It was a formal occasion. At times the community representatives seemed uneasy talking about TB and the questions that were raised during that time underscored the extent to which TB is a highly stigmatised disease. The meeting concluded shortly after the Somali

community members stated that they supported the research going ahead but wanted to consult with community elders.

I maintained contact with community leaders for another eight weeks. These were nervous times for me and I occasionally wondered if we would have to start all over again with another group. During this time I was invited to various meetings at the Pan-African Centre in Three Kings with key community representatives, particularly those with whom I would be working closely. The president of the community was very supportive of the research and assisted me greatly by introducing me to other key people in the community who were involved in the area of health. I was also introduced to the community member in charge of the health portfolio and was advised to make him my key contact person. This arrangement continued for a number of months until a new person was given the health portfolio and the point of contact was returned to the community president. In many ways the president of the ASCA acted as a gatekeeper and sponsor throughout the research process and his support had a profound influence on the success of this study. He is highly respected by the community and this enhanced both my access to people and my credibility particularly for those who were otherwise suspicious of me. His advice and counsel proved to be incredibly valuable particularly when dealing with a sensitive topic such as TB.

In August 2003 I discovered that the research had been approved at a community meeting on 21<sup>st</sup> July 2003. In accordance with university guidelines, fieldwork did not commence until my research proposal was accepted and my registration confirmed after one year of provisional candidacy. During the intervening months, however, I sought to familiarise myself with the Somali community and participate in community events.

## **Engaging with the Somali Community: first steps**

Initially, engaging with the Somali community was quite difficult as I was in essence a stranger to the people I was hoping to work with. It was also a time of great learning, highlighting to me the extent to which research is an interactive process involving the worlds of the researcher and participants. While this research is primarily focused on the TB and health experiences of Somali people in Auckland, there were also numerous insights into the issues surrounding cross-cultural research. While I am by no means the focus of this research project, during this chapter I will present key discoveries and challenges in the hope that this might illuminate and bring to life the material presented in later chapters. At times I draw on excerpts from my research journal (presented in boxed sections) to "...bring the reader to the research site with me, perhaps to see what I saw, to feel what I felt" (Cassell, 2002:182)

As I embarked on the research I was quickly inundated with accounts of how NOT to do cross-cultural research. The Somali community, along with other refugee communities, has been repeatedly approached to participate in various academic research projects, government agency

consultation exercises and Non-Governmental Organisation (NGO) projects. Community members described frustration at the practices of other researchers and a sense of w(e)ariness at being researched, particularly when research projects offer little to the community in the way of funding or resources yet cost a great deal, particularly in terms of investment of time and goodwill. I am grateful that community members shared these views with me as they have reinforced to me the moral obligations of researchers working with ethnic communities and strengthened my own resolve to conduct myself in an honourable and ethical manner.

One of the main concerns expressed by people involved researchers who do not approach the community in the right way. Some people described this as the 'back-door' method whereby researchers form a relationship with one community member who then claims to be the 'voice of the community' as a whole. People told me that there are appropriate ways to approach communities and that it is important to respect community structures and the position of leaders. The formal meeting of elected leaders of the Somali community to discuss the proposed research with the Project Team as described earlier, reflected this commitment.

I also had a number of conversations with community members who detest the way in which some researchers come into communities, extract information and then talk about the community at various conferences and within publications. This complaint highlights the way in which some researchers fail to engage with communities, with the subsequent research outputs serving only to benefit the career and prestige of the researcher rather than the community of interest. Kearns and Dyck advocate the formation of partnerships with research participants in order to "allow them to participate in co-creating a deeper understanding of their world" (Kearns and Dyck, 2004:378)

Another key issue is the way in which the priorities of communities can be very different to that of researchers. Similar ideas have been raised in Dyck's (1995; 2006) research with immigrant women in Canada. In terms of my study, although TB is seen as a terrible disease, its priority pales in comparison to issues such as uncertainty over immigration status, lack of income support and separation from family members. The importance of TB in comparison with more pressing concerns was clearly evident when I asked one interviewee about TB beliefs in Somalia:

*Jody	So back in 1993 what did Somali people living in Somalia think about TB?
Barir	That time it was war time, so people they were not in TB issues, everyone was just worried about are we going to die, there were children dying all the time so it was a big issue then...

As a researcher who has entered the community with a pre-defined topic of interest I have had to learn about the priorities of the community and seek to operate in a way that acknowledges and supports these priorities. In some instances it was a juggling act, but the two are not necessarily mutually exclusive. For example, Ishraq experienced considerable stress and uncertainty being

separated from her mother and siblings. Despite efforts to re-unite with her family through repeated applications to the New Zealand Immigration Service, her plea had fallen on deaf ears. In this instance I attempted where possible to help Ishraq navigate the labyrinth of application forms, rules, regulations and sometimes unhelpful attitudes of immigration officers. TB undoubtedly has been a large part of Ishraq's life but is only one of the issues she faces.

## **Participant observation and fieldwork**

In order to study the social world of Somali people living in Auckland, I realised that being a part of this world would be instrumental in furthering my own understanding. Participant observation is increasingly advocated by health geographers as a way to gain insight into the life experiences of research participants (Gesler and Kearns, 2002). Participant observation provided rich contextual information, particularly at the early stages of the research before I began TB-focused interviews. As the later section on positionality will elaborate, while participant observation is a valuable methodological tool, it is an inherently power-laden situation and the identity and 'place' of the researcher needs to be taken into account.

One example of this is how Somali people would often refer to me as a medical doctor or nurse and ask me medical questions about their own health. When asked to give medical advice, I referred people to the appropriate source such as their local General Practitioner (GP) or PHN. While I cannot know for certain, I suspect that this perception had developed due to my embodied identity as a white, educated, female talking about health issues. Cindy Horst (2001) noted a similar occurrence as she reflected on the process of conducting research with Somalis in refugee camps in Kenya. She described how as a 'white visitor', she was assumed to be someone with power and resources (i.e. such as a donor, selector or journalist), able to assist refugees with resources or the opportunity to resettle. This in turn influenced the accounts and information people would share with her. In my situation, I tried to clarify this situation by explaining that I was studying towards becoming a 'science doctor' rather than a 'medical doctor'. Nevertheless, this perception of me as a medical authority figure potentially influenced the way in which people viewed me and interacted with me.

Where possible in social situations, I endeavoured to be an active participant rather than passive observer. At times this was not appropriate due to my positionality. My ability to participate in *Eid* celebrations (following the month of *Ramadan*) was limited by the fact that I am not Muslim in faith. The opportunity to participate in community events was also shaped by my femaleness as social events are highly gendered. Some Somali men are very reluctant to interact with women in a public setting, particularly a non-Somali, white, New Zealand-born female (see later section on positionality). At the outset of my research, advisers recommended that I greet men verbally and not shake their hand as I would customarily do in most social situations. This proved to be sound advice however towards the end of my research, as I became more familiar and 'known' to the

community, some men would offer their hand in greeting. In the beginning it was also suggested that I pay attention to my dress and that in order to respect Somali, and Muslim values, I dress modestly covering as much 'skin' as possible. Where possible, I was told to wear skirts rather than trousers. The one occasion early on in my research when I digressed from these recommendations during the heat of summer, participants' disapproval of my 'below the knee' trousers was quite clear. From that incident onwards, I tried to ensure I was well-covered at all times.

While I endeavoured to dress and act in such a way as to respect the cultural and religious values of the Somali community, there were times when my understanding of Somali views were challenged. Ordinarily, public gatherings involving both men and women tended to be quite formal. After one event I remember chatting with a small group of men and women about the process of finding a spouse. One individual then stated that single Somali males were renowned for being (in his words) 'horny' and that this was expected of young men. He then joked about a friend whose spouse was returning from Australia that night and how she would have a good time that night. I felt quite embarrassed and shocked at this frank discussion. Prior to this occasion, I had never witnessed the topic of 'sexuality' (let alone the notion of female sexuality), being openly raised for discussion outside the context of discussions on reproduction or HIV education programmes. Abu-Lughod (1986) makes a similar point regarding bawdy conversations she observed during her fieldwork with Bedouins in Egypt.

I tried to allay my discomfort at the situation by trying to humorously suggest that the wife was going to have a good time because of all the presents her husband was bringing back with him. The individual completely ignored my feeble wisecrack and continued in his discussion of sexual relations for several minutes until another person called him away. I also remember another instance when my perception of Somali modesty was challenged. One female participant was describing a lump on her neck that she was concerned about. She then removed her shirt and walked across her living room bare-breasted to show me the lump. She asked me to feel it and tell her whether I thought it was TB or not. I explained that I wasn't a doctor and unable to offer a medical diagnosis. I remember feeling shocked at this person's willingness to disrobe in front of me, particularly given that it was my first appointment with this individual.

I was also advised to avoid broaching sensitive topics such as clan identities and female circumcision (FGM). I followed this advice from the outset. However as I got to know people better they started raising such issues with me of their own accord. I began to ask some participants about such matters and found some people were very sensitive and defensive. For instance a few individuals denied outright the existence of clan rivalries. This observation has also been noted by other researchers who have worked with other Somali communities around the world (El-Solh, 1991; Griffiths, 1997).

Following the recommendations of Emerson et al. (1995), I kept a research journal throughout my study and made notes that I wrote up after leaving each interview or interaction. In the cases where participants declined to be tape-recorded, these notes formed the basis of the transcription that followed. For those who allowed me to tape-record the interviews, I transcribed the conversation verbatim as soon as possible after the interview. Transcribing these discussions enabled me to reflect on the interviews and the way in which I had asked particular questions. I decided not to take notes when involved in participant observation as I wanted to keep the interaction relaxed and comfortable. At the conclusion of these events, I would make notes afterwards. Towards the end of my fieldwork I found it harder and harder to make these notes as it felt uncomfortable writing about conversations I had with people whom I now considered friends. It would be like going out for coffee with an old school friend and then taking notes about what we had discussed! While I am aware of my ethical responsibilities as a researcher, human relationships are not always able to be neatly divided into 'Personal' and 'Professional' suitcases. As this research progressed I did observe the boundaries between these two dimensions blurring as friendships developed with individuals whom I encountered during the research process. This is not surprising given the duration and depth of interaction however, it did make it difficult at times to distinguish between my role as 'friend' and 'researcher'.

### *Positionality and reflexivity*

In the process of telling a story, it is important to identify what the storyteller brings to the narrative process (Cloke, 2002). In academic terms, this draws on concepts of positionality and reflexivity. McDowell (1992) suggests that 'we must recognize and take account of our own position, as well as that of our research participants, and write this into our research practice' (McDowell, 1992:409). In Dyck et al's (1995) research with immigrant women, they suggest that reflection on the researcher's positionality and role in the research relationship can provide valuable data that can help illuminate the research findings and process. This idea is supported by Valentine (1997) who argues that it is critical to acknowledge the different power relationships between the researcher and participants. To address these concerns, participatory action research has been developed as a means to meaningfully involve participants throughout the research process. Geographer Vera Chouinard (1997) for instance, involved disabled people throughout the research process in terms of design, conduct and analysis stages.

Abu-Lughod's (1986) discussion of her positionality during her ethnographic research with Bedouins in Egypt is an excellent example of this. She reflects on the implications of her own Arabic heritage, religion, gender and marital status and the degree to which these influenced her social relationships with her participants as well as the research process itself. Unlike me, Abu-Lughod shared key identity characteristics with her participants (namely having an Arabic father and sharing the Muslim faith) that assisted her acceptance within the community. While such an idea is sometimes known as being an 'outsider' or an 'insider' in terms of the group of people in

question, this fails to recognise the subtleties of human relationships. While Abu-Lughod was accepted by the Bedouin community, there were times of ambiguity where there was considerable social and cultural distance between Abu-Lughod and her participants.

These shifts towards greater recognition of the influence of the researcher upon the research process (Cassell, 2002) have evolved in response to positivist research traditions which promoted the idea of the researcher as an all-knowing, all-seeing objective observer able to see the world and declare universal truth. Conversely, in recent decades, post-modern critiques suggest that knowledge is limited, partial, socially constructed and that the researcher is not a detached observer but influences every stage of the research process from inception through to data collection, analysis and ultimately, knowledge production (Hay, 2005). Building on this, reflexivity refers to what the researcher brings to the research process both in terms of identifying characteristics such as ethnicity, gender, age, family status and education levels and also views, experiences and assumptions.

While I wholeheartedly embrace the importance of being aware of and engaging with issues of positionality and reflexivity, it is not a straightforward thing to do. Rose (1997) challenges the extent to which researchers can be fully aware of our positionality while others caution against the dangers of too much self-reflection, leading to research that is focused on self, or at best, navel-gazing (Limb and Dwyer, 2001; Shurmer-Smith, 2003). While this research is explicitly focused on the TB and health experiences of Somali people in Auckland, the process itself of conducting this research has yielded numerous insights, into both TB experiences and the issues surrounding cross-cultural research.

In many ways the process of carrying out this research can be thought of as a journey. The following sections document this journey into fieldwork which reflects my multiple positioning in the field and also affords glimpses into several aspects of Somali lives and community organisation in Auckland.

### *Sewing the seeds of friendship*

After the initial consultation meeting, ASCA leaders suggested that I attend the Somali woman's sewing group held weekly at a local church hall. This seemed to be a somewhat ironic location for a Somali gathering given that most Somalis I encountered were devout Muslims. As it transpired, the local church was one of the few organisations that do not charge a hall hireage fee (apart from a small donation towards electricity use - \$1 per woman per week). Although I was nervous at the thought of attending a sewing group due to my own inadequacy on the handicraft front, I was desperate to get to know people. This group was felt by community leaders to be an appropriate gathering for me to attend as it was an all-women group and was my first experience of Somali social events. The sewing group was partly funded by the ASCA and Refugees as Survivors, a

health organisation focusing on mental health needs of refugees. This group was established as a means of strengthening connections and networks between women in this refugee community thereby addressing the high burden of mental health needs which have been documented within refugee groups (Ministry of Health, 2001; Jackson, 2006). A sewing tutor was employed to help the women learn how to sew. Initially women began with simple tasks such as repairing holes in their children's clothes, gradually progressing to the construction of garments from scratch. Although I did not sew anything myself, I was frequently called upon to thread the sewing machines and unpick crooked hems! In addition to sewing, every second week a guest speaker would be invited to address the women on topics such as employment, legal rights, food hygiene and immigration issues. The immigration session was very well attended and particularly colourful as the women presented their stories of separation from family members and the struggles that they had encountered when trying to navigate through the immigration system in order to reunite with these family members.

I was taken to the sewing class by the community representative in charge of health issues. This community representative was male and his discomfort at walking into a hall full of Somali women was clearly apparent. He introduced me and departed, leaving me with the programme co-ordinator. I chatted with her and was slowly introduced to the other women in the room. The narrative below describes one of my first encounters recorded in my field notes.

*I met three or four women. Most seemed quite nervous to speak with me in English. I would introduce myself and invariably the first question would be, "Are you married?" My reply, "Yes", was met with a faint smile and look of relief. The next question quickly followed, "Do you have children?" Somewhat taken aback, I replied "not yet" and that I was wanting to finish my qualification before having children(!!!). This was met with astonishment that I was married but didn't have children. This same conversation happened week after week. On one occasion, one woman probed further and checked if I was currently pregnant. I found out many months later that it is often customary for women to become pregnant immediately after marrying. In cases where conception was delayed, it was assumed there are fertility problems!*

This encounter highlighted for me the extent to which the researcher and the researcher's identity is inexplicably linked to the research task at hand. Who I am was of great interest to the women I was meeting, and my identity, in terms of gender, relationships and family came to affect the way in which people related to me (see Abu-Lughod (1986)). Because I was a married woman, people interacted with me in a way they would not have had I been single. In a similar vein, as I was at that stage childless, this also influenced the way in which people perceived and interacted with me. The subsequent birth of my daughter towards the end of my fieldwork signalled a change in my status and position in the way my Somali participants viewed me. Once I became a mother, I was included in new conversations and treated as someone who 'understands' the issues faced by

parents and mothers in particular. Frequently I was told 'now that you're a mother you would understand.....' (whatever issue we happened to be discussing).

**Figure 6 Three sewing group participants**



Issues surrounding identity emphasised to me the way in which research amongst a cultural group different to my own is an inherently complex task. Gender relations are highly differentiated amongst this group as men and women occupy quite distinct social spheres within the community. It is true to say that my research experiences were dominated by social gatherings of women and children and after many months I became accustomed to this and greatly enjoyed these times. To my own surprise, I too became somewhat more reserved amongst mixed-sex gatherings. At one stage I became concerned that my research would start to reflect the views of women only, however, as my research journey progressed I was fortunate to spend more time with men. While there undoubtedly was a heightened level of formality and reservation, I was lucky to meet men who were very open to having conversations with a New Zealand-born female such as myself.

These conversations were invaluable as they helped me to better understand Somali social relations.

Initially, I found the sewing group quite a difficult time. Many of the women were very reserved and it took a number of months before some would talk to me and participate in conversations. I also discovered that a large proportion of the women whom I met were extremely direct to the point of being blunt. I remember times when I would greet someone and ask them a question only to be met with a curt reply at which point they would turn their back on me. As time went on I learnt that this was not intended as an insult, but was merely a reflection of the way in which Somali people tend to be very direct. I can recall one occasion when a lady whom I had only met briefly, commented that I was looking quite fat compared to when she first met me!

**Figure 7 Somali sewing group participants hard at work**



One of the reasons that the early months were so challenging was due to language. I discovered that only a small handful of the approximately thirty women who attended the programme could speak English, despite some living in New Zealand for up to 10 years. The remainder knew a few English phrases but not much more. This greatly limited the extent to which I could converse with the women without the assistance of an interpreter. I gradually started to learn some Somali words and phrases and this was a key turning point in the way in which women responded to me. It seemed to me that at the point that I started to show an interest in relating to them in their language, they started to open up to me. Learning and working in the language of participants has

long been a foundational premise of ethnographic research (Malinowski, 1922; Nanda and Warms, 2007). As noted by Sarsby (1984) “A willingness to learn a language may be the most important factor in establishing good relations with informants” (Sarsby, 1984:106). Developing meaningful partnerships and engaging with community environments is also an important dimension of conducting ‘culturally safe research’ (Kearns and Dyck, 2004).

I became an object of fascination in my attempts to learn Somali and I soon learned that I was one of the first New Zealand-born people they knew who had tried to learn some Somali. I started writing down key phrases and words in the back of my research journal and would practice at any opportunity. Many times this saw the women dissolve into fits of raucous laughter but I did not mind this as it allowed me to break through the walls of reservation I encountered for so many months.

I look back on the sewing group with fondness despite the difficulties of getting to know people. As my research journey progressed, it turned out that many of the women I met at the sewing group also attended other various meetings and groups I participated in. In some cases, women from the sewing group later shared their TB experiences with me.

## *Students*

One of the key ethical principles that I have consciously carried with me throughout this research is to not simply be an ‘extractor of information’ but to work collaboratively alongside the Somali community. At the very outset I told community leaders that I wanted to contribute to the wellbeing of the community in some way. One could glibly state that the findings of the research would inherently benefit the community (which I do sincerely hope will happen), however, I recognise that I have an even greater opportunity to contribute throughout the research process itself (Herman and Mattingley, 1999). Community leaders suggested that I could help some of the young people in the community who were struggling with their tertiary studies and incurring large student loans. At that stage there were no programmes being offered to young people in the community. After following up this idea with community leaders for several months it was suggested that I meet with three female tertiary students in the community to get a sense of the issues at hand. It took several months to organise this meeting as the students were busy with working commitments.

In January 2004 I visited the home of one of the students and met with the three women. They talked about their experiences in tertiary education and the challenges they faced. They described the difficulty making the transition from high school to university and that there was no-one to help them. As they said “At school everything is done for you but when you go to university you have to figure it all out for yourself. No one tells you...” Together we brainstormed the different issues with which they would appreciate help with. This list included topics such as essay writing, revision skills, memorising skills, time management, presentation skills and job hunting advice. The

students were enthusiastic about the prospect of creating a time for students to meet together, learn and share experiences. They also thought it would be a good opportunity to get to know other Somali students as they said they did not have many opportunities to mix with other young Somali people.

This suggestion was taken on board and in February 2004 I ran a group for Somali tertiary students. We met at the Pan-African Centre at Three Kings. Fifteen people turned up to the first session, 13 males and two females. Three male leaders from the ASCA were also present. We began with introductions and socialised until someone arrived with six *Halal* pizzas. We talked over pizza and then I began to introduce myself and talked about the possibility of forming a student group. The group then brainstormed about possible topics to cover. Popular choices included how to decide what to study, advice on getting jobs, help with assignments and time management. In the middle of brainstorming the males stood up, said it was time to pray and went up the stairs. I remained with the girls who said they were not able to pray as they were menstruating.

When the men returned, the discussion then shifted abruptly as one young Somali man began conducting a focus group as part of a Ministry of Social Development consultation exercise for refugee youth. I had not realised at the outset, but it had been decided to combine the students' group with this focus group. One of the lessons I learnt very early on is to be very flexible as things tend to change quickly without notice. I was asked to take notes as the focus group progressed. The young Somali man then asked questions about the various challenges refugee youth face. It was a fascinating discussion that yielded vigorous debate. Interestingly the debate seemed to centre on the varying perspectives held by the different generations present in the room. Of particular concern to me was the viewpoint held by some that there were too many research and consultation exercises going on amongst the community. One speaker felt cynical and said that despite sharing their opinions no-one was really going to listen and act upon the suggestions. The session concluded at about 10pm and proved to be a valuable insight into issues from young people's perspectives and the way in which these same young people interact with older generations and those of the 'host community'.

After the first meeting three other sessions took place on the topics of decision making, time management skills and essay/report writing skills. As each session progressed attendance lowered and it became harder to get students to attend. As I talked to people about this situation it became apparent that part-time (or not so part-time) work was the key issue. Students were working very long hours in addition to attending university/polytechnic courses. For many, it was difficult to fit in any extra commitments (such as this group) on top of their busy lives. Those who were attending were doing it more out of loyalty to the community leader who invited them. I discovered that many of these students were not just working to supplement their student lifestyle but also their families. Some students in their late teens/early twenties were sending remittances

back to family members in refugee camps in Somalia. For some families, students are the only household members able to find work and therefore become the main breadwinners.

Due to the difficulties experienced by young people in attending this group I began to re-evaluate the rationale for holding it. At the same time I was approached by community leaders to assist with report-writing for the adult literacy programme. I realised that was a tangible way in which I could use my skills and experience to contribute to the community.

### *Adult literacy programme*

The adult literacy programme began in 2002 and aims to help Somali adults learn English, numeracy and computer literacy skills. The programme developed because of the number of Somalis who were struggling and dropping out of mainstream English-As-A-Second-Language (ESOL) training programmes. This is in part due to the fact that Somali teaching and learning styles are very different from those in New Zealand. As a result, the community association applied to the Tertiary Education Commission (TEC) for funding to run a 'by Somali for Somali' ESOL programme. The programme received funding and now operates five nights a week and includes assistance with transportation. This is important as many female learners do not have cars or driver licences. The programme is particularly effective as it employs Somali trained teachers. This means that the teachers can customise the lessons to the learning styles of Somalis. Men and women are divided into separate classes as they usually feel far more comfortable interacting with members of their own sex thus resulting in a more conducive learning environment.

As I began improving reporting systems I became overwhelmed at the task at hand. The funding received by community association to provide the programme was in jeopardy due to problems with reporting quality. The funding, (a six figure amount) was incredibly important to the community association and I began the task of trying to resolve the issues and mediate between programme staff and the TEC. Reporting requirements were particularly stringent and even I, as a university educated person, who speaks and writes English as a first language and with plenty of past experience in form-filling, struggled to comprehend and deal with the neo-liberal jargon e.g. 'measurable literacy outcomes', 'project delivery analysis' and 'assessment process analysis'. It is only too clear why programme staff, all of whom have limited written English skills, struggled to comply with reporting expectations given the complexity of the quarterly reports. In addition to completing the reports, I also worked with programme staff to create written assessment tools and systems, records of attendance, lesson plans, individual learning plans, and regular assessment schedules. This required numerous meetings with programme staff and many hours of work, but did help address the TECs concerns with the programme. It was a heavy workload for me but was incredibly valuable as it enabled me to interact with community members in a new way. I visited the school occasionally to have update meetings with the teachers and enjoyed participating in the

lessons. It was a particularly useful means of getting to know Somali men. Up until this point I had mainly been interacting with women and attending women’s programmes. I was in some ways nervous about interacting with Somali men as I had never done so in a large setting (apart from meeting male community leaders who I had come to know well).

After nearly two years of assisting with this programme I decided to step down in June 2005 due to my own burgeoning time commitments. It was a difficult decision to make.

*Evaluations and reports*

In conjunction with assisting with the adult literacy programme, I was also invited to assist in evaluating three health promotion programmes funded by Auckland Regional Public Health Service in collaboration with other health organisations. These were the pilot nutrition programme (Lawrence, 2005f), full nutrition programme (Lawrence, 2005d), youth soccer programme (Lawrence, 2005e) and a women’s swimming programme (Lawrence, 2005b; 2005a). Photographs taken during these programmes are displayed below.

**Figure 8 Opening match of the Somali youth soccer programme in Mt Albert, Auckland**



**Figure 9 Attempt at goal**



**Figure 10 Participants in the Somali Women's Nutrition Train-the-trainer programme**



**Figure 11 Muslim women's swimming programme prizegiving**



I was asked to conduct these evaluations as I had experience in carrying out research within the Somali community and also in research design and techniques most appropriate for this community. For each of these programmes I designed and conducted the evaluation and also attended the various health promotion sessions. This was invaluable as it enabled me to build upon the contacts and relationships I had already established, learn about health and wellbeing issues and how community members viewed these issues. It also enabled me to provide health practitioners and community leaders with resources and reports outlining the need for, and impact of such programmes. Some of the findings of these reports will be cited throughout the Literature Review and Results chapters.

During 2005 I was invited to prepare a paper that would be used in the Auckland Regional Settlement Strategy. The aim of this strategy was to provide a co-ordinated approach towards the resettlement of refugees and migrants. My report aimed to describe the health issues of refugees and health system responses (Lawrence, 2005c). The paper that was produced was amalgamated with a variety of other reports to produce the 'health' chapter within the final strategy document (Manukau City Council, 2006).

## *Weddings*

After my repeated efforts to get to know people in the community I continued to persevere in asking community leaders whether there were any community or social events that I might be able to attend. There appeared to be weddings held on a fairly regular basis and at every possible opportunity, I mentioned that I was interested in attending. During late January 2004 I was told that there was a young woman in the community (Nuwwarrah) who would be happy to take me to her cousin's wedding. I arrived at Nuwwarrah's house on the day of the wedding to meet her and find out where the wedding was to be held. I was welcomed into the family home and was struck by the way in which it was so similar to other Somali homes I had visited – filled with the aroma of incense, Arabic script adorning the walls, pictures of Mecca, a wall unit with dainty tea sets and heavy richly-coloured curtains. I once commented on this degree of similarity when visiting Khalisah one day. She remarked that only the poorest of the poor do not have a wall unit and tea set in their home. According to one community representative Durar, such household objects are a legacy of Somalia's colonisers. Durar proudly boasted that Somalis have however usurped their English colonisers in the tea-consumption stakes!

After being welcomed into Nuwwarrah's home, I joined her brothers and sisters who were relaxing in the lounge watching what appeared to be a Somali wedding video (a pastime I discovered is common to nearly all families with whom I spent time). Her brothers and sisters were inquisitive and bombarded me with a barrage of questions, as reflected in an excerpt from my research journal:

*"...Nuwwarrah's brothers and sisters were very curious. Asked me lots of questions about being married, what each of my rings were for, how much they cost, whether I had kids, what my husband's name was, what he did, whether my car was mine or my husband's!"*

We talked about weddings and what usually happens. Normally there is an engagement party where the groom asks the bride's father (or closest male relative) if he can marry her. Usually this has been previously discussed. The groom then arranges payment to the bride's family. Normally the groom gives every male attendee an envelope with cash. The groom is also responsible for paying for the engagement party. The engagement party is usually attended by men with the women preparing and serving the food and socialising in a separate room. A wedding then takes place at some stage after this engagement party. In the interim, the groom is responsible for completely setting up a new home for his bride. The wedding then follows. Ordinarily there are separate wedding parties for the men and the women however I have seen a combined wedding party on some overseas wedding videos. The wedding party is a large community event with the bride and groom's female relatives responsible for putting on the festivities. Because the community in New Zealand is so small, other community members often help out. Some women cook, decorate the hall or help with other preparations.

Nuwwarrah and I drove to where the wedding party was taking place. Because the bride was a cousin of hers, Nuwwarrah was going to go early to help out with the decoration. Keen to be involved I also offered to help and arrived a few hours later. We began decorating the hall with balloons, ribbons and swathes of brightly coloured fabric. A high-backed wicker chair, akin to a throne was decorated and placed at the head of the room for the bride to sit on. Gradually the guests began to arrive and Somali music was played. I was asked all of a sudden if I would be happy to video the wedding party. I was quite nervous about this prospect given that I had never videoed an occasion like this before and the thought of me, a complete novice, being responsible for the wedding video (or a bad wedding video as the case might be) was terrifying. The following year one of the bride's relatives thanked me for taking such a good wedding video (phew!).

The request for me to videotape proceedings also surprised me on another, more conceptual, level. At the outset of my research I discovered that many of the individuals I encountered were very reluctant to have their photograph taken. This proved to be a continuing source of disappointment for me as I was unable to visually record the richness of my research experiences. According to one person I spoke with, this dislike of photographs is because many Muslims believe that the act of being photographed will be used against you on Judgement Day. Others believe it is wrong to have the eyes photographed but do not mind being photographed with their backs to the camera or with their eyes covered. While this was the majority view, there were some individuals who were not so concerned with being photographed including those individuals who appeared in the Metro magazine in 2003 (Rapson, 2003).

I reluctantly began videoing the proceedings and found it a good way to observe what was going on around me. The women formed a circle and were clapping and swaying in time to the music. A woman then made a high pitched ululating call, which, as I found out later, signals that the bride was about to enter the room. The bride entered the room with four bridesmaids wearing brightly striped dresses. This I discovered later, is traditional Somali wedding garb. I was somewhat taken aback that the bridesmaids had their heads uncovered, hair fashioned into intricate braided hairstyles. Then one woman began beating a small hand drum and reciting a poem written in Somali about the bride, her family and her country. It was a rhyming poem with a distinctive metre. The chant was divided into verses and between each verse two or three women would go into the middle of the circle and dance by stamping their feet rhythmically in time to the drum. Many danced with a scarf, holding each end and putting it over their head. Dancing was circular and as the dancers danced the onlookers would clap and chant encouragement to the dancers. It was fascinating to watch and quite unlike any other wedding I have attended. The dancers at times seemed to challenge each other in a 'dance-off'. It was a wonderful time, particularly to see the women so carefree, relaxed and jovial.

**Figure 12** Preparing to go to a wedding. A photo of me wearing traditional Somali dress (*dirac*) pictured beside the Somali flag



**Figure 13 A Somali wedding in progress**



After a while the dancing stopped and the bride went off to get changed. The women served dinner. There was chicken, rice, *canjeero* (a savoury pancake made with rice flour) and *suugo* a tomato based curry sauce. After the meal, the bride returned in a new outfit. According to one person, the three costume changes during the wedding party is symbolic of weddings held in Somalia which last for three days, with the bride wearing a new outfit each day. Eventually, I was relieved of my videotaping duties and became part of the circle of women watching the dancing. The dancing changed somewhat as the bride now joined in the dancing and women would each take a turn to hold her hand and sway in time to the music. I was pulled by the hand to the front of the room and joined in. I can only imagine what the bride, who I had never met, must have thought of me as a complete stranger, being at her wedding. After six hours the wedding slowly began to wind down. The bride's husband arrived shortly before midnight and once again the women lined the walls of the hall and made the high pitched ululating sound. The groom then took his bride and left the room. The women followed and cheered as the wedding cars left the event.

### *Friendships*

As I became more familiar with the community and the community became more familiar with me, I began to be invited to various community events including Somali Independence Day celebrations, parenting programmes, refugee forums and various consultation exercises. At the start of my research I had to wait for many months to be invited to a wedding however, towards the end of my fieldwork, I had to turn invitations down! I remember meeting people for the first time and if the discussion turned to the topic of weddings a number of people cried out "Oh, you are the white

woman at the Somali weddings!” Apparently my presence at such events was a topic of interest and discussion. One person even asked me if one of my parents was Somali.

In many ways this sense of familiarity occurred because I had been involved with the community quite a long time (nearly four years at time of writing). As noted by Shurmer-Smith (2003):

*“Ethnography cannot be rushed. If you cannot spend at least three continuous months with the people you want to write about, you might as well forget about them. Less than this and the best you will come up with is the view the people themselves would like to project, tempered with one’s own gut reactions; it will be subjective in the bad sense. It takes a long while to appreciate the other people’s subjectivity, to realise when they are lying or deliberately trying to impress, when they are joking or winding their ethnographer up” (Shurmer-Smith, 2003:251)*

Due to my involvement with the Somali community over a number of years, people have had time to get to know who I am, what I am about and that I can be trusted. While this may not be the case for everyone (as the section on ‘Rumours and Suspicion’ describes), feedback I have received suggests that this is the case. Community members have told me that my willingness to become involved in many aspects of community life has helped me to become accepted and trusted. I believe this is partially due to my philosophy of not wanting to simply research the community from an aloof, detached viewpoint but to become involved, get to know people and to help in whatever way I could. Throughout the course of my research I became involved in a variety of ways including:

- When friends had babies I would drop over a gift for the baby
- I was a referee for a participant looking for a job
- I helped edit assignments
- I assisted with wedding preparations
- I transported people to various places
- I put people in touch with services such as ESOL tuition
- I advocated for participants experiencing difficulty with housing/immigration/income problems
- I helped people search for jobs
- I assisted with applications and forms
- I lobbied for additional resources for the community
- I assisted community members carrying out research

Touched by some of the dire circumstances faced by participants, I always tried to take a small gift with me to people’s homes when visiting for follow-up interviews. Sometimes I would take fresh fruit or treats for the children.

As my involvement continued, these acts were reciprocated and over time I became fortunate enough to develop friendships with particular individuals. I have enjoyed countless cups of sweet, milky Somali tea and have been made to feel welcome in people's homes. I was particularly touched on one occasion in January 2005 when I was recovering from surgery to receive four phone calls from community members wanting to know if I was alright and whether I needed someone to come and look after me. On the birth of my daughter Sophie in January 2006, I received the following text message from one community leader with words of congratulations and an exhortation to stay at home for 40 days following the birth (as is the case in Somali custom) and be tended to by female family members. The message said:

*This is great news sister. I pray Sophie will have great life and health. I hope Sophie will protect and respect you, Peter and our nation. Jody, stay home for 40 days. Hope you recover good and thanks for the beautiful name. I think Sophie, she is a member of the Somali community. Best wishes to you, Sophie and Peter.*

A few weeks later I was visited by three other community members laden with many beautiful gifts for my daughter. I was greatly touched by their kindness and generosity.

On reflection, this period of intensive community participation proved to be an instrumental precursor for subsequent research into health, illness and TB experiences within the Somali community. Once I was permitted to begin interviewing after the 12 month provisional registration period, I found that this time of familiarisation had established trust and goodwill that was essential particularly when broaching sensitive issues such as TB. The following section outlines the participant recruitment process that heavily depended on the relationships established during the community familiarisation stage. I also present a brief epidemiological profile of the 114 Somalis notified with TB in the Auckland region between 2001 and 2005 from which my subsequent research participants were drawn from.

## **Participants and the recruitment process**

During the course of this thesis I interviewed a wide variety of people including individuals with TB and their families, people in the wider community and key stakeholders such as community workers. There was considerable diversity in the demographic background of those I interviewed. A significant number of people were reluctant to share their personal details with me (see section titled 'Rumours and Suspicion'). However, of those who were open with me about such matters, a number of interesting trends emerged. The first was the extent to which my group of participants shared a strong demographic similarity to the wider Auckland Somali population as a whole. Approximately half of all participants originated from urban areas in Somalia and tended to be highly educated, with previous work experience in the fields of science, business and medicine.

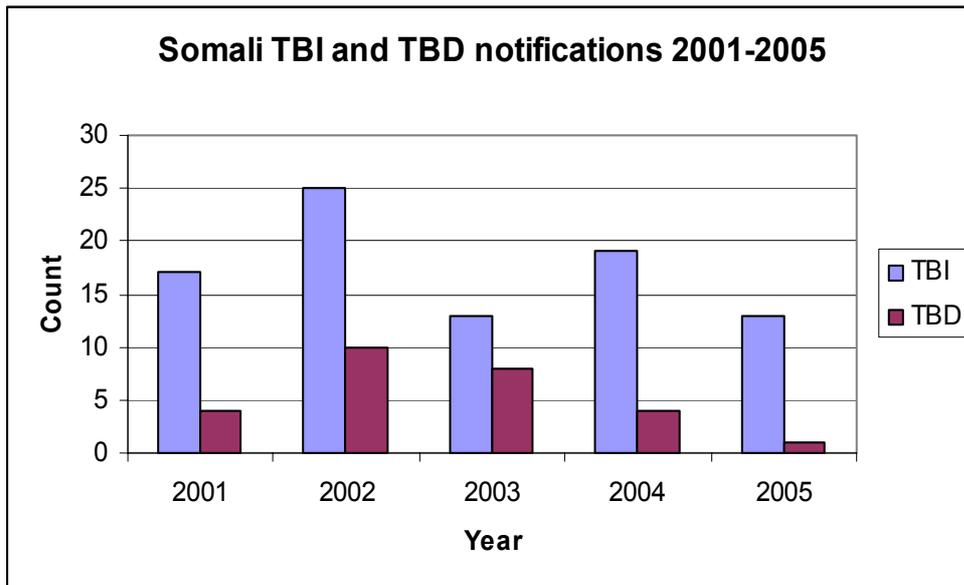
The other half, originated from rural parts of Somalia, had limited education levels and was typically involved in pastoral agricultural activities. Mirroring the characteristics of the wider Auckland Somali population, most were between the ages of 25 and 49 years of age with a higher proportion of women than men. This reflects New Zealand's refugee quota policy that has special provisions for 'women-at-risk'. Many of these women were lone-parents with a large number of children (sometimes numbering up to 10). The majority of my research participants had arrived in New Zealand via the UNHCR quota with smaller numbers of asylum seekers and family reunification refugees. Many of these demographic characteristics are reflected upon within the context of individual life stories, presented throughout findings Chapters Six through to Nine.

In terms of participant recruitment, a variety of methods were employed. With the extensive period of community participation I engaged in prior to commencing TB interviews, I met many individuals within the contexts of community programmes I was involved in (e.g. sewing, swimming, nutrition and adult education). In accordance with ethics guidelines, when I began TB-focused interviews, the first approach was made by public health nurses (PHN) working for Auckland Regional Public Health Service. The PHNs would tell the patients about the TB project and ask whether they would be willing to participate in the study. Some individuals requested a meeting with me to find out more information. If people agreed to participate, the PHN would pass on their contact details to me. This type of approach was decided upon as PHNs had an established relationship with TB patients.

Recruiting participants with TB proved to be extremely difficult. First of all, notification data was requested from the ARPHS database. For the purposes of this study all notifications for individuals with a recorded ethnicity of 'Somali' or birthplace of 'Somalia' were retrieved. This was done to ensure all potential Somali individuals with TB were included in the study. It is possible that some Somali individuals with TB have been missed out if their ethnicity/birthplace was not recorded or not accurately recorded. Some potential participants may have been omitted if their birthplace was not in Somalia (a number of Somalis born post-1990 were born in refugee camps in neighbouring countries such as Kenya and Ethiopia). Once these numbers of notifications were established, I was given the name of the PHN assigned to each case. I then contacted the PHN who then made contact with the individual.

Between 2001 and 2005, 114 Somali individuals were referred to Auckland Regional Public Health Service as depicted in Figure 14 overleaf. The majority of these people (81) received TBI preventative treatment. In total, there were 27 Somali people within the Auckland region notified with new cases of active TB between 2001 and 2005. This results in an incidence rate of approximately 1,800 per 100,000 for the Auckland Somali community over this time period (based on my population estimate of 1,500 – see Chapter Six for further discussion).

**Figure 14 Somali TB notifications 2001-2005**

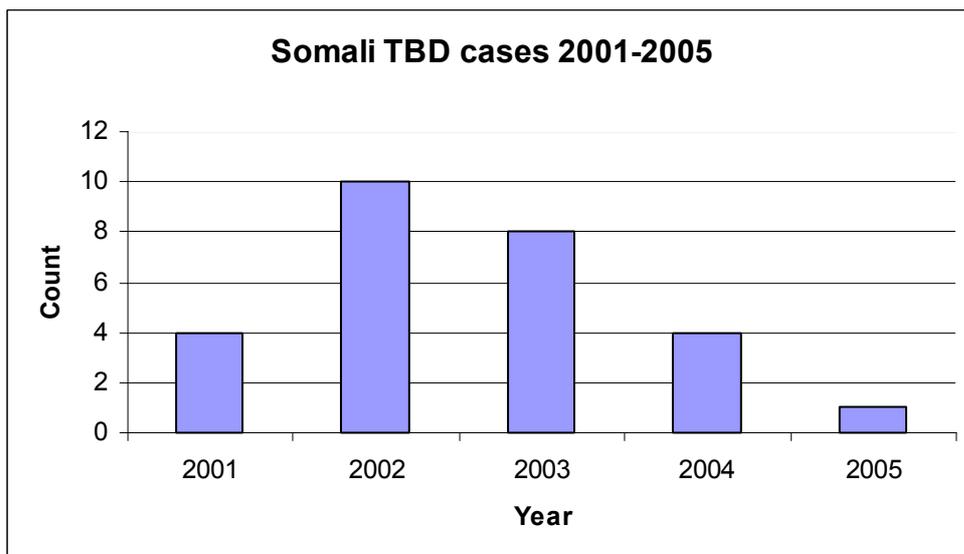


Data provided by Auckland Regional Public Health Service, 2007

Similar rates were recorded by Das et al. (2006b) for Somalis between 1995 and 1999 (1924.4 per 100,000). Interestingly, if the Auckland Somali population count from the 2001 Census is used (546), this increases the incidence rate to 4,945 per 100,000. This discrepancy highlights the importance of collecting accurate and comprehensive population data.

While these rates are very high, the numbers of Somali notifications have steadily decreased since peaking in 2002 as shown in Figure 15.

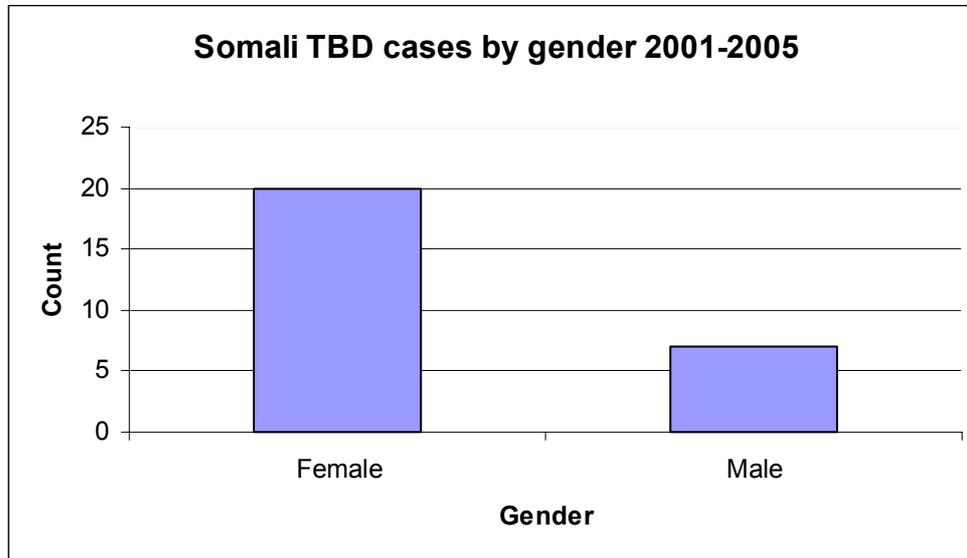
**Figure 15 Somali TBD notifications 2001-2005**



Data provided by Auckland Regional Public Health Service, 2007

Of the 27 new cases of active TB, 74% occurred in females (Figure 16). This pattern may reflect the higher proportions of Somali women who have settled in NZ (as described in Chapter Six).

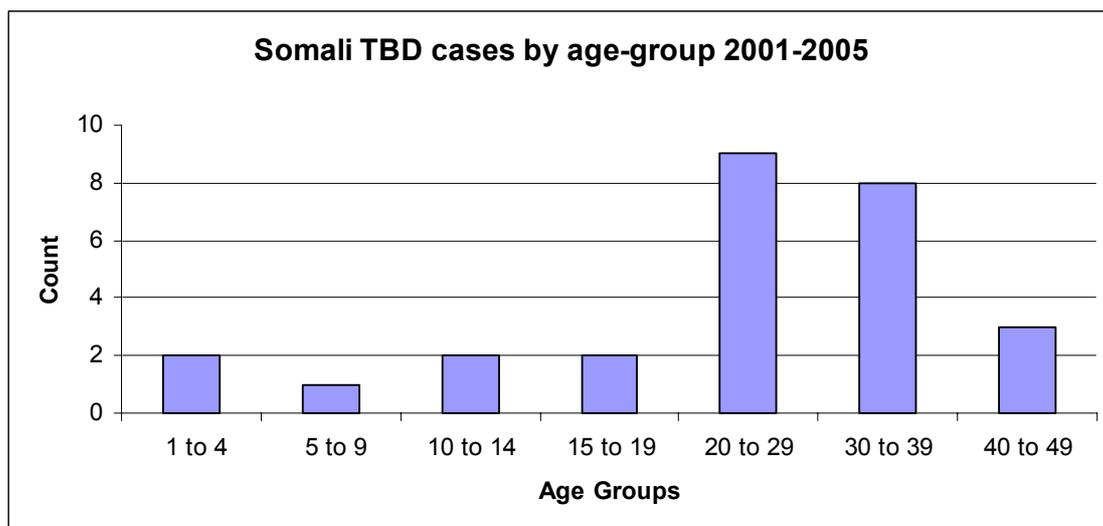
**Figure 16 Somali TBD notifications by gender**



Data provided by Auckland Regional Public Health Service, 2007

There was also an interesting pattern in terms of the age group distribution (Figure 17). The majority of TB cases occurred in young adults between 20 and 39 years of age. This distribution is a feature of the youthful characteristic of the Auckland Somali community with very few individuals over 50 years of age. This is in part due to low life expectancy in addition to the effects of the Civil War which claimed the lives of many adults.

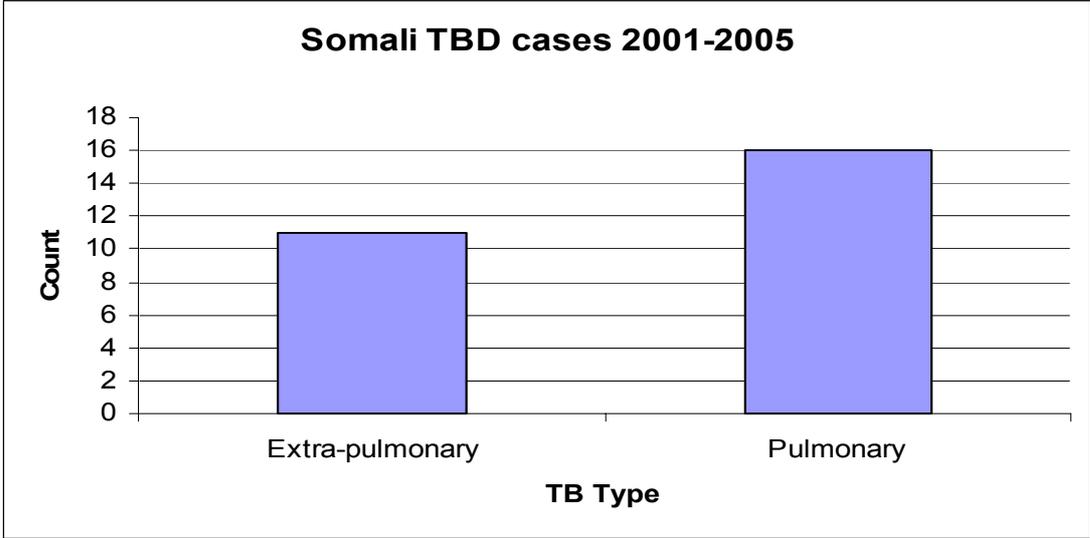
**Figure 17 Somali TBD cases by age-group**



Data provided by Auckland Regional Public Health Service, 2007

Of the 27 Somali TBD notifications (Figure 18), quite a large proportion experienced extra-pulmonary disease (41%). This is quite high given that internationally, it is estimated that only between 10-20% of all TBD cases are extra-pulmonary (Yang, Kong and Wilson, 2004). Higher rates of extra-pulmonary disease are often found in young people, ethnic minorities, people with HIV/AIDS and reactivation TB.

**Figure 18 TB type of Somali TBD cases 2001-2005**



Data provided by Auckland Regional Public Health Service, 2007

In terms of the interval between arriving in NZ and developing TB, data suggests that few Somalis come to NZ with active TB. According to data in Figure 19 overleaf, only two individuals were notified as having TB shortly after arriving in NZ. The average length of time between arriving in NZ and developing TB is 3.4 years. This is similar to the findings of the Ministry of Health in terms of overseas-born TB notifications (Ministry of Health, 2003a). It also stresses the need to be aware of the living conditions and resettlement experiences of Somalis when considering the burden of TB within this group.

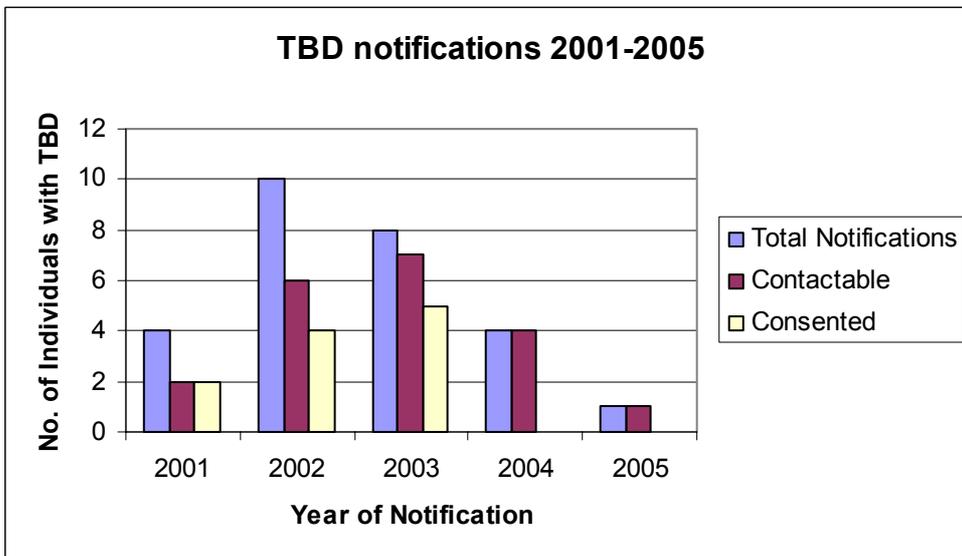
**Figure 19 Interval between arrival in NZ and notification of TB - Somali TB notifications 2001-2005**



Data provided by Auckland Regional Public Health Service, 2007

Of the 27 Somali TBD notifications between 2001-2005, 20 of these individuals were able to be contacted as depicted in Figure 20. Of the remainder, some had moved out of Auckland while the telephone numbers of others (as stored in the ARPHS database) were no longer functioning. The high proportion of people who were no longer contactable reflects the considerable mobility amongst the Somali population in general. Nielsen (2004) documented similar observations in her research with Somalis living in Denmark as did Warfa et al. (2006) in the United Kingdom. As would be expected, notifications dating back to earlier years (2001 and 2002) tended to be less contactable than more recent notifications.

**Figure 20 Somali TBD Notifications 2001-2005**

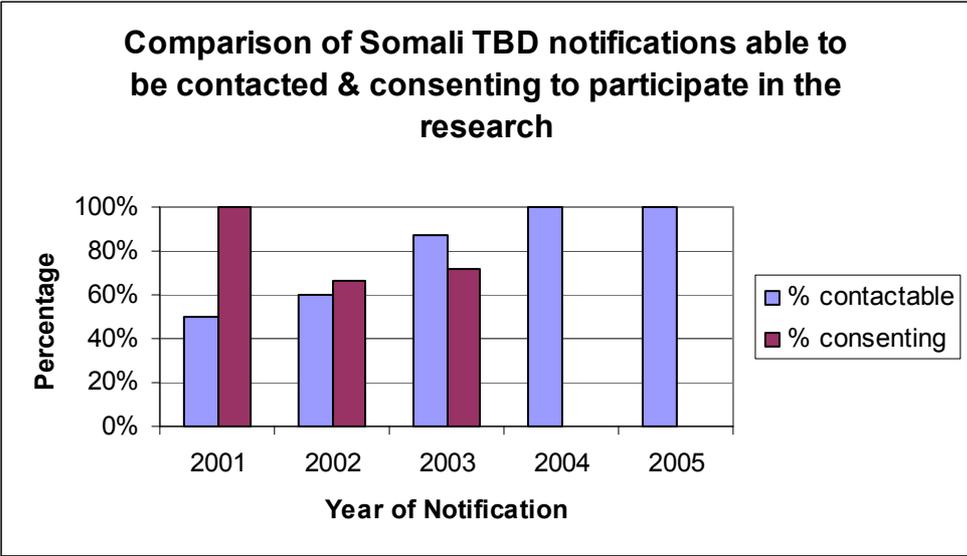


Data provided by Auckland Regional Public Health Service, 2007

Of the 20 Somalis able to be contacted, 11 agreed to be interviewed. Another two individuals whose notification status was unconfirmed at the time of this research also agreed to be interviewed after being approached by their PHN. Of the nine individuals who refused to participate, I found it interesting how some were initially interested in participating but had changed their mind by the time follow-up contact had been made. The main determinant of this appeared to be the influence of a family member who actively discouraged the individual from participating.

An interesting trend evident in Figure 21 is that those notified in earlier years tended to have a lower percentage of people able to be contacted, but a higher proportion of people who consented to participate. It is difficult to speculate as to the reason behind the trend of decreasing proportions of consent. There are a number of possible explanations. Because the first approach was made by PHNs, a lot depends on the nature of the person’s relationship with the PHN. Those individuals who do not have a close, trusting relationship with their PHN are less likely to participate. One possible contributing factor was the change in PHN areas of responsibility (as described in Chapter Nine). This meant that nurses with many years of experience in working with Somali patients were shifted to different geographical areas. These rates of refusal were very disappointing as it is those who are suffering from stigma whose experiences need to be better understood. A similar experience was noted by Dyck (2000) in her research with women. Those who were not politically mobilised were difficult to access.

**Figure 21 Comparison of proportion of Somali TBD notifications able to be contacted and subsequently consenting to participate**



Anecdotes from the PHNs also indicate that the individuals who declined to participate tended to be those most affected by the stigma and isolation caused by having TB. In other words, they were often people who were frightened of talking about TB and distrustful of a Pakeha researcher who they had never met. As noted by Jacobsen and Landau:

*“In any particular refugee community, there are groups of people who are particularly difficult to reach, due to norms of public display, voice, or simply their work and living conditions. Insecure conditions, coupled with widespread distrust, may also mean people are less likely to agree to be interviewed” (Jacobsen and Landau, 2003:12)*

Another possible reason why none of the Somalis notified with TB in 2004 took part in my research relates to adverse publicity within Parliament and the media regarding refugees, disease and Somalis. In 2003, in an oral question to the Prime Minister, a query about ‘third world diseases’ made by Rt Hon Winston Peters was subsequently followed by specific reference to Somali people (see Table 6 overleaf). Although it is difficult to gauge, such ideas may have contributed to the reluctance of Somalis to participate in this research.

**Table 6 Parliamentary Debate Excerpt, 2nd September 2003**

Rt Hon Winston Peters                      How can [the Prime Minister] have confidence in a Minister of Immigration and a Minister of Health who have allowed to come into this country, and now to clog up the wards in North Shore and Auckland hospitals, hundreds of people with Third World diseases including tuberculosis cases where the wards are busting to overflowing-and 70 percent are immigrants-and how can that be a responsible way of defending the health of the New Zealand people

Rt Hon Helen Clark                      As I understand it, there is screening for a disease like tuberculosis. However, it is always possible that some people present false, fraudulent X-rays. I can say to the member that the Government does not tolerate that at all, and, if there is any evidence that people have done such, they will certainly be prosecuted.

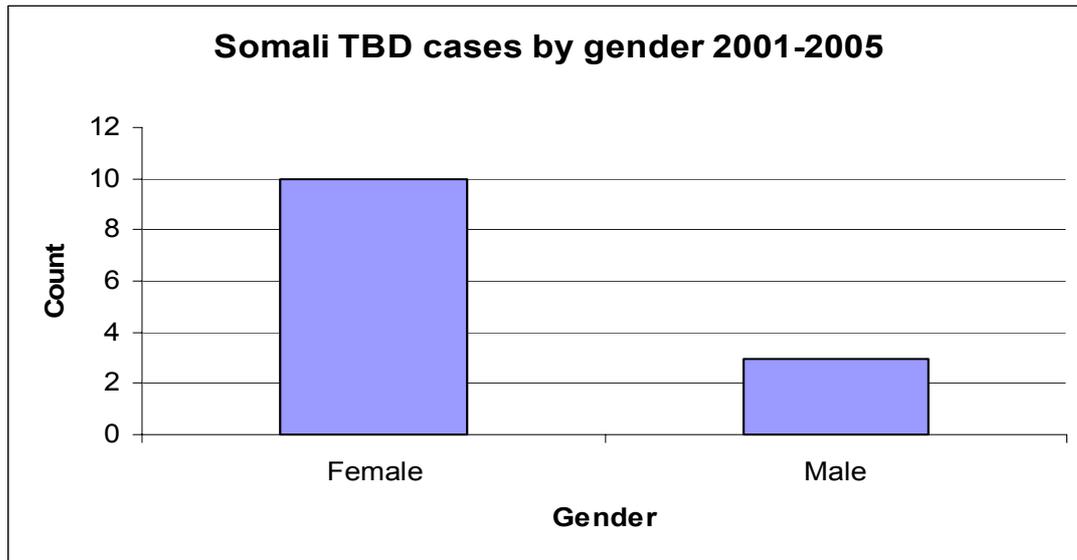
Rt Hon Winston Peters                      How can the Prime Minister make that claim when she knows full well that a great number of the Somalis, for example, never had any test given to them in the first place and were let out early, prior to having testing, on the basis that they had to be reunited with their own people? Given that there are hundreds of cases, and that we now have Third World diseases that we thought we had defeated, how is that a responsible way for a Minister of Immigration and a Minister of Health to conduct the affairs of looking after the health of this country?

Source: (Hansard, 2003)

Contacting and following up participants took a considerable amount of time and resources. In some cases numerous messages would be left before I was able to speak to the individual. Often I had to work through the interpreter who would try to make contact with the individual. This was not easy, in part due to the high degree of mobility within the community. As my research progressed I began having an introductory meeting with respondents before launching into the interview to make sure that the individual was happy to participate. I started doing this after a number of people agreed to participate but changed their mind once I arrived. One of the reasons why contacting participants was complicated was due to the fact that interviews had to be arranged in co-ordination with interpreters, participants and myself. This proved to be difficult as participants tended to be living in extended family situations with many family members to take care of. Finding time for a one-hour interview was a difficult task that required interviews to be made well in advance. Many times I arrived at the agreed time for the interview only to find that the person was not home or not able to complete the interview for various reasons. On one occasion, I could not complete an interview as a family member had just called for an ambulance and the interpreter and I found ourselves being asked to assist in sorting out the complicated situation that had arisen.

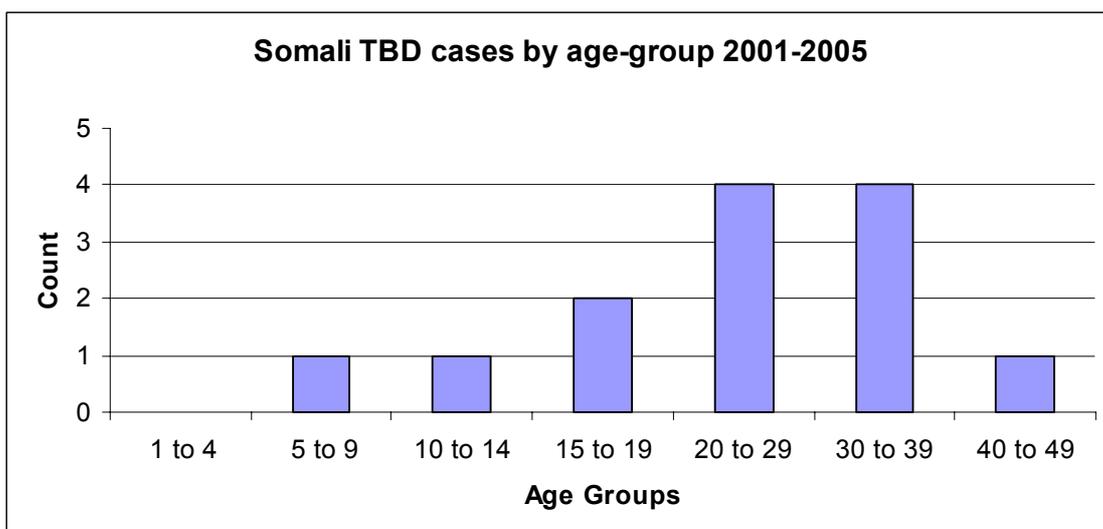
The group of 13 Somalis with TBD whom I interviewed proved to be very similar in composition to the profile of all Somali TBD notifications between 2002 and 2005 that has been outlined although some individuals were unable to recall specific information about their illness e.g. timelines or type of TB. Of the 13 participants, 10 were female which is a similar distribution to the total number of Somali TBD notifications (Figure 22).

**Figure 22 Somali research participants by gender**



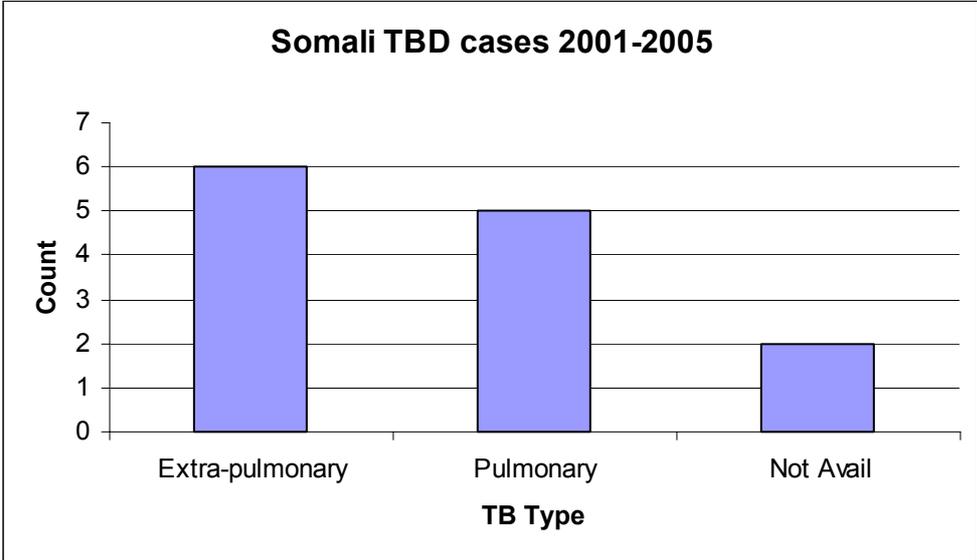
There was a similar age-group distribution as the total Somali TBD population with most individuals falling within the 20-39 year age band (Figure 23).

**Figure 23 Somali research participants by age-group**



There was a relatively even split between individuals with pulmonary and extra-pulmonary disease (Figure 24). For the two individuals whose TB status was unconfirmed this information was not available.

**Figure 24 Research participants by TB type**



In addition to the 13 interviews conducted with people who were notified with TB disease, another 12 individuals with TB infection were interviewed. Between 2001 and 2005, 81 Somalis were given TBI preventative treatment through the Auckland Regional Public Health Service. As my primary focus was on the experiences of those with TBD, my first priority was to endeavour to contact all possible notifications during the period of study. With the high rates of refusal of Somalis with TBD, I began organising interviews with people with TBI who expressed willingness at being involved in the research.

Interviews with people with TBI provided valuable contextual information about people's understandings of the illness and experiences of the treatment process. Those with TBI were largely recruited through networks I had established during my fieldwork using the snowball sampling method. Frequently I would interview an individual about TB and find that other household members were being treated for TBI and wanted to contribute to discussions. This occurred in a number of situations where entire families were being followed up for TBI. In some cases, one family member had developed TBD and infected other household members. In two cases, PHNs approached two people with TBI whom I subsequently interviewed.

## Interviews

Semi-structured interviewing was one of the main methods employed in this study. Semi-structured interviews are a particularly valuable methodological tool as they enable the researcher to cover a series of themes while also allowing participants to construct their own accounts of their experiences in their own way. The aim of the interviews was to understand how an individual experienced and made sense of events that had occurred in their life and how these had contributed to, and shaped, an individual's encounter with TB.

Interviews were held between March 2004 and November 2005. Where possible, second interviews were held to follow up issues that had been omitted or only briefly covered in previous interviews. The interviews collected information from the participants about their individual life stories and experience of TB (See Appendices 7-10 for interview questions). I also tried to gain an understanding of Somali understandings of health and disease more generally. Interviews lasted on average between one to two hours. Before embarking on the TB and health questions, I endeavoured to establish a rapport with participants. Some participants seemed quite wary of me and it took some time to establish dialogue beyond asking questions and receiving one-word answers. At times I found it difficult to get participants to open up, as demonstrated in the example below.

Jody	What do you think causes TB?
Raha	Don't know – just got it
Jody	What are the different kinds of TB?
Raha	Don't know
Jody	What are the different ways that TB can be spread?
Raha	Don't know
Jody	How do you know if you have TB?
Raha	I just had it.

What this excerpt omits to portray is the length of time over which this interaction took place. The participant took a long time to formulate each response. Furthermore, while this participant was not forthcoming in her responses to me at the time, she contacted me many times over the course of my research for a chat or to request my assistance with various tasks. After one interview, Raha asked if I would be a verbal referee for a job for which she was applying.

Other interviews were the opposite. I would initiate the conversation asking them to tell me about the events that led them to New Zealand. This would be followed by a monologue or life history with very little prompting, reflecting Jacobsen and Landau's (2003) comment that interviewing refugees is an inherently difficult process as revealing personal information can be used against the individual at a later stage.

I also found that some participants experienced difficulty answering questions on perceptions of health and disease. One question in particular, 'What does the word health mean to you' was particularly problematic. Through a process of trial and error, I learned that abstract questions on notions of health and disease were difficult and that I had to narrow the focus of my questions and use specific situations/examples to get people to think more generally. For instance, instead of asking about health generally, I would ask about specific things people do to maintain good health. Often the ensuing narrative would lead to discussion of more abstract ideas about health in general which had been the original focus of my question.

At the outset of an interview, a Participant Information Sheet was provided (see Appendix 4) and key points translated by the interpreter. Participants were offered a small gift as a token of appreciation for helping me with my research such as a \$20 petrol, grocery or Warehouse voucher. Participants were asked if they were happy for me to view their Public Health medical notes. Most individuals agreed. In addition, the consent form (Appendix 5), included a question about whether people were willing for the interview to be taped. Often, this question was met with considerable nervousness and subsequently only seven participants consented. For those who did not consent to their interview being recorded, I took handwritten notes instead. Tape recording proved to be difficult in part due to the settings in which the interview took place. Eleven interviews were conducted within the home and this tended to involve many other family members sitting in on the interview. Most households included young children who would frequently accost the tape recorder as a novel toy. I ended up taking an activity pack with me to interviews containing crayons and paper to help entertain the children. Because of the degree of difficulty in recruiting participants I was happy to have the opportunity to speak with individuals at all, although the settings often precluded taking a clear sound recording. This was in part due to the presence of background noise such as the TV or young children playing and interacting with the participants. A number of times the tape recording was virtually un-transcribable.

After consenting to be interviewed, participants were invited to select a venue of their choice for the interview. While 11 individuals were interviewed within their homes a variety of other settings were also used including a shopping mall, the backseat of a car in a carpark, the Public Health office and at one participant's workplace. These locations were selected by participants so as to minimise the chance of being 'found out' or associated with TB. There was a sense of covertness – one participant wanted to be interviewed in a carpark so their family would not know that they had participated, while others wanted to actively avoid using the home-space as an interview setting.

One thing that happened when conducting interviews was I would arrive at a person's home to talk about TB, and would end up carrying out the discussion in the presence of other family members. This was something I had not experienced before as a researcher and was quite unfamiliar territory for me. It resulted in its own unique challenges as I had been previously accustomed to the dynamics of one-on-one interviews. In some cases the family members wished to participate in the

conversation and this was often very beneficial as it provided additional perspectives on the topics at hand. It also meant that I recruited a number of individuals with TBI as in many cases the individual with TBD lived with other people with TBI. One shortcoming of group interviews is that it potentially censored the openness and honesty of participants due to family dynamics and power relations within the household. This did not tend to happen often as, in many cases, a family member had operated for the individual as an interpreter throughout the whole TB process.

As many of my participants were mothers, in most situations children were present at the time of the interview. This also presented unique challenges for mothers who were caring for up to ten children at one time. Sometimes I felt like an intruder placing another demand on an already over-stretched mother. I remember one occasion when I was interviewing one female participant in her home whilst her husband cared for the children in another room. Every few minutes the children would burst into the room and climb all over their mother. Increasingly frustrated by this, the mother sternly spoke to her children in Somali making vicious chopping motions with her fingers. The children stared at me wide-eyed. Later she told me that she had told her children that I was here to circumcise them in an effort to stop them interrupting us!! This threat was clearly not taken seriously as the children returned to the room and began using the crayons and paper I had brought with me.

Although interviews were chaotic, noisy and inter-mingled with the everyday responsibilities of housework and child-care, they enabled me to share in a brief moment of people's days. I particularly enjoyed interacting with the children. After learning some basic Somali words and phrases I would try and talk to the children. The results of such attempts were fascinating. In one situation I said to a young boy – "*Meeqo sano jirtaa?*" (What is your name?). His eyes nearly popped out of his head and he turned inquisitively to his Uncle. He looked confused as though he couldn't believe what he was hearing. His Uncle laughed and told him in Somali to reply to me. The young boy then began pointing to various objects within the lounge testing my knowledge of Somali.

In addition to interviewing people with TBI and TBD, I met with nine other community stakeholders in order to add contextual data to the study. Stakeholders came from a variety of sources and included medical professionals, community workers and refugee workers from both New Zealand and Somalia. These interviews occurred somewhat spontaneously and tended to be prompted from a chance meeting at different refugee/community events. They proved to be enormously beneficial particularly in terms of Somali resettlement experiences described in Chapter Six.

## Focus groups

Another (methodological) tool I utilised in this study was that of focus groups. In total, I conducted three focus groups. The first included six community members who had participated in the TB education programme conducted by ARPHS in 2002. The second group included 14 Somali men who discussed a variety of issues surrounding health and TB while the third group consisted of eight Somali women and also covered health and TB issues. Community leaders were paid by the TB project team to assist with organising and facilitating these focus groups.

I selected focus groups as a research technique in order to learn about the way in which Somali people understand issues of health and disease. As Somalis comprise an oral-based society, focus groups are an excellent way to explore the range of views, knowledge, experiences and preferences on a given topic. Furthermore, they also encourage discussion and debate of particular ideas that may not occur in a structured interview or questionnaire (Bedford and Burgess, 2001).

The use of focus groups has been critiqued on a number of levels (Bedford and Burgess, 2001; Cameron, 2005). Firstly, because focus groups rely on group interaction, the quality of discussions is dependent both on the level of interest and degree of comfort experienced by participants. Interpersonal relationships between group members can also be important, on one extreme one may have participants who feel reluctant to share their views in the presence of other group members who are perceived to be more 'knowledgeable' about the topic at hand, while others may dominate discussions, obscuring the views of others. Focus groups also require a highly-skilled facilitator to direct the conversation, probe and encourage participation. Nevertheless, these limitations aside, focus groups are a useful way to canvas the views and perceptions of a wide variety of community members.

I recruited members for each of the focus groups in different ways. For the TB educators, each person was approached by the community president who organised the meeting at the Pan African centre. The discussion was led by myself and tape-recorded with the consent of all the participants. The Somali men's focus group was conducted by two male community leaders, as my presence would inhibit the conversation and would potentially make some male participants uncomfortable. Furthermore, because most participants speak little English, it made more sense to translate the discussion into English after the event rather than hold up the flow of conversation during the focus group. I held a number of training sessions with the two leaders to assist them in their role of leading the discussion and taking notes. Due to the difficulties experienced during the one-on-one interviews, I decided to get the focus group facilitators to take notes rather than to try and tape-record the discussions. The discussion leader verbally translated the Participant Information Sheet and obtained verbal consent from each participant.

Participant recruitment was a difficult issue, in part due to the sensitive nature of the topic and also due to the time commitment required by participants. In order to overcome this challenge, the first focus group was conducted at a Somali men's ESOL class that took place at the Adult Literacy School previously discussed. In total, 14 men took part. Refreshments were provided to thank people for participating.

A similar approach was used to recruit participants for the women's focus groups. In this instance, a trusted community leader invited a variety of women to her home to discuss health and disease issues. This leader was paid to lead the discussion while another community representative assisted with note-taking. Once again, although I would have been able to attend, because of the language issues it made sense to translate the discussions into English after the event rather than during the discussion. As with the men's groups the discussion leader and note-taker were given training on focus group facilitation techniques. Participants were also offered refreshments to thank them for their time. In total eight women participated.

After the two focus groups I held a debriefing session with the facilitators to discuss how the groups had gone and to translate the narratives into English. It also provided an opportunity for the facilitators to reflect on the interactions between different group members and the themes that emerged.

## **Interview analysis**

The first step of the analysis process occurred during transcription. In total, hundreds of hours of interviews, focus groups and participant observation were transcribed. While this took many months to complete it was valuable as it enabled me to reflect on the different ideas emerging through these encounters. Once transcription was complete I began familiarising myself with the interview data by undertaking several close readings of the material. Through doing this I began noting interesting ideas, surprises and contradictions.

In order to assist in making sense of the large amount of interview material, I used N6 software designed to assist in the analysis of qualitative data. Transcripts were coded line by line and categorised under different headings. As noted by Hammersley and Atkinson (1995) "the process of analysis involves, simultaneously, the development of a set of analytic categories that capture relevant aspects of these data and the assignment of particular items of data to those categories" (Hammersley and Atkinson, 1995:208-209). In other words, categorisation assists researchers in organising their fieldwork material so that relationships and patterns can be seen.

Coding was an iterative process with categories and sub-categories constantly changing, merging and being re-worked as the analysis process progressed. Using N6 proved to be very valuable as

both a transcript storage and retrieval mechanism and also as an analytical tool. Categories were able to be repeatedly changed and cross-referencing done with ease. Yet as Crang (1997) suggests the coding process is largely a creative one, that draws heavily on how you “make sense of material using the knowledge you have developed through research and reading literature” (Crang, 1997:188). The themes and patterns that emerged during the analysis process are discussed in detail in Chapters Six, Seven, Eight and Nine.

## Interpreting

Issues surrounding language were significant during the interview process and required the assistance of interpreters. The use of interpreters is not entirely unproblematic and has its own challenges on a number of levels. Firstly, the use of interpreters means that the interviewer is unable to know for certain how the question has been translated and what information is being included in the response. At times I suspected the response had been ‘sanitised’ as the translated response appeared quite different from the other non-verbal cues I observed. As my knowledge of Somali increased I was able to better tell what was happening as the interpreter and participant interacted. Secondly, the use of an interpreter meant that asking one question took three times as long as normal, as my question had to be interpreted, the participant would respond and then the response would be translated back into English for me.

Thirdly, I gained a sense that a number of participants found it hard to trust their interpreter. In part this is a feature of the Somali community being very small and that ‘news travels fast’ via informal networks. For instance, I remember being present in someone’s home when an ambulance was called. The ambulance arrived and within two minutes nearly ten Somali relatives (who did not live at the address) were at the door. They had seen or been told that an ambulance had arrived and had come to investigate. Some participants were very nervous about using certain interpreters. This was noted by Jacobsen and Landau who described how using interpreters/research assistants from the same group as research participants potentially risks:

*“...transgressing political, social, or economic fault-lines of which the researcher may not be aware. In highly sectarian countries, like Congo or Burundi, it is quite possible that a research assistant may be associated – by name, appearance, accent, style of dress – with a group the respondent either fears or despises” (Jacobsen and Landau, 2003:9).*

Given the long-held tension and acrimony between particular clans and sub-clans, such an observation is very pertinent for the Somali community living in Auckland.

Interpreters play a very important role within interview encounters. As participants were able to choose their own interpreters, I worked with a large number of different interpreters during the research process. There were however a small number of trained interpreters that I worked with

quite often. In many of these cases I observed that these interpreters played an active role in the interview process. One interpreter described to me how he had encouraged one interviewee to elaborate on his one-word answers and think about why he holds his views. Another interpreter said that she went to a lot of effort to reassure one participant that it was 'safe' to talk to me and to open up about the topic of TB. I came to value the relationship I developed with these interpreters greatly and found that they assisted me greatly in 'interpreting' situations and understanding the views and experiences of Somali participants.

Because I wanted to ensure that participants felt as comfortable as possible, I asked participants whether they wanted an interpreter and who they would like that interpreter to be. Some participants said they wanted no interpreter due to these issues of trust. I would then meet with them and often experienced great difficulty in communicating with them as their English language skills were limited and my Somali was even more limited. Participants repeatedly apologised for their poor English and felt embarrassed at the difficulties they faced in communicating with me. I tried to reassure people by saying that my Somali was far more limited than their English. Once participants felt less self-conscious about their language skills, they relaxed and were more open. Another interesting angle on this issue occurred during one interview where halfway through narrating the story of their journey to New Zealand the participant stopped and asked whether another Somali person would be translating the tape for me. I reassured the participant that I would be the only person listening to the tape, and the narrative continued.

Other participants selected an interpreter but would often choose an untrained interpreter such as a family member. This situation also presents difficulties as in some cases, the interpreter only had slightly better English than the participant. The use of a family member also means that the individual has had no formal training and may experience difficulty translating and using technical language specific to TB. It can also make some topics difficult to talk about. In the case of a young teenage boy interpreting, it was difficult to address topics such as the refugee journey and the events that had happened in Somalia. My experience was that only a few parents had fully discussed this situation with their children who had, at the time been very young. It can also pose difficulties talking about sensitive topics such as childbirth and relationships, a topic that women would normally talk about together. Nevertheless, because of the difficulties experienced in recruiting participants in the first place I was more than happy to be able to speak with the individual at all.

## **Ethics**

There are a number of ethical issues that need to be acknowledged in this research. Of utmost concern to me was the need to protect the privacy and anonymity of my participants and this informed the way in which I conducted myself throughout the research process. For individuals with TB, stigma is still strong and I made every effort to ensure that participants would in no way be

harm through participating. Confidentiality and identifiability were two key issues. At the beginning of each interview I emphasised to participants that what they said to me would remain with me alone and that they would not be personally identifiable. In order to preserve anonymity, pseudonyms have been used and personal details which could make the individual identifiable have been changed. This includes names, occupations and spatial locations. The use of pseudonyms in itself is not straightforward as there are relatively few Somali first-names with some participants sharing the same name. I did not want to erase the Somali identity by assigning English first-name pseudonyms or refer to individuals simply as a number. After much thought I decided to use Arabic pseudonyms based on character qualities (such as courageous, beautiful, sincere, compassionate) reflecting the strong connection Somalis have with Arabic through the Islamic faith and social, cultural and economic ties with the Middle East.

As TBD participants were recruited by PHNs there is a possibility some may have felt compelled to participate due to the PHNs authority figure status. As a precaution, when I first met with participants I would go through the participant information sheet orally, emphasising that participation was voluntary and would in no way come to effect their treatment. At the beginning of interviews, I discussed the aim of the research with participants and would provide them with a participant information sheet and consent form. At the beginning of the study the TB Project Team had the participant information sheet translated into Somali however, I soon discovered that many Somalis struggled to read written Somali. A formalised writing system was only introduced into Somalia in the 1970s, and many adults are unable to read or write in Somali. This is in part due to the fact that Somali people are part of an oral-based society. This meant that I needed to employ alternative research methods such as interviews, conversations and participant observation.

This resulted in a few issues as New Zealand is a written-based society, and the ethics process is certainly based on writing. Yet I have found that introducing paper to a research encounter denotes a sense of imposed authority, surveillance, risk and fear. Paper makes barriers. Asking a member of a partially literate population to sign their name on a piece of paper on which there are many words (i.e. a consent form) regardless of whether it is written in English or Somali, seems to raise suspicion for people for whom signing a piece of paper can be the same as signing your own death warrant. This is the legacy of a long and bitter civil war, where anything written about a person could be used against them. Though designed to protect research participants, consent forms can serve the opposite function in the minds of many Somali; the forms cause them to feel vulnerable and at-risk. For Somalis, the pen (and paper) can indeed be 'mightier than the sword'. In light of the issues discussed above, the project approached the Auckland Ethics Committee to enquire whether we could obtain verbal consent rather than written consent. In August 2004 this request was granted.

Throughout the course of my research I faced numerous ethical dilemmas. This is highlighted in one entry in my research journal where I have reflected upon the ethics process:

*The ethics process is designed to protect and safeguard researchers and research participants alike. Yet, as I have discovered, the consent process is more of a 'safety-net' at the 'bottom of the cliff' in terms of the research process. This has become clearly apparent to me working within a cross-cultural setting. I have realised that so many of the day-to-day, seemingly mundane decisions that researchers have to make are not specified within ethics' regulations and thus require individual researchers to draw on their own philosophy or sense of personal ethics when interacting with others.*

In recent times, there have been efforts amongst the research community to acknowledge and address ethical issues that arise during the course of cross-cultural research. Kearns and Dyck (2004) suggest that culturally safe research includes both the physical and emotional safety of participants and the researcher.

In my view, it is important for researchers to not only conduct themselves in a culturally respectful and therefore ethical way, (i.e. preventing harm), but also to work alongside communities and support those communities in achieving their own goals and therefore contribute to overall wellbeing. Although my research was on TB, a topic that was certainly not of priority to the community, I sought to support the community in addressing their priorities - including employment, language, family reunion, housing and income support.

Of utmost concern to me was the need to protect the privacy and anonymity of my participants. This proved to be difficult at times, and sometimes I had to be very careful to inadvertently avoid identifying families with whom I had worked. In the numerous conversations I had with community leaders, people would say "Oh, they're a TB family" or suggest that "So and so had TB". I had to be very careful in my response and tried to avoid answering at all so that I would not have to lie. One thing I was conscious of was that my identity could come to impact upon the lives of those with whom I was working. Before embarking upon specific TB interviews, I was fortunate to have completed over twelve months of general community familiarisation. My involvement in a wide range of community programmes including those of nutrition, youth, education, sewing and swimming meant that I had met people within a wide variety of settings and that I was not solely associated with TB. I was conscious that some individuals, whom I had come to know well, might be identified publicly given their friendliness with me in public settings. It just so happened that many of the participants whom I had met in the course of conducting formal TBD interviews also happened to be those same people I would meet in a social or community context.

Another ethical issue was that of truth. During my research I noticed that 'truth' is not absolute but is rather a flexible entity that is shaped according to circumstances. This is a potential minefield as public opinion and media discourses regularly cast aspersions on the integrity and legitimacy of refugees and migrants (Lawrence, 2003). Social services and health workers presented a range of

discourses about refugees ranging from being 'vulnerable and struggling' through to being 'liars and cheats'. Horst (2001) similarly describes the politics of truth in her research with Somalis living in Kenyan refugee camps.

There are a number of reasons for this notion of flexibility in 'truth'. Firstly, the ability to present particular accounts is an important survival mechanism successfully used by people who are fleeing from violence and living in the harsh refugee camp conditions. Secondly, personal accounts are presented in such a way as to ensure maximum assistance and help. This is particularly evident in the area of income support, where it is in the family's interests to access the maximum entitlement.

I also had the sense that individuals were trying to present a particular image of themselves to me. In particular I noticed this during the early stages of my research where I was told by certain community leaders that there were no clan rivalries, divorce or men with multiple wives in the Auckland Somali community. I later found out that this was not the case and that people were trying to present the image of the Somali community as being 'modern', 'educated', 'progressive' and 'law-abiding'. Another potential minefield is the accuracy of personal information for those who have been sponsored to NZ. Time and time again individuals would admit that they had immigrated as being someone's husband for example, when in fact they were a distant cousin. In order to achieve their own resettlement dreams, they had skillfully negotiated New Zealand's immigration legislation that permits reunification of immediate family members. Inevitably, this shaping of the truth would come to light and result in numerous problems, such as when the 'wife' requested her own publicly-provided house because she was not 'married' to the man who had sponsored her. The process of analysing people's accounts was a challenging one, and I had to remind myself not to assume the role of judge, as I firmly believe in the value of allowing individuals to construct their own accounts of their realities and experiences, whilst recognising that such accounts are inherently only partial.

## **Rumours and suspicion**

One of the main barriers I experienced in conducting fieldwork was that of suspicion. A number of other researchers working with Somali people have also recorded this (Horst, 2001). While it is not true of all Somalis, suspicion is something I came up against many times during the course of my research and is an understandable response, given the events that took place in people's lives during the civil war. As a consequence, to distrust people is a well-practiced survival mechanism.

At the beginning of my research I toyed with the idea of conducting a census in order to better ascertain the size and characteristics of the Somali population however I was advised by community leaders that this would not be a good idea and that community members would be very suspicious about me, the reasons for collecting personal information and what would be done with

it. I then asked community leaders if they could do an informal census based on their knowledge of how many households within each sub-clan grouping live in the Auckland area. This too was a difficult exercise and attracted some suspicion as to why such questions were being asked. Horst (2001) recounts a similar experience whilst conducting a headcount of Somalis in a refugee camp in Kenya. Shetty et al. (2004) researched TB knowledge, attitudes and practices amongst London Somalis using a questionnaire. Initially participants were suspicious of the questionnaires fearing that the researchers were in fact from the BBC and would use their names as part of radio or television documentary. Furthermore, Shetty et al. experienced difficulty collecting demographic data as participants were reluctant to reveal information such as date of birth, marital status, home address, income, and occupation (Shetty et al., 2004). I similarly encountered difficulties in collecting demographic data from individuals that I knew well who had TB.

Near the beginning of my research project a small article was published in a community newspaper stating that there was a TB research project underway in five different communities in Auckland, including amongst the Somali population. Some weeks after this article, I became aware of rumours circulating amongst the community concerning the subject of my research. One rumour was that I was visiting community members testing them for TB. Whenever the subject arose, I tried to reassure people that I was simply trying to understand people's experiences and understandings of health, disease and TB. This incident highlighted the extent to which there is a great deal of sensitivity about being associated with TB. From that point on, I became very careful about naming the Somali community whenever the research project was featured within the media. Other researchers have similarly faced issues in the publicising of the results of their research. Horst (2001) reflects on the implications of making public some of the findings of her research with Somali refugees in Kenya. She notes that her research results could potentially attract the attention of the authorities and further disadvantage those who are struggling to survive. Wilton (2000) documents the political pressures he faced when deciding how to disseminate the findings of his research about opponents of residential facilities for people with disabilities.

One example of this suspicion about my research occurred when I contacted a participant who had told his PHN that he was happy to be involved in my study. I phoned the participant and arranged a suitable interview time with an interpreter. For nearly 20 minutes I explained the research to the participant and asked if he had any questions. He said "No, everything is fine". The next day I was speaking to a community leader who had received a phone call from the participant wanting to know who I was and what I was doing. After receiving reassurance from the community leader, the interview took place the next day. The community leader said that "People get very suspicious when it comes to TB". In particular, individuals were concerned about why the Somali community was being 'targeted' for TB research. I explained that the project was looking at experiences of people with TB in five different population groups in Auckland. I observed that this tended to have a reassuring effect on those who were concerned about TB being linked with the Somali population.

Another example of the degree of suspicion I encountered occurred when I transported Ulfah to her chest clinic appointment. As noted in my research journal:

*“On the way Ulfah mentioned how she took the vouchers I had given her (thanking her for participating in the research) to the supermarket and before picking up any items, asked an employee ‘Do these work – yes or no?’. The person said yes so she went and bought some grocery items. In the car she said to me that she thought it might be a ‘forgery cheque’ so wanted to get it checked out. We laughed about it together and I said I wouldn’t give her a fake voucher – she laughed and thanked me again and again for the vouchers then kissed my hands a couple of times. Ulfah then asked, “Are you a doctor or nurse?” I said that I was studying to be a science doctor. She looked towards the sky, lifted her hands and said a few words in Somali. She said that she prayed that Allah would make me a doctor quickly”*

In many ways, the degree of suspicion and nervousness connected with TB is due to the ongoing stigma that is associated with the disease.

## **Stigma and the research process**

My own experience of carrying out research within the Somali community emphasised to me that TB is still regarded as a dreaded disease with significant social consequences. When I mentioned that I was researching TB I was regarded with suspicion and concern. I was challenged on numerous occasions to justify why the Somali Community had been singled out for attention. The root of these concerns seemed to be that the Somali community would be publicly associated with the disease and become even more discriminated against (see Chapter Six for more discussion about the discrimination faced by Somalis living in NZ). I observed this same reaction when it came to other health initiatives such as an HIV awareness programme. While concerns about the study seemed to be allayed by explaining that there were also four other communities being researched within the wider TB project, there was a great deal of sensitivity around the public acknowledgement of what I was doing.

Stigma also meant that I had to be careful in the way in which I conducted myself throughout the community. On a number of occasions community representatives would refer to particular individuals or families as ‘TB families’ or ‘TB people’. It did reveal that TB can indeed impact upon the identity and standing of an individual and that TB status is publicly traded knowledge.

PHNs that I spoke with also shared similar experiences and had found that Somali clients were particularly sensitive about others finding out their TB diagnosis. One PHN recounted an experience when she had been accompanying a Somali client to the Chest Clinic at Greenlane

Hospital. She had greeted another Somali patient in the waiting room and was later remonstrated by her original patient for speaking to another Somali person. The first patient suspected that the PHN was disclosing personal information about them.

The sensitivity around the subject of TB also shaped the way in which I conducted my fieldwork. At times, to avoid detection interviews were held in clandestine locations. One participant was interviewed in the backseat of my car in the carpark of a local sportsground while another person was interviewed in a food-court at a shopping mall. Another example of this sensitivity was manifested during focus group discussions that were held. Because of the sensitivity surrounding TB, it would have been extremely difficult to recruit participants had I advertised it as a TB discussion. On the advice of community leaders, the focus groups were labelled as a general discussion on health issues that included a small number of questions relating to TB. Questions were framed in such a way that people were asked in a group setting, about general perceptions of TB rather than being asked to share their own personal (TB) experiences. Nichter (1994) observed a similar phenomenon amongst Phillipinos in his research on TB.

## **Up close and personal – reflections on the realities of research**

Within human geography, there is a growing impetus for researchers to engage with ethical and social justice issues at both a theoretical and practical level (Valentine, 2003) particularly in recent feminist and disability studies scholarship (e.g. Chouinard, 2000; Dyck, 2000). Cloke (2002) argues that while some geographers have sought to understand the experiences of, and give voice to the 'other' that:

*“...it is easy to detect in human geography an abstract, intellectually fascinated, but often uncommitted sense of the other. However, with some significant and notable exceptions, I believe it is far more difficult to discover in contemporary human geography as a whole a sense for the other which is emotional, connected and committed” (Cloke, 2002:591).*

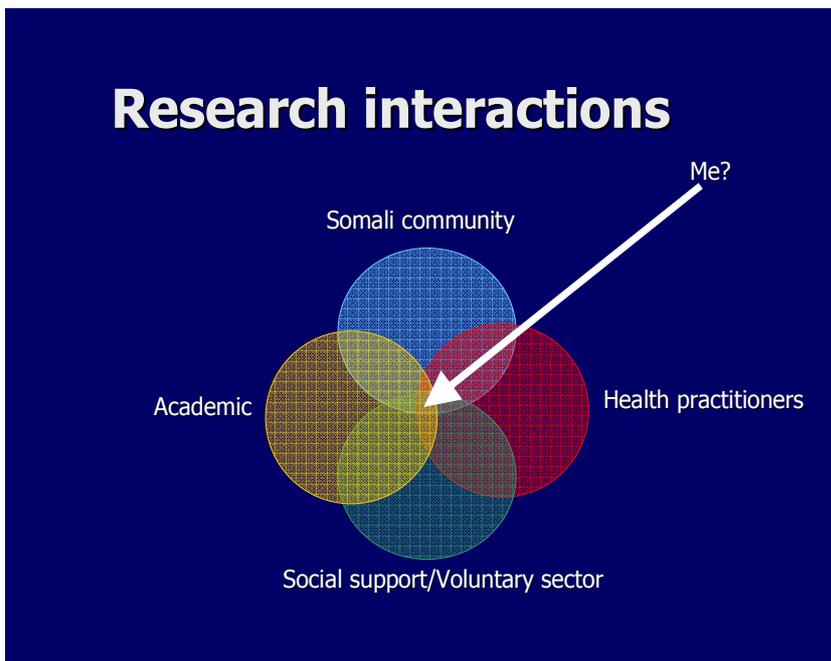
Shortly after commencing my PhD, I attended a seminar presented by a visiting academic on the place of emotions in research (Bondi, 2003). It was an insightful yet novel coupling of two quite disparate concepts. Most academic writings I had read up until that time were predominantly factual or descriptive, rarely addressing issues of emotions on the part of either researcher or 'the researched'. Yet as I have discovered, engaging in research with people is an inherently emotional task whether we care to acknowledge it or not (Davidson, Bondi and Smith, 2005).

Conducting research is a messy business and once my fieldwork was complete, I approached the task of 'writing up' this thesis with much trepidation, as described in the following entry in my research journal:

*Quite frankly, the thought of writing this scares me. The task of having to write a 'story' seems so concrete and fixed compared to the messy fragments of my research thus far. Rather than a coherent story with the requisite beginning, middle and end, my research seems to be chaotic – a messy and fluid collection of events and people; conflict and tension; elation and despair. Writing a story out of this menagerie seems to make it something that it is not. I feel a sense of pressure of moulding dynamic, living, breathing encounters with the people with whom I work with onto paper. Will the regulations and rigidity of academic writing capture the messiness and clutter? Will it do justice to describe on paper the lives and experiences of a people for whom pen and paper are regarded with suspicion and fear?*

As I reflected further upon my fear of writing up my fieldwork, it became apparent that this was in part influenced by the multiple roles I occupied; the demands and constraints of each of these roles and the difficulties in translating between each of these worlds. Initially I portrayed this sense of tension using a simple visual diagram (Figure 25).

**Figure 25 Visual representation of my research interactions**



An excerpt from my research journal below explains further:

*Part of the quandary in which I find myself, is in simultaneously engaging with so many different worlds. My first effort to capture this feeling was in a simple circular diagram. The diagram is inherently flawed and my poststructuralist, post-modern training and leanings critique the way in which I am placed at the centre, perhaps akin to the way in which our forefathers believed the sun and planets orbit the earth. Yet these are the limits of capturing a moving, dynamic world within the confines of a one dimensional, static medium. Yet flaws aside, it does speak to the multiple 'worlds', arenas, settings and actors with which and whom I find myself engaging. It is perhaps the speed at which I have to move myself in and out of these multiple dimensions that is at the heart of this challenge. In one single day I might find myself in the home of a Somali woman with children noisily playing in the background, talking to the woman of her experiences as a widowed mother, coming to a new and very foreign country in which she can neither speak the language nor participate in New Zealand society. We might talk in pidgin 'Somglish' – an agglomeration of my limited Somali vocabulary and her English; talking with hands, eyes and universal sign language – the language of travellers and sojourners throughout the world.*

*Next, I might be bustling off to university fighting the choking traffic. A mere 10 kilometres in distance but many galaxies away from the woman to whom I was speaking with. A new vocabulary is employed here – we speak of discourses, theory and methodological underpinnings. A setting where there are supervisors to meet, forms to fill out, presentations to give and outputs to put out. Packaging the 'real-life' or the 'concrete' experiences of individuals into academic molds.*

*Cut to the overloaded health professional, hopelessly behind schedule rushing to meet a three o'clock appointment. Here there are diagnoses to make, meetings to attend, referrals to make and eligibility criteria to meet. A world where the political tight rope is indeed narrow and precarious. This is where contractual obligations meet the bumpy road of patient/client/user needs. This is where words such as best-practice, funder-provider split, transparency and management pepper the air.*

*Each of these worlds is by no means static, discrete or independent of each other but are overlapping dimensions, each with their own priorities and challenges. Transitioning from each of these worlds is a challenge, each have their own lingo, rules and uniforms. My place within each of these dimensions varies – from researcher, helper, friend, ally to student.*

*Functioning in so many worlds has led me to ask questions, not dissimilar to the children's book entitled, 'Are you my mother?'. I have asked myself, where do I really belong in the*

*mix of things? To the institution that trained me from whom I am an 'output'? To the people for whom I am researcher, friend, advocate and helper? To the practitioners who are struggling to meet the needs of a politically unpopular group and need some "evidence" to influence the decision makers in positions of power to mandate and resource professionals to do the work they are already doing? To the people who have to find the funding to meet the needs of the needy?*

*So here I am with the quandary of representing the worlds of so many different people, people with their own priorities and constraints – and packaging it all in to a form which will be acceptable in the eyes of academics who have their own priorities and constraints. How do I keep all of these different stakeholders happy? Each with their own stake in this research.*

As the account above illustrates, transitioning between each 'world' became increasingly problematic, in part due to the increasing density of relationships between myself and others. My sense of obligation to the many different kinds of people whom I had come to know throughout the research process was quickly becoming a heavy burden. My fear of undermining or causing harm to these stakeholders through the course of my analysis and discussion was also a factor.

For me, the research process has been, for want of a better metaphor, a rollercoaster experience with dizzying high points and stomach turning lows. At various low points along the way I joked to friends that I was tempted to give up and go and work for Pak N Save (a New Zealand supermarket chain). At times my research was so complex that the idea of having a manual and repetitive job was particularly attractive. I call these my 'Pak N Save' moments. During one such moment however I realised with a start that many of the Somali people I had met, had repeatedly tried to, and dream of working at 'Pak N Save' and that for them it is not an 'escape-from-reality-mechanism' but a goal and aspiration. This realisation was sobering and caused me to reflect on my assumptions and, some would say, arrogance.

In terms of research encounters, one example which I wrote about in my research journal was particularly emotive as the following excerpt recounts:

*I drove home blinking back the tears after a visit to the home of Hala. Hala is larger than life. She is always so happy to see me, exclaiming “Hello sister” after opening the door followed by a kiss on each cheek. This particular instance we were cooking together. Hala had remarked on a previous occasion that she wanted to learn how to make, in her words, “white soup” that she had been given during her hospital stay for TB. I thought long and hard about what the white soup could be. After a process of deduction I guessed that it was probably either potato or cauliflower soup. After a quick flick through my sturdy ‘Best of Alison Holst’ cookbook I decided to cover all bases and make Cauliflower Potato soup. I typed out the recipe in very simple English as Hala speaks little English and then sourced the ingredients – cauliflower, potatoes, onion, green herb stock, milk and a quick trip to the nearest spice shop to find Halal chicken stock. Hala and I began the preparation, chopping the vegetables and putting them in a stock pot to boil. It was then I realized I needed some pepper and salt. I asked Hala if she had any, and she pointed me in the direction of her pantry. I opened it up and was shocked at what I saw. The pantry was completely bare but for a packet of rice, some spices and flour. It made me stop and think about my concept of what it meant to ‘have an empty pantry/fridge’. I had never in my life seen such an empty pantry. It was bare. I flashed back to a memory of me as a child complaining to my mother that we did not have any food in the house, which can be roughly translated as we don’t have any ‘snack/sweet/instant food’. Hala’s pantry had no food.*

*We continued to cook and after an hour and a borrowed food processor later, we had made “white soup”. Hala’s two children kept us company in the kitchen, the youngest of whom managed to find a packet of Raro juice crystals which were being rapidly being devoured. Both children emerged from a bedroom ten minutes later with sticky orange faces. At three o’clock a horde of young children returning from the local primary school, swarmed in the front door,. Hala began to cook ‘Somali rice’ for their lunch – basmati rice with sultanas, frozen peas and carrots and spiced with cardamom. As more and more children arrived I decided that it was time to slip out quietly as Hala had numerous children to mind and feed. As I said my goodbyes Hala followed me to the door with a large bowl which she thrust into my arms. I looked inside and there was Somali rice covered with beef bones. I looked at Hala, thanked her profusely but said I couldn’t take her food and that there was far too much for me and my husband. I said that she had all of those children to feed. No matter how hard I tried she insisted. I tried to refuse politely without offending her, and eventually gave in. As I walked to the car I realized what this gift meant and the enormity of it. For a woman, with an empty pantry and many children to feed, to give me a huge bowlful of rice and meat was truly overwhelming. I felt so touched and so overcome at her gesture. It was a heart-wrenching and truly emotional drive home. How could a woman who has so little give so much?*

This particularly moving incident is one that will remain with me for many years to come.

As well as being an inherently personal and emotive task, conducting cross-cultural research has meant that I have learnt as much about myself as I have about those I have come to know (Shurmer-Smith, 2003). It is important to be aware of the way in which our personal values and beliefs can come to influence research encounters. One example of this arose when I first began the task of familiarising myself with the Somali community. This was much more difficult than I anticipated and as I reflected on the reasons why, I realised it was in part due to my own values and the way in which I had usually approached the task of meeting people. This is aptly described in an entry into my research journal:

*One lesson I remember being taught as a child was about politeness and that I was not to invite myself to other people's houses but was to wait until I was asked. When I began my research and was beginning the process of getting to know the community I struggled with how I should go about getting to know people. After that initial meeting I maintained contact with a community leader and mentioned that I was interested in attending any community events or gatherings. Not surprisingly, no 'invites' emerged. I decided to repeat this request in every conversation I had with him but to no avail. My long-held value of waiting to be asked was spectacularly unsuccessful in assisting with my need to get to know people. Pride aside, I began to invite myself along to people's houses and to various events. This was extraordinarily difficult and uncomfortable at first but I have grown more accustomed to doing this in the need to progress my research.*

Another value I have become aware of is that of timeliness. When I began working with Somali people I found that I would always be the first to arrive at meetings. It caused me to reflect on why I noticed this and remembered back to my childhood and the way my mother repeatedly talked about the importance of being 'on time', preferably early. As embarrassing as this was during my teenage years, the importance of being on time has remained with me throughout my adult life. Yet, when I started working with Somali people I found that time tends to be treated as a very fluid concept. Ten o'clock can quite easily be 10.15 or 10.30 and I have learnt to build this into the way I work. An example of this is recorded in my field notes:

*One example is a nutrition focus group I had organised. We told all the women it will start at 10.30 in order to be able to start at 11.00am. The Somali concept of time was discussed in the writing of Jeanne d'Haem, an American Peace Corps volunteer in the 1970s (D'Haem, 1997). D'Haem wrote about her experiences of learning Somali and living in a Northern Somali village. On one of her journeys she repeatedly asked a man when the truck was due to arrive. The man simply said, that the truck will be here when it arrives and no sooner. D'Haem continues to reflect on the way in which Somali people live not by watches and alarms but by the rhythm of the rising and setting of the sun and the tasks which must be accomplished in between. Although life in Auckland, New Zealand is much different, aspects of this can still be observed. I love to watch the way in which Somali women walk with purpose, hijab's billowing in the breeze yet never in a rush. I have never seen Somalis rush, rather everything happens in its own time. One exception to this occurred during a meeting at a community centre when a fire alarm sounded. By the time I had recovered from the shock of the ear-splitting siren and realised what had happened, twenty five Somali women and their children had bundled themselves out of the room. I was astounded at how quickly they had evacuated. Many seemed very frightened and panicked – perhaps a remnant of the refugee experience.*

As these examples demonstrate, the values we hold as researchers are important and can come to influence the course of our research and the way in which we interact with others.

Like many researchers (Emerson et al., 1995), withdrawing from intensive fieldwork was a difficult time. Often I felt torn between my desire to remain connected to the people I had worked with for so long and the need to complete my thesis. I became quite resentful of the 'writing-up' process as I felt it had pulled me away from doing something I had enjoyed so greatly. In the end I gradually stopped attending community programmes and events however I maintained personal contact with a small handful of individuals. At times community leaders would ask me to become involved in new programmes and initiatives and I found it very difficult to say 'no' in these situations. All in all, it was quite a painful process.

## **Summary**

This chapter has considered the methodological issues that arose during the course of this research project. As the aim of this study is to consider the lived experience of TB, qualitative methods such as ethnography, narrative, participation observation and focus groups lent themselves to considering the wide array of social, political and economic influences on people's lives. In this chapter I have outlined both the logistical and practical aspects of this study including participant recruitment, data analysis and community consultation as well as the ethical and

philosophical dimensions of carrying out research across the divides of language, ethnicity, gender and power. While the Somali community was spatially located only a few kilometres from my home and the university, the social distance that had to be traversed between these different worlds was indeed immense and at times overwhelming.

In total, I interviewed thirty-two individuals and interacted with scores more through extensive participant observation and community participation. It took a great deal of time and effort to establish the trust and credibility necessary for the discussion of sensitive issues surrounding health, wellbeing and personal journeys. Recruiting participants for TB interviews proved to be highly problematic with many individuals refusing to participate. This was in part due to the continuing stigma attached to the disease and the level of suspicion about me and what I was doing. Interviews were however a rich and rewarding opportunity to learn about the issues individuals face and the way in which they make sense of their world. They also offered me the chance to spend time in people's homes and catch a glimpse of the texture of everyday life.

I was also fortunate to participate in community life in a number of different settings and in a number of different roles ranging from researcher through to evaluator, report-writer, videographer and friend. I was able to share in important community events such as weddings, soccer matches and consultation meetings as well as the mundane realities of everyday life such as errands, cooking and childcare. Becoming involved in the community was not a simple task and was at times a tumultuous process of self-doubt and despair. Yet, just as equally, it was a rewarding time as people welcomed me into their homes and their lives.

Throughout the research process I learnt far more than I contributed. It was a challenging yet rewarding time. I am glad that I became involved as I did as it enabled me over time to build up trust and relationships that proved instrumental in carrying out TB interviews. I am also glad because it gave me the chance to contribute rather than simply extract information from the community and benefit only myself. One negative of the process was that it became difficult to balance the demands of my study with those of my community involvements. As I began the process of writing up I had to start reducing my workload and this was a time of sadness for me as I felt as though I was letting people down.

In this chapter I have endeavoured to bring together a wide range of disparate issues at both the conceptual and the practical level. This is in some ways mirrored in the chaotic nature of this chapter that seeks to address the wide range of constraints and stakeholders involved in the research process as a whole. I have reflected upon the research process itself and have consciously chosen to reveal the messiness and emotions of the research journey as opposed to producing a polished and sanitised account of my time working with Somalis living in Auckland. In doing so, I have aimed to locate myself within the project and to consider the way in which my positionality influenced the study. Understanding and acknowledging such matters is essential in

order that meaningful and valuable findings are produced. These findings are discussed at length in Chapter Six, Seven, Eight and Nine.

## **Chapter 6: Out of Africa – The establishment of a Somali presence in Auckland, New Zealand**

*“To think about culture and health requires thinking through the flows and connections through which local lives are lived and the terms of integration and inclusion negotiated. ‘Migratory meanings’ have been brought to [Canada], but are remembered, re-crafted and reconstituted in the context of gendered and racialised local, lived experiences” (Dyck, 2006:14).*

Somalis first started arriving in New Zealand in significant numbers in the early 1990s in response to the civil war in Somalia. Somalis are a highly visible population group due to both outward differences in terms of skin colour, appearance and behaviour and also in terms of beliefs, values and identity. This chapter aims to describe the resettlement experiences of the Somali community in Auckland including transformations of Somali identity and cultural practices and the role of the Auckland Somali Community Association. Drawing upon interview narratives, participant observation and community participation, I build a picture of the challenges Somali refugees face in rebuilding their lives in New Zealand. To date, there has been no detailed research into settlement outcomes of the Auckland Somali community and only a few other studies elsewhere in New Zealand (e.g. Beth Jenkinson’s research with Somali women living in Hamilton (Jenkinson, 1999).

In this chapter I argue that it is imperative to understand the everyday experiences of Somali refugees in line with the socio-ecological model of health which contends that socio-economic, political and cultural issues have a profound influence on health, wellbeing and the development of disease such as TB. By elucidating the challenges Somalis face on a daily basis in terms of insecure income, tenuous employment, scarce housing and limited social support, I endeavour to establish the general context or ‘breeding ground’ that is facilitating the sustained burden of TB amongst this population. Only by understanding and addressing these determinants of health, will the TB burden be reduced amongst groups such as the Auckland Somalis.

### **Sizing up the community: estimating population size**

One of the first and foremost community characteristics is that of population size. While this seems relatively straightforward, it has proved inordinately difficult to estimate accurately the size of the Somali population. Essentially, the problem is that official statistics seem to significantly under-represent the true size of the population. In New Zealand, the 2001 census results suggest that there 1,770 people born in Somalia living in New Zealand. Of this, 546 were recorded as living in

Auckland (Statistics New Zealand, 2001; 2003). Anecdotal evidence from community leaders estimate the size of the Auckland Somali population at around 1,500. Hopkins (2006) notes that in Britain, census figures suggest that the number of Somalis living in Britain is 43,373 half of what community organisations estimated (90,000). A similar trend has been documented by researchers working with the Somali community in Hamilton. According to Bedford (2004):

*“The Somali are known to have been suspicious of the census and its purpose and, as will be shown below, there was a high level of non-response to a number of the census questions. Drs. Bernard and Pauline Guerin’s...recent household survey of all Somali families in Hamilton confirms that there was under-enumeration during the 2001 census” (Bedford, 2004:368).*

Guerin and Diiriye (2004) conducted an informal census amongst Somali households and found that of the 405 Somalis who could have completed the 2001 census, only 260 did so. Over 140 individuals said they did not complete the census.

Anecdotal discussions with a wide range of Somali community leaders repeatedly emphasised that the Auckland Somali population was approximately 1,500. In order to try and address this anomaly between official figures and community estimates, alternative indicators of population size were sought from government agencies such as the Ministry of Education, Housing New Zealand and the Ministry of Social Development. These too indicated a smaller number of Somalis than expected. For instance, according to data supplied by Housing New Zealand, within the Greater Auckland area there are only 59 households headed by someone of Somali nationality (Housing New Zealand, 2004). Furthermore, according to figures supplied by the Ministry of Education there are only 72 Somali students attending primary or intermediate schools in the Greater Auckland region, for whom the school is receiving ESOL funding from the Ministry of Education (Ministry of Education, 2004).

Part of the problem of establishing an accurate count is a question of how ethnicity is collected and classified. For many organisations, ethnicity of smaller minority groups is simply classified as ‘other’ if it is collected at all. Indeed the category ‘Somali’ appeared first in the 2001 census. Prior to that Somalis were included in a general African category. While this is done for reasons of convenience it effectively obscures the true nature of minority populations. Another problem with official statistics is the different categories people fall under. For example, some Somalis might record ethnicity under a general ‘African’ category rather than ‘Somali’. Birthplace data is problematic in that a significant proportion of young people were born in refugee camps outside of Somalia. Using immigration data is also problematic given the variety of immigration streams Somalis have arrived under including refugee quota, asylum seekers, family reunion, visitor’s permits or labour migrants.

Another complicating issue is the high degree of mobility amongst the Somalis who frequently move both within the city, country and overseas. Somalis also undertake seasonal migration in search of employment, particularly to the Hawkes Bay region for fruit-picking. Guerin and Diiriye (2004) noted that between 20 and 80 individuals may have missed being counted due to seasonal employment. There is also a high degree of household mobility whereby individuals reside in a number of different locations. This mobility and lack of fixed abodes is problematic given that the census assumes a stable place of residence and asks respondents to complete the census on their 'usual residence'.

A second problem with official data collection is that of suspicion. As noted by Bedford above, some Somalis are quite suspicious of the census and its purpose. Some of the individuals whom I interviewed openly admitted that they had not filled out the census form. This suspicion is a legacy of the civil war during which having facts recorded about oneself on paper was something very dangerous and to be avoided at all costs. As noted earlier, I was advised against conducting a census in Auckland. I then asked community leaders if they could do an informal census based on their knowledge of how many households live in Auckland within each sub-clan grouping. This too was a difficult exercise and attracted some suspicion about why such questions were being asked. According to community leaders there are approximately 300 households within the community with an average of five individuals per family although some households number up to fifteen. Leaders estimate the size of the Auckland Somali community at 1,500 and the national Somali population at approximately 4,000.

As the above discussions show, counting and being counted is an inherently political undertaking. Yet population estimates are very important and under-enumerating minority groups contributes to existing marginalisation through minimising their existence within New Zealand society. As noted by Reinken and Kearns "...individuals (and groups) who are counted inadequately may lose representation of their needs in policy development or funding of services" (Reinken and Kearns 1994:20). Under-enumeration influences the distribution of resources within government services which are often based upon census population estimates. For instance, District Health Boards are allocated additional funding for particular groups, most notably those living in the most deprived areas. By failing to accurately enumerate the true extent of this population, health services are stretched as while some of these people are not counted, they still continue to require health services, often at higher rates than the general population. Accurate enumeration also influences our understanding of the rates of disease. By under-counting population size, diseases appear to be more prevalent than they actually are. In summary, under-enumeration further reinforces existing disadvantage for marginalised groups.

## Reconciling with the past and living with loss

In order to understand more fully the resettlement outcomes of Somalis living in Auckland, it is important to outline the context that has resulted in their moving to New Zealand. While the historical and socio-political events leading to Civil War have been detailed in Chapter Three, the ways in which these events have impacted upon people's lives at an individual level have yet to be discussed. This is important as refugees not only face the task of adapting to a foreign environment but also to reconciling and addressing events of the past with which they live on an ongoing and everyday basis. The story of one of my participants, published in a New Zealand Immigration Service book on the experiences of refugee women is a typical example of the journeys and experiences faced by the refugees in my study. Many of my participants found it very traumatic speaking about their past and did not want to go into great detail about the events that had occurred prior to arriving in New Zealand. Despite my interest in such matters as a researcher, I recognised that the ongoing trauma of the past required great sensitivity. As a result I did not probe or ask additional questions about topics that might have caused distress. As a result, Idil's story is one of the few 'complete' accounts that are available to me of the refugee journey. Furthermore, while this chapter is structured according to individual resettlement challenges, it is important to consider people's experiences in their entirety. Idil's story below touches on many of the themes raised in this chapter – flight, loss, separation, violence and suffering.

### Idil's story

*Before the civil war in Somalia we had a good life. I lived with my father and mother. My father was a university graduate and a general manager. My mother was also educated and was a secondary school teacher. We had a big house, cars and a big farm.*

*I graduated as a doctor in 1989 and I was working in a hospital in Mogadishu. One year later the civil war broke out.*

*When the attackers first came they tortured us, but we had good neighbours and they ran and said, "These people are very good people, why do you want to kill them?" The attackers were mostly drunk. They hit me in the chest with a rifle butt.*

*My auntie was raped. Sometimes when I was at my house I would hear crying, and in the morning someone would tell me three or four women from our tribe had been raped. They cried, but nobody helped them. Every night I couldn't sleep because I thought they would come to my house and rape me.*

*After he had been 17 days in Mogadishu, my second brother was killed. He was studying at university in Karachi, Pakistan and was on holiday in Mogadishu. He was astonished when we told him not to go out, that they would kill him. He said, "Why would they kill me?" – he thought we were mad. He went to another village quite far from ours to see what was happening, and they did kill him. He was 24 at that time. We did not know he had been killed at first. My mother and I ran and searched every day, even though we were afraid if they captured us they would rape us. Eleven days later we found out he was dead.*

*Later on my father and brothers went to the other side of Somalia and my mother, some of my brothers and I went to Kismayu.*

*When we arrived in Kismayu, the war had already spread there. They even killed the doctors working in the hospital, they killed so many people. My mother said to me, "You can't stay here, go to Kenya."*

*To get to Kenya, we had to take a ship from Kismayu to Mombasa. The soldiers wanted money (US\$60 from everyone), so I sold some gold for money. Some of the others had parents in Mombasa who agreed to pay when they arrived. A lot of people did not have any money.*

*A lot of bad things happened before we even got on the ship. This was the worst day of my life...*

*We (myself, two brothers and two cousins) had to take a bus from Kismayu to the harbour, which was about two to three miles. We gave money to people who would take us to the boat (about US\$70). These men brought buses. We were mostly women, children and wounded. There were two road blocks along the way. When we got to the first one, they said, "Ah, you bring all the people who are fighting against us. We must kill them, you can't take the bus through here." The people helping us said, "No, they are mostly women and children, leave them." The others said, "We must kill them", and then they opened fire. I put my head on the seat to protect my head and my heart. If bullets got my heart, I knew I would die. Sometimes I think I am very lucky I did not become mad, or get killed.*

*There were 396 people on a small scrap-metal ship for 11 days. There were no sleeping places or places to wash – everyone had to sleep on the deck.*

*Utange camp in Mombasa was very bad. There were only basic huts with no beds. In the morning it was very hot and at night it was very cold. There were more than 20,000 people in the camp and we had to queue for everything – the toilet, food, water to drink. All day*

*everyone queued for something. There was not enough food for everyone, so we were given only ration cards – but there were so many people without ration cards, so we had to share our food with them also.*

*It was a mixed camp, but there was no problem, no violence, no rape – only the difficulty getting food, water and toilet. The other camps nearby were worse. At night there were killings, rape, and people were burned.*

*I was working at the camp hospital when a group from UNHCR came and wanted to interview “women-at-risk”. They asked me what country I would like to go to and I said Australia. They told me I must await two years to go to Australia, and said “How about New Zealand?” I did not know anything about New Zealand at that time.*

*It was still five months before we could leave for New Zealand. It was like five years for us.*

*At Mangere they welcomed us, gave us lots of food, clothes and also schooling. I only brought a few possessions, some clothes, a photograph album, my documents and some medical equipment.*

*When we first came from the airport, I looked at the ground. It was very green and very beautiful. Compared to the camp, Mangere was the best hotel in the world. The Refugee and Migrant Service and all the teachers and the nurse were very kind and good.*

*I still keep in contact with my family in Somalia. My father is still on the other side of Somalia but he is OK. I would like to go back to Somalia to visit, but I would not live there again.*

*I want to work as a doctor in New Zealand and to specialise in gynaecology. I am working hard to improve my English, so that I can sit an exam that will recognise my qualifications as a doctor in New Zealand. I would like to work for the Red Cross to help the Somali people who are suffering in the war (Department of Labour, 1994-59).*

## **Remembering home: war and the search for safety**

When asked to describe life back in Somalia, a theme that consistently emerged was that of loss. These narratives of loss first came to the fore due to events around the time of the civil war, but came to be compounded and re-lived on an ongoing basis due to difficulties encountered in the resettlement process. While experiences of loss have been documented amongst many refugee populations (Buckland, 1997; Zarowsky, 2004), a number of participants, without prompting from

myself, linked this sense of loss to their subsequent development and experience of TB (this will be discussed in Chapters Eight and Nine).

Between 1989 and 1992, Somalia was thrown into disarray with the eruption of fully-fledged combat between rival clan groups. Many Somalis were injured or killed in the ensuing conflict while some witnessed the deliberate torture or injury of family members or friends. As discussed in the following section on health and disease, such events have a profound impact on mental health.

As a result, many people fled their homes, leaving their lives behind and embarking on a risky journey towards safety. As recounted by one individual:

Abal	There was a war in there so I can leave, I had to leave. We had to leave all the cars and the houses, everything, and yeah, we had to take nothing, even no food, nothing, just walk. When we came to Kenya, you know, the refugee camp, my husband he was dead there so life was getting really hard.
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This made life even more difficult for Abal as she was now the sole head of the family and in a very vulnerable position.

The journey itself was also a traumatic process. One individual describes the process of fleeing the conflict. According to Barika her clan was being pursued and so they were on the run. This was a harrowing, perilous journey that had disastrous consequences for her family. Barika described the efforts of her family to flee the conflict:

Barika	We get all of them sick, malaria
*Jody	Oh really
Barika	Because seven days no food, no drink, no nothing. Just running. And then we just drinking the water, you know, on the [side of the] road
*Jody	Oh so the malaria was bad?
Barika	And my Dad died malaria. All of our family they got malaria. And there no doctors, the only doctors, you know banning, they stole money do that one. My dad died, my brother died.

Another participant recounted how his family fled Mogadishu for Ethiopia. He states:

Adil	And that's when we tried to flee and then we went from Mogadishu to Ethiopia
*Jody	How did you get there?

Adil	And then we, just through the borders, through from town to town although not quite sure because we were so frightened and most of our journey was nights and days.
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Over 14 family members were cramped in two cars as they sought safe haven. According to Adil, their aim was to reach a UN camp as they believed they would be safe there. The journey itself was not straightforward and they passed through many towns and villages in a highly risky undertaking.

While camps have been constructed as refuges from violence, many of those who lived in the camps were subjected to overcrowding, malnutrition, rampant disease and lack of personal safety (Clinton-Davis and Fassil, 1992; Kalipeni and Oppong, 1998). Many families struggled to survive and frequently shifted to other camps in search of a better life. Barika notes:

Barika	The life was so very very hard. It's different. We had a different life in refugee camp. Honestly.
*Jody	Oh absolutely, yeah
Furat	You know, at night you know, the robbers they just come and take your stuff away from you. They come to your house and they kill you.

The threat of thieves and bandits was a recurring concern for many individuals. Barika recounted how the camp where they lived at for a number of years would lock their gates until the following morning. Nevertheless robbers still came. Barika recounted how the camp was divided into four blocks and each block into units with approximately 17 families. The robbers would start at unit one and by unit two the inhabitants had made enough noise that the police arrived.

Survival at the camp was a struggle with camp rations not being enough to support an individual (Horst, 2001). As a result, inhabitants had to find a way to generate income often through trading small goods purchased in nearby towns. This placed refugees in tenuous situations as many were not supposed to venture outside the camp and faced punishment if caught. The overcrowding, insecurity and poverty experienced at the camps resulted in some leaving in order to seek a better life. Adil noted how he and a group of friends left a refugee camp in Ethiopia in order to try and earn some money to send to their families to assist their survival. Adil began this journey which involved traveling throughout Africa before being able to save enough money to afford the services of people-smugglers in Zimbabwe.

Others relied on the hope of being resettled overseas. One family were accepted by the UNHCR for resettlement but had to fight for a number of years to make the journey. This was felt to be due to the corruption of the immigration officials in Kenya who often sold places on refugee resettlement programmes to those who could afford to pay. Khalisah spoke about how she was

originally accepted to be resettled in Australia however another family purchased her place on the quota and is now living in Australia under Khalisah’s name. It was many years until Khalisah was found another place on a resettlement programme, this time to New Zealand.

After a long wait and battle with immigration officers Abal found that her family had been for emigration to New Zealand. As the transcript below depicts:

Barika	That's what they told us to pay [for a place on the quota], but my mum doesn't have money to pay. But we been in Nairobi and we suffering and when they surprise me they tell us the flights already. My Mum was making the morning shopping, buying something and the other lady comes “Oh Abal I saw your name on the board, you flight is 1 August”
Abal	1 August!
Barika	Yeah she just came and she just said “Make ready, make ready we are out”
*Jody	You obviously remember that day very well!
Barika	Yeah and we didn't even ready. We just everyone put the clothes on and just run to airport.

As the above accounts demonstrate, the civil war and flight from conflict was a perilous and dangerous time. Many families spent up to 10 years in refugee camps, lives put on hold in the hope of resettlement.

**Experiencing loss: Separation, isolation and identity**

It is important to remember that the civil war also resulted in the separation of families. One participant recounts how she become separated from her parents and siblings as she and her brother were visiting their grandmother at the time the war broke out. As a result, her parents and siblings fled in one direction while she, her brother and grandmother fled in another direction.

Ishraq	1991 when they start war me and my brother you know was go to visit my grandmother and we stay with my grandmother three days and in three days they start you know war and we was with my grandmother and the people they are running. I was, I was 6 years or 8 years I think yeah and they start war and me and my brother...we are running you know to another country and I lost my mother and my father and my sisters all, I lost my clan. Until now I didn't see them.
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While this loss occurred prior to migration, such loss tended to be acutely felt after resettling in New Zealand. Many participants were still in a state of grief over the loss and separation from family members. Some experienced considerable ‘survivor guilt’ and grief that they were safe in NZ while other family members remained in a perilous situation in refugee camps in Somalia.

The resettlement of only selected family members has meant that many are without the social support resources they were accustomed to in their home country. Social support is a key determinant of health particularly for refugees and migrants (Dunn and Dyck 2000). According to Simich (2003) the ability to use personal and social resources to obtain social support is critical to reducing stress, maintaining health and well being, and achieving eventual self sufficiency (Simich et al., 2003). One participant I interviewed described how the separation of family members and lack of social networks had affected her:

Ghadah	Stress, because some of my family away. Headache, not sleep. In Somalia I was working, had relatives to help me and a nanny and life is cheap. I paid someone to wash and cook. Here there is no one. Can make stress. Can make unhealthy. In Somalia I work as teacher. Now work with kids day and night, no relief. You can't make friends here because we are busy with daily life.
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In Somalia, people often lived in extended family relationships. Being resettled in countries such as New Zealand has invariably meant that these family relationships are torn apart. Participants reported considerable hardship living in nuclear families without the support of extended family members. Others also cited the importance of neighbours, who in Somalia were like family members. One participant recounted how her neighbour would smack her children and reprimand them if they were being naughty and that this was an entirely appropriate behaviour for the neighbour given their closeness to the family. One participant mentioned the absence of social support networks when describing the difficulties she faced settling into her home after arriving from the MRRC:

Ghadah	The difficult time. At Mangere they cooked the food. [Here in Mt Roskill] No car, have to pay bills, transport, language, can't ask for help. In Somalia, neighbours are part of the family. Here we can't ask neighbours for something. Children communicate with neighbours, I can't.
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Given this disruption of social networks, many refugees when they arrive begin the process of trying to bring over their family members. One of the respondents in Bern McGown's research noted how her mother living in Canada was attempting to bring over every person she knew in Somalia as a means of recreating her former life as much as possible (Berns McGown, 1999).

This is a complex task as in New Zealand law only dependent family members are able to be reunited although this is a long and complex process in itself. This view of 'family' however, is vastly different from Somali notions of family where a 'cousin' may be considered as close as a brother or sister. Many families are battling with immigration rules and regulations in the effort to bring family members to NZ. For a number of individuals, this has become an all-consuming effort.

By way of example, I had attended a sewing group session which featured a speaker on family reunification from the New Zealand Immigration Service. It was the largest turnout of any sewing group I had attended with women bringing along documentation and accompanying family members to interpret for them, in their efforts to lobby the Immigration official for assistance. I was asked by a number of women to write down long lists of names of family members for submission to the speaker following the session.

Yet despite this erosion of social support and resources, it is important to acknowledge the efforts made by individuals in order to recreate such networks. Buckland (1997) found that women created new systems of support. For example the telephone is a key way in which social support is established. Instead of visiting the neighbour for advice, people can now ring for friendship and support. Sisters and aunts may shop together and assist one another with childcare. Evidence of similar practices is particularly evident amongst the Auckland Somalis where in order to make and sustain social relationships, telephones have become a critical means of overcoming physical separation. One individual jokingly told me that Somalis were often on the telephone and indeed this observation holds some truth in my experience.

### *Isolation*

Nevertheless, a number of individuals report a sense of isolation living in New Zealand without any close family members. This isolation refers not only to other Somalis but also in terms of isolation from wider New Zealand society. There is a vast literature on the degree to which migrants interact in the social, cultural, economic and political world of the country of settlement (Valtonen, 2002). This is variously called integration, assimilation, incorporation or adaptation; depending upon one's philosophical standpoint on the validity of the presence of immigrants in the country and views on to what degree immigrants should adopt the practices, views and behaviours of the host society. This has long been a highly charged topic within political circles, particularly given concerns over the numbers of migrants in New Zealand and concerns over their 'consumption' of resources such as welfare benefits, state housing and education (Ip and Friesen, 2001; Bedford, 2002). Israelite (1999) notes that integration is also influenced by the distance between country of origin and settlement – the further the distance, the greater the difficulties in integrating. In many cases the first generation of migrants preserves the ways of life of country of origin while subsequent generations take on the norms and lifestyles associated with country of settlement. This is particularly obvious within the Somali community with parents frequently seeking to preserve cultural practices, views, language and values within the younger generation amidst concerns that they are 'losing their culture in New Zealand' (this will be elaborated upon later in this chapter).

The Auckland Somali population is highly concentrated in the Mt Roskill area. Mt Roskill is a highly diverse suburb that is home to people from many different nations. While these groups live in close spatial proximity to one another the social distance is vast. As the excerpt below depicts, one

participant felt somewhat vulnerable within the area and had minimal social contact with neighbours or those outside of her Somali circle of acquaintances. Of interest though is the indication that the younger generations were having greater contact with others living in the area:

*Jody	Do you like the area you live in?
Abir	Yeah it's a nice place
*Jody	You like Mt Roskill?
Abal	Yes
*Jody	What do you like about it?
Abal	Mt Roskill, Mt Albert, Three Kings, Avondale
Abir	Yeah, there's a lot of people we know in here
*Jody	Lot of Somali people?
Abal	No Somali. Area not Somali, not Somali. Samoa, Tonga. All bigger
*Jody	And do you speak to your neighbours
Abal	No
Abir	No. Not all but the children they talk to us.

The causes of social isolation are debated. Kusow (1998) suggests that some Somalis react to discrimination and the resultant devaluation of their status by limiting their interactions primarily to the Somali community. This strategy, he argues, allows them to maintain the identities they had established in their homeland rather than accept the racialised identities available to them in Canada (Kusow, 1998). Israelite et al. found that structural factors such as the long length of time before residency status is granted and legalized also limits refugees' ability to integrate into mainstream Canadian life (Israelite et al., 1999:11).

Not only do many Somalis struggle with a lack of social support but also with that of physical isolation. Given that much of the Auckland region is designed with vehicles in mind, those without cars are significantly limited in their ability to venture outside their home. This is a primary reason why so many Somalis wish to live in the Mt Roskill area to be close to other Somalis who have clustered there. Women in particular are hampered by a lack of transportation. Those who have the resources to purchase a car often drive unlicensed due to difficulties in gaining full drivers' licences such as cost, language barriers and difficulties in negotiating the various stages of the testing process. I recall a sewing group session in which I participated in 2003 when a policeman came to talk to the women about road safety. As noted in my field notes:

*One of the women asked the policeman whether he would answer her question as a brother or as a policeman. He said a brother. The woman then said that all the cars in the carpark were being driven [illegally] on learner licences. After the session the interpreter told the policeman that the woman was joking but confided to me that the woman's claim was in fact true (21 November 2003).*

As a result, there have been a number of road safety programmes to assist Somali women in gaining drivers licences. These programmes have been funded by the Auckland City Council and the Land Transport Safety Authority (LTSA) and have been attended by over 200 women who were previously driving without the correct licence.

## *Discrimination*

Discrimination is a highly sensitive topic that can be studied from a number of different levels. Writing from Canada, Danso notes that refugees are also susceptible to being constructed within the media and popular discourses as the unwelcome 'other', competing for scarce resources such as income support, housing and jobs (Danso, 2001:3). At the macro level, some have explored the way in which policies provide for, or exclude groups such as refugees and migrants (Mortensen, 2007). Within the New Zealand context, official recognition and provision for the needs of refugees and migrants is limited after arrival. In recognition of this shortcoming, an integrated settlement plan is currently being developed to assist with the resettlement needs of refugees and migrants (New Zealand Immigration Service, 2004a). Part of this lethargy I would suggest is due to the fact that policy-makers have only relatively recently grappled with the creation of policy that reflects the special relationship between Pakeha and Maori although this too is fraught with difficulties (Oh, 2006). As a result there are a number of initiatives which provide for the needs of Maori within policy and service delivery in the fields of health, education and social welfare. At the same time as this has occurred, with the arrival of new settlers from many different nations, New Zealand has become increasingly multi-cultural. While the characteristics of this population are highly diverse, there are significant groups of refugees and migrants who have high and complex needs. These needs are a relatively low priority on the political agenda in comparison to the rightful need to address Maori grievances with the Crown. As a result, efforts to address and assist refugees and migrants have been ad-hoc, patchy and largely dependent on the good-will and efforts of a small number of individuals within government agencies. Nevertheless, it is important to acknowledge the significant contribution of such initiatives such as ON-TRACC (Transcultural Care Centre for Children) providing assistance to refugee families with high and complex needs and the efforts of the Refugee team within the Ministry of Education. Yet many of these programmes are limited term and dependent on insecure funding. Furthermore ongoing public debates regarding refugees and migrants mean such initiatives are vulnerable to political vicissitudes and shifts.

At the local level, political ambiguities towards refugees and migrants have been manifested in a real and visible way. This has also been noted in Buckland's study which described increasing levels of racism towards Somalis living in Ottawa, and women in particular due to their style of dress (Buckland, 1997). Within the present research participants cited a variety of problems such as one family who found that their neighbour had dumped rubbish on their property, name-calling

(one woman who veiled so only her eyes showed was called 'ninja' by her neighbours) and Somali students being teased by others at schools using the slogans of aid agencies such as 'A dollar a day'. Another individual had the goal of representing New Zealand on the sports-field, however he felt that this had not occurred due to his skin colour. Other research within the Mt Roskill area also described accounts of tension between different ethnic groups in the area (Lawrence, 2003). Some have suggested that these tensions had resulted due to the visibility of the Somali community, animosity over refugees' 'privileged' access to scarce resources such as housing and income support, cultural misunderstanding and wider discourses surrounding the place of refugees and immigrants within NZ society. Tensions escalated in 2001 with the conflict between groups of Somalis and Tongans/Samoans on the streets of Mt Roskill. This culminated in the death of a Tongan man, Elikena Inia with two Somali men subsequently being arrested for his murder (New Zealand Herald, 2002). The accused men were subsequently discharged without conviction.

### *Wealth and resources*

Not only has the civil war physically displaced people but has also displaced people's status whether that be employment, economic, educational or social standing. While refugees are often constructed as impoverished victims, some Somalis who became refugees were of the elite classes – well educated with considerable wealth and assets. Yet as noted by Gundel (2002), it was mainly the elite who were able to be resettled overseas. While many of Somalia's wealthy had the financial resources to flee the country, the vast majority were left behind. With the destruction of entire villages and towns, people who once were wealthy, with good jobs and qualifications were forced to flee to safety alongside those from lower classes. One participant recounts her experience in terms of the loss of material resources and what it meant for her:

Ghadah	I had to leave. We had to leave all the cars and the houses, everything. We had to take nothing, even no food, nothing. Just walk. When we came to Kenya, you know, the refugee camp, my husband died there. So life was getting really hard. Coming to NZ was good, but I thought you know I don't belong in NZ. I feel you know, my heart is in my country. Because in my country I had big home and big family. Lucky. But NZ, no big family, no big house.
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A number of other participants also mentioned that the loss of material resources which had been acquired after many years of savings and hard work was particularly devastating.

Many of these individuals were unable to return to their homes and continued the journey towards safety. While those people may have preserved their lives, their former identity and status has been significantly damaged. A number of research participants lost their wealth and status in society. This sense of loss was compounded during the resettlement process as 'status' in the homeland failed to be translated into the country of resettlement. One example of this situation is

that those individuals, with high levels of education and professional qualifications whose attainments have not been recognised in New Zealand, have struggled to find employment in their field of expertise and have subsequently lost an aspect of their identity on which they may have worked for many years to achieve. A number of individuals whom I met during the course of my research were doctors, nurses, scientists, journalists and businesspeople, many of whom have been unable to attain employment in New Zealand.

Not only do Somalis experience loss in terms of loved ones and social support but also in terms of identity. While all participants were explicitly Somali, when asked to identify themselves the components of that identity changed considerably. Some felt as though they had 'lost themselves' and everything that they used to hold dear. People's memories of their homeland are very different from the reality of their nation today. Some grieve for the country in which they used to live. Individuals have also lost a sense of rootedness and belonging due to forced displacement and the destruction of sites of significance. A number of participants have ruefully commented that their homes and land are now occupied by people from opposing clans and that they will never be able to return. One community representative described how her family had to leave their home which was subsequently commandeered by a family from the rival clan and who continue to live there to this day. She reflected on how she had raised all of her children in the home and that she wished she had been able to retrieve her family photos before fleeing. Not only do many Somali refugees face multiple and ongoing losses but also numerous challenges during the resettlement process itself.

### *Resettling in New Zealand: disappointment and shattered dreams*

While being resettled in NZ was a hard-won privilege for some, it turned out to be disappointing for those who had hoped they would be able to start a new and better life but found that life actually got more difficult upon arrival (Lawrence and Kearns, 2005). Despite strong communication networks, refugees leaving camps for abroad have high hopes for their new lives. This is in part fuelled by the large amount of remittances sent from abroad and media portrayals of Western countries. One research participant described how she believed that life in the West was one of wealth and comfort with streets paved in gold and unlimited resources and opportunities. A similar phenomenon was observed in Horst's research with Somalis living in Minneapolis (Horst, 2004). Somali migrants lamented about how their relatives living back in Somalia used to assume they were wealthy just because they were living in the United States.

### **Income**

Nearly all of the participants in my research were reliant on government welfare to support themselves in NZ. Although there is no comprehensive data available, international research demonstrates that Somali refugees compared to other migrants groups, have among the worst

indicators of living standards in terms of employment, accommodation and health status (Fangen, 2006). Finances proved to be one of the strongest resettlement challenges for the individuals with whom I worked. It was clearly a challenge to survive on government welfare, particularly since when, on arrival in New Zealand they had nothing and had to start from scratch. While those receiving income support were grateful for the provision of such assistance, it has proved difficult for many to pay for day-to-day living costs. One participant described the difficulties she faced when confronted with a very expensive electricity bill during the winter months. Some families face extreme hardship. One family I got to know had a bare kitchen pantry, save for a bag of rice and some spices. During the course of my research a swimming programme commenced as a means of providing Somali (and other refugee women) with a culturally appropriate space for physical recreation (Lawrence, 2005b; 2005a). This programme was established at the request of Somali women, yet many did not own swimsuits and were simply unable to purchase such 'luxury' items. In order to allow women to even participate in the programme, individuals responsible for staffing the programme personally fundraised and made donations for the purchase of swimming costumes for the women.

## Employment

One of the most important contributing factors to the financial hardship experienced by Somalis is the difficulty surrounding employment. Although there is a lack of comprehensive data, research conducted by Fisk (2003) suggests that up to 85% of refugees are unemployed. This figure is supported by my own observations during my fieldwork. Employment is particularly important as research suggests that the most important determinant of a sense of well-being was employment, as having a job mitigated symptoms of worry and depression (Stephenson, 1995). This is particularly evident among men whose role was traditionally defined in terms of the ability to be the breadwinner for the family. Numerous commentators have documented the difficulties experienced by Somali refugees in accessing employment opportunities. In Canada, Danso identified employment as a major resettlement issue for refugees (Danso, 2001). He found that in Toronto, despite 95% of Somali and Ethiopian refugees having at least a high school education, 38% of Somalis and Ethiopians were unemployed while 69% were considered to be underemployed. Underemployment is a particularly strong issue. Due to Somalis' marginal position within society only occupations that are regarded as dangerous, poorly-paid and undesirable by other groups, tend to be available for Somalis such as work in commercial laundries, factory or labouring work.

According to community leaders these high rates of unemployment are due to a variety of factors including Somalis' lack of English, transferable skills and discrimination and also to reticence on the part of New Zealand employers to employ Somali refugees. Over the last five years however, the Auckland Somali Community Association (ASCA) has implemented a number of programmes to improve employment outcomes. In 2005-6, 14 Somali youth participated in workplace training in the fields of telecommunications, banking and construction. Six have since gained full-time

employment. The ASCA runs other programmes including homework centres for school students, adult literacy classes and small business programmes all of which have had a profound impact on the education and skill sets of Somalis. According to community leaders, approximately 40% of Somali refugees are now employed. The most common occupations in order of importance include those of labouring, factory work, taxi driving, supermarket work, working as a teacher aide, interpreter or NGO resettlement worker. In the Mt Roskill area, the Mt Albert Pak N Save supermarket has long been one of the largest employers of Somalis, a contribution that has been acknowledged by the ASCA during its annual Independence Day celebrations on which occasion a plaque of appreciation was given to the owner. Another important employment opportunity is that of fruit picking. This seasonal work has resulted in hundreds of Somalis (and other refugees) temporarily migrating to the Hawkes Bay every summer. According to the Community President, fewer Somalis (between 50 and 60) now go fruit picking as more have since obtained more regular employment (Warsame, 2006).

Interestingly, women and teenagers appear to be the most successful in obtaining employment. These tend to be part-time jobs and subject to seasonal demand but are an important contribution to total household income. A number of women have set up informal businesses trading goods, such as jewellery, perfume, food and clothing that have been imported from Somalia or the Middle-East. This is similar to what Al-Sharmani (2006) found in her study of Somali women in Cairo. In this study, more women than men were able to generate income by working as maids and child-carers or engaging in trading activities such as selling homemade food. This however poses difficulties as women have to care for a large number of children and also provide a living. Al-Sharmani writes "The stress of caring for a large number of children and sometimes younger siblings, leads some mothers to develop psychosomatic symptoms. Female caregivers often complain of chronic headaches, body aches, insomnia and abdominal pain, problems for which their doctors often do not find physiological causes" (Al-Sharmani, 2006:63).

Despite financial constraints, it is important to acknowledge the creative ways in which individuals deal with such constraints. Some take on additional jobs such as taxi-driving which can be done outside normal working hours. One respondent who was trying to raise money for a wedding began taxi-driving at the weekends and in the evenings after his full-time job finished.

Another strategy employed to resist financial marginality is the dispersal of family members throughout the world. As described in Chapter Three and in Idil's story at the beginning of this chapter, this is a long-held Somali tradition from nomadic times when family units would break up in order to ensure survival and to maximise access to resources. Al-Sharmani notes that families dwell in multiple nations to resist "legal, economic, and/or cultural forms of marginalisation in host societies. Whether it is related to their inability to work and make a living, to live legally in a host society, to secure good education and opportunities for social mobility for their children or to be racially and culturally accepted in the host society, resisting marginalisation involves renegotiating

the nature as well as the varying levels of integration that diasporic Somalis can find or strive for in different nation-states” (Al-Sharmani, 2006:72). Al-Sharmani documents how the Somali community in Cairo is comprised of Somali families who are citizens in Western countries and Somali refugees. Many of these families moved to Cairo to overcome the marginalisation they had experienced in the West and to secure a middle-class lifestyle for themselves and their children. In many cases, mothers have relocated to Cairo with some of their children, typically leaving their husband and remaining children behind. These women have established businesses and trading connections and have climbed the social class ladder.

## Education and language

Closely related to challenges related to income and employment are issues of education and language. As discussed, while a number of Somalis have tertiary qualifications many of these are not recognised in New Zealand. This reinforces a sense of vulnerability and isolation from the wider structures and opportunities of New Zealand society. As a result, those individuals have lost the status they once enjoyed in their homeland. It also presents challenges in terms of finding a job. Some have undertaken retraining but this, in conjunction with English language learning, represents a significant investment in terms of time and finances. As a result, many of these individuals are currently unemployed or are unable to find employment that reflects their qualifications and experience. Nevertheless, a number of individuals are particularly resourceful in utilising their skills. One individual whose university qualification and 21 year experience was not recognised upon arrival in New Zealand began using their English language skills to voluntarily assist others. As she became well-known to service providers as an interpreter she later became involved in ASCA-run programmes and, after a number of years, gained full-time employment as a teaching assistant. Others whose qualifications are not recognised have had to change their field of expertise, dependent on what opportunities are available. Many professionals have become interpreters, teaching assistants or educators on ASCA-run programmes. These job opportunities tend to be distributed according to experience (i.e. former teachers have been employed to run the adult literacy school and homework centre).

There have however been a small handful of individuals who have undertaken English language tuition and subsequent tertiary education. Only a small proportion have gained employment upon graduating from such programmes and many struggle to find a job alongside the many other New Zealand-born applicants.

Part of the problem is that on arrival, high proportions of Somali refugees do not speak or write English. Estimates from the Ministry of Education suggest that 80% of refugees arriving in New Zealand have less than four years schooling (Ministry of Education, 2003a). A number of refugees whom I encountered during my research are still struggling to communicate in English despite residing in New Zealand for up to 10 years. These language issues are a significant barrier for

individuals in participating in New Zealand life and in accessing the opportunities required for everyday life. One community leader felt that English difficulties were particularly pronounced amongst Somalis compared with other refugee groups. Buckland found that language difficulties experienced by Somali women living in Canada could result in isolation and depression and decreased self efficacy (Buckland, 1997).

While there are a number of ESOL programmes within Auckland, Somali refugees often experience difficulties accessing them due to cost, transportation, family responsibilities and education delivery style. Women, especially those who are sole parents in New Zealand find this particularly difficult due to transportation costs, enrolment fees and problems with securing childcare. Furthermore, those attending full-time English language classes are required to be on a particular welfare benefit that is less desirable than the standard welfare benefit as it is only received during school terms. In addition, Somali students experience difficulties with mainstream ESOL providers as the mode of delivery and learning styles to which Somalis are accustomed are very different from New Zealand where great importance is placed upon independent learning. In Somalia, a great deal of emphasis is placed upon rote learning, competing with peers and oral communication. As a result of these difficulties a high proportion of Somalis have dropped out of mainstream ESOL training programmes with no improvement in English. In consequence, the ASCA has applied for funding from the TEC to provide adult literacy services (as described in the participant observation section of Chapter Five). The programme commenced in 2002 and receives funding for classes five nights a week with learners being provided transportation. This is particularly important as many learners, particularly women, do not have cars or drivers licences. The programme is particularly effective as it employs Somali trained teachers. This means that the teachers can customise the lessons to the learning styles of Somalis. Furthermore, lessons are split into men and women's classes which is important as time and time again, women and men tell me how they are far more comfortable interacting with members of their own sex and are therefore in a conducive learning environment.

Nevertheless some participants recounted the strategies they had used in order to improve their language skills. For some this meant seeking out free ESOL courses such as those run by community organisations or churches. Others sought out the help of New Zealand born friends or neighbours. Another said that she practiced her language skills on strangers she met in the streets. She said that on one occasion she became lost and was helped by a stranger at a bus-stop. She reflected that she had enjoyed the encounter as it provided her an opportunity to interact with a 'Kiwi'.

Given these challenges, a number of participants with whom I worked had dismissed the option of seeking further training simply due to the high costs of so doing. One alternative is the services offered by the Home Tutor Society that organises volunteer tutors to visit the homes of families and to provide one-on-one assistance. This option is sought after, particularly by mothers who would otherwise find it prohibitive to attend lessons. Given that the home tutors are volunteers there is a

very long waiting list for these services. A number of times I was asked by individuals whether I would be willing to be a tutor.

Not only are education issues experienced among adults but also young people and children. Internationally, research has demonstrated the difficulties Somali children face when attending Western schools. Scott (2001) and Alitolppa-Niitamo (2002) found that Somali parents reported that their children had difficulties with school such as homework, teachers, class-work and behavioural problems resulting in suspension.

When I commenced this research, one of the pressing issues for community leaders (and it continues to be the case) was the welfare of the younger generations. Those who had been raised in refugee camps have struggled to adapt to an entirely different mode and style of education. In order to address this situation, a study support centre has been established by the ASCA in 2006 at a local high school to assist secondary school students with their schoolwork. Nevertheless there have been a number of Somali students who have stopped attending school and are struggling to obtain employment. Others had been enrolling in tertiary courses and incurring large student debts yet struggling to achieve passes. As a result I assisted in running a group for Somali tertiary students as described more fully in Chapter Five. In addition, a number of initiatives were created to assist young people with training including the workplace training programme described above. I was particularly touched at the way in which community leaders celebrated each time a young person obtained a full-time job.

Participants' accounts have also indicated a number of difficulties in terms of education for younger children. Part of the problem arises from the fact that many children have spent years in refugee camps often where there are no schools. Furthermore, due to the tenuous financial situations of families, children perform an important economic function and contribute to the income of families. In one family I interviewed they described how each child generated income by selling items such as sweets, ice-blocks and cigarettes to others in the camp. As a result when they come to New Zealand, many are unfamiliar with the concept of sitting in a classroom for the day. In addition, some face ongoing trauma relating to the events that have happened in their life. One school principal interviewed in research conducted in the Mt Roskill area described how many primary-school aged refugee students were frequently violent and how the school had to provide students with social workers and support to deal with trauma from the past (Lawrence, 2003).

Furthermore, due to the nature of the refugee experience, many students have often not attended schools yet are placed in a classroom with peers of a similar age group and expected to be able to cope. On the other hand, other participants complained that their children were put in classes based on ability. This resulted in 11 year olds learning alongside children many years younger than themselves. As a result, these situations often produce frustration and negative behaviour. Community leaders were occasionally called by parents to assist in the situations where Somali

students had been expelled from school. In addition, because most Somali parents only have basic education and language skills it impacts their ability to be involved in school life. In one study, one parent reported feeling a sense of disempowerment that she was unable to read her child's school newsletter, let alone participate in other school activities or help with homework (Lawrence, 2003). There are also important cultural differences at work. While participating in the Adult Literacy classes one community member described the nature of education in Somalia to me. There, teachers are held in great esteem and parents view the education of their children as being the sole responsibility of the teacher. As a result, parents tended not to be involved in the education of their children at home, such as homework for example. This is in contrast with New Zealand where parents are expected to closely participate in their children's education. In order to address these issues the ASCA has established a homework centre at a local primary school. Somali teaching assistants staff the homework centre and assist students with current homework and to catch-up on material they have struggled to comprehend. This is a particularly important initiative given the difficulties many parents have with assisting with their children's homework.

## Housing

Another important determinant of health and wellbeing is that of housing which plays a vital role in the resettlement experiences of migrant groups. Housing is often closely related to issues of income and employment that have been previously discussed. Housing provides not only material shelter and protection, but also a sense of security and protection. Inadequate housing has a number of negative effects including increasing risks of respiratory disease and mental illness (Hyndman, 1998). Lilley (2004) examined the housing experiences of Somali people living in Christchurch, concluding that Somalis are a vulnerable housing group.

In New Zealand, the rental housing market is split into privately owned and state owned. Following neo-liberal reforms in the 1980s and 1990s, the state housing sector was restructured and as a result public housing stock was more narrowly targeted at those in greatest need (Murphy and Kearns, 1994; Murphy, 2004). For refugees who arrive in New Zealand as part of the annual quota, Housing New Zealand undertakes to settle refugee families in state housing and they are placed at the top of the very long waiting list. This is a considerable undertaking given the high demand for state houses. However, it is not easy to find suitable homes for refugees. Much of New Zealand's state housing stock was created in an era where the notion of the nuclear family reigned supreme. Many refugee families are large with up to 10 children. Finding suitable homes is extremely difficult. In one case I encountered a large family that was housed in two homes that were far apart. This was problematic as the family was unable to afford a car and had to make a difficult decision as to who would live with whom.

When a home is found for a refugee family it can also cause problems due to location. In some cases Housing New Zealand finds a home for a family but it is not accepted as it is either far away

from the established community or unsuitable. In one household I worked with where there was evidence of overcrowding, Housing New Zealand had suggested a home approximately 20 minutes (by car) away. The family refused as it would mean they would be separated from the community and would make commuting to schools, friends, mosque and community events particularly problematic as the sole parent was not able to drive. This decision was not well received by Housing New Zealand staff who were reluctant to offer further assistance given that the first offer had been declined.

For those who were fortunate enough to be resettled into a Housing New Zealand home, other problems were encountered. Many participants complained that their homes were cold and damp and that this contributed to poor health, particularly amongst children. Requests to Housing New Zealand for carpeting had been declined. One participant had raw sewage leaching through her garden and experienced considerable difficulty trying to address the situation with Housing New Zealand. In the end, she requested the assistance of her public health nurse who was treating her for TB to write to Housing New Zealand to try and get a transfer. Another participant described how there are eight people in her family sharing a 2 ½ bedroom house. When one family member contracted TB, this was soon spread to other family members due to the level of crowding.

The relative shortage of state houses and the long waiting lists means that if tenants move out of their house they are not automatically entitled to another state house but re-join the waiting list. This is of particular relevance to Somali refugees who are highly mobile. Their mobility has proven to be difficult for a number of families who have been involuntarily settled in other cities in New Zealand but have relocated to Auckland for additional family support. They find themselves in a situation of not being entitled to a state house and required to find accommodation within the private rental sector. This is not a straightforward undertaking and a number have reported difficulties finding a home let alone affording high market rents. A number of Somalis have stated that they experienced discrimination based on their skin colour and nationality. One person rang about a home but when she went to view it was told that it had been let. Some overcame this issue by using New Zealand born people to assist them in their search.

Not only do Somalis experience profound challenges in establishing new lives in New Zealand and in coming to terms with events from the past, but the migration and resettlement process has influenced Somali culture and identity, as discussed in the following section. Being Somali in New Zealand involves ongoing processes of negotiation and re-interpretation.

## **Being Somali in New Zealand: Culture, identity and resettlement**

While the term 'culture' is used on an everyday basis it is often difficult to define (Gesler and Kearns, 2002). One school of thought suggests that culture comprises of material objects, social relations and ideas. Nevertheless, it is important not to reify culture and to situate it within its

historical, economic, social, political and geographic contexts (Mitchell, 2000). Furthermore it is important to acknowledge that culture is dynamic, contested and produced by particular sets of social relations and may be applied to groupings of different sizes and scales (Gesler and Kearns, 2002).

While Somalis are generally very proud of their nationality, the dominant form of social organisation is clan groupings. As documented in Chapter Three, conflict between various sub-clans was the primary reason behind the development of fully-fledged civil war in 1992. Throughout Somali history, leaders have favoured members of their own sub-clan in the distribution of resources and power - leading to conflict, suspicion and feelings of injustice. In New Zealand, all clan groups are represented, with the majority of Auckland Somalis originating from the Darood clan, in particular the Majeerten, Marehan and Warsengeli sub-clans. One individual estimated that 70% of Auckland Somalis are Darood, 20% Hawiye, 10% Isaaq with only one family from Rahanweyn.

At the outset of my research, I was advised not to probe into clan identities as this was, and continues to be, a sensitive issue amongst Somalis. As my research progressed, individuals I had come to know talked about how different community members belonged to particular clans and of the clan-based links and connections between different people. I gained the confidence to ask about clan issues and, as noted by El-Solh in her research with London Somalis, found that while clan consciousness “tends to be denied in front of outsiders, its incidence is far from negligible” (El-Solh, 1991:545). While some individuals recounted that clan divisions were no longer important in New Zealand and that Somalis are ‘all one community’, others spoke of the other ways in which clan identities remain an important part of life in New Zealand. One community representative was nervous when speaking about clans and sought reassurance from me that his comments would remain anonymous and confidential. This individual felt that speaking about clans could potentially exacerbate existing divisions. The respondent felt that clan divisions were still very real and influenced the way in which people interacted with each other. Suspicions of individuals from warring clans still seemed to be strong, and ‘baggage’ from the civil war still evident. This individual lamented the way in which members of one particular sub-clan believed themselves to be superior to all other sub-clans and expected preferential access to resources and opportunities, as had been the case in the past in Somalia. Writing in the context of England, Hopkins (2006) found that some of her participants preferred non-Somali assistance organisations as they were not troubled by the same clan divisions of other Somali-run organisations. I similarly encountered such sentiments with some individuals being happy to share their story with me but not with other Somalis. This raised issues in terms of using interpreters (see Chapter Five for further detail).

Clan politics proved to be a significant issue for the current leader of the Auckland Somali Community Association. As discussed in the following section, the ASCA provides a number of programmes offering employment opportunities for Somali individuals to co-ordinate these programmes. At the outset of his tenure, the current leader found that previous leaders had

distributed such opportunities to members of their own sub-clan grouping thus perpetuating clan based suspicion and conflict. The new leader however consciously sought to allocate employment opportunities to individuals representing all clans and sub-clans. This proved to be a challenging task as at times he was questioned by members of his own sub-clan as to why he was doing this. Nevertheless, his commitment to such an endeavour has remained strong and has helped the ASCA rise above the crippling clan-based politics that occurred in the 1990s. The ASCA is unique in that it represents all sub-clan groups who have mobilised together (though not always in harmony) to create a strong and vibrant organisation that provides a wide array of social support and services to the Somali community.

While clan identities are important, social organisation has been slightly modified within the context of New Zealand due to the relatively small size of the community. In Auckland, people interact with people from other sub-clans more than they might have ordinarily done in the past. For example, in historical times Somali women were required to stay home for forty days following the birth of a child. The woman's female relatives would care for her and her household while the new mother cared for the baby. This practice has been reinstated within New Zealand however, due to the fact that many individuals are living in New Zealand without family members or other sub-clan members, this task of caring for new mothers is shared amongst female community members of different sub-clan identities.

In international accounts of Somali settlement, clan-based politics are particularly pervasive and acrimonious with clans being spatially and socially segregated from one another (El-Solh, 1991; Griffiths, 1997). This does not appear to be the case in Auckland. While clan politics do remain due to the legacy of the past, there is evidence that many Somalis have developed new and enduring relationships with individuals from other, and at times, formerly opposing sub-clans. One individual recounted how many of his friends are from formerly 'enemy' sub-clans. This may be in part due to the small size of the community which has necessitated greater inter-clan contact and also to the enterprising efforts of Somali elders and ASCA leaders in building links between individuals.

One interesting incident that supports the notion that inter-clan conflict is not as pervasive as it once was raised by the current ASCA leader. He noted how those who have left the ASCA and established rival organisations (elaborated upon in next section) are not from opposing sub-clans but from his own sub-clan. His view is that these disagreements have occurred not because of clan politics but because of conflict over power and resources.

While clan identity and relations are a very difficult topic to talk about, accounts from community members suggest that clan groupings are important and that there are strong bonds that endure between sub-clan members. Nevertheless there appears to be a greater degree of interaction and co-operation between sub-clans at the public level. The inner thoughts and beliefs of Somalis on

clan relationships are much more difficult to gauge. Historically, marriage has been an important mechanism through which inter-clan relationships are strengthened. This continues to be the case due to the high proportion of arranged marriages although amongst the younger generations there does appear to be some evidence of 'love matches'.

On the other hand, the influence of Islam on Somali identity and culture is celebrated, openly discussed and shared. Islamic teachings pervade every aspect of life for Somalis, providing guidance and instructions on daily life including relationships, values, ethics and health practices. As discussed in Chapter Three, while Islam has long been a feature of Somali life, since the Civil War there have been accounts of religious intensification (Berns McGown, 1999; Tilikainen, 2003). This is a very interesting topic and one that prompted discussion when I raised it with community members. Some felt that this had occurred because of the belief that the Civil War was punishment from Allah for failing to follow him diligently. Some had a sense that renewed religious fervour was due to the isolation of Somalis from wider New Zealand society and that people had felt scared, alone and vulnerable and had turned to religion for reassurance and as a means of preserving Somali identity in a hostile world. One community representative recalled how, prior to coming to New Zealand, religious leaders in the refugee camp had warned women to veil themselves as people in New Zealand would try to stop them being Muslim. Increasingly Islam and Somali identity have become more closely intertwined in terms of health beliefs and practices, as will be discussed in Chapter Seven.

Veiling is perhaps one of the best examples of this religious intensification. According to respondents, prior to the Civil War most women were not veiled and wore western style clothing or Somali *dirac* (loose cotton skirts/dresses). Nowadays in New Zealand most women are veiled albeit to various degrees. Some wear full hijab with only the eyes being visible. Others wear a loose scarf wrapped around the head. Only a very small handful of women do not veil. Similar to the findings of Fangen (2006) the degree to which women have veiled has become an important determinant of identity. One woman who was not accustomed to veiling in Somalia felt pressured by other community members to start veiling. This pressure mounted to the point where she felt as though her credibility was being damaged by her decision not to veil. She now veils loosely when venturing outside the home.

When discussing with individuals about decisions to veil or not, they stated that it was a personal decision and one made by each person. When asked about the topic of my research at various family or social gatherings I would frequently be told 'oh those poor oppressed Somali women' and asked about veiling. Yet in most cases I got the sense that the decision to veil was less about women meeting the wishes of their husbands and more about their desire to demonstrate respect for the teachings of the Koran, to be modest and to maintain a sense of religious identity in a secular, though historically Christian-based society. Although the Koran stipulates that veiling should occur once girls reach puberty I was surprised to see many female babies and toddlers

veiled. This according to their mothers is to ensure that they are accustomed to being veiled so it is not a big transition. Many report that because their children see their mothers and female relatives wearing scarves, many wish to copy them and follow suit.

An interesting observation that I noted during my research was that women in Auckland tended to veil more than other women in New Zealand and abroad. I first made this observation while watching a Somali wedding video with a friend who concurred that quite a few Somali women in England and Canada did not veil at all and went so far as to state that some were openly lesbians! This individual, associated veiling with moral and ethical purity. I asked many people why Auckland Somali women tended to dress more conservatively compared with others, however, most people were unsure. One person thought it was due to the values espoused by religious leaders in Auckland. Another individual felt it was because Auckland's community was smaller than other international Somali communities and not as well integrated. If the latter were true, veiling is a somewhat defensive means to protect women from the harsh reality of the world in which they now live.

Increased devotion to Islam was observable in a number of different ways. One important place is that of the home. Tilikainen (2003) found that because most Somali women are mothers and home-makers, the home is an important religious space. With the challenges of resettling in a foreign environment, Islam and religious practices such as prayer times, washing rituals and fasting has provided a sense of continuity and control in a world that is often foreign and unwelcoming. Writing on her fieldwork experience in Helsinki, Finland, Tilikainen writes, 'Women's principal religious space is the home, where they recreate Muslim space by religious practices and decorations. Koran calligraphy, pictures from Mecca and prayer timetables decorate the walls beside a bus timetable and clock' (Tilikainen, 2003). This could equally be describing my fieldwork experiences in Auckland. Nearly all of the homes I visited were adorned with Koranic wall-hangings and images of Mecca. Adherence to Islam was displayed in a visible way from the washing containers in the bathroom through to prayer mats. Use of the home space is in accordance with Islamic prescriptions and gender roles with women and men often socializing in different spaces. The kitchen is the heart of the female space. Women are most often in charge of meal preparation, of which Koranic teachings regarding *Halal* (clean) and *Haram* (unclean) food come into play. Unlike Tilikainen's experience of women who interpret this command to varying degrees, all women I encountered were very strict about ensuring all food was *Halal*. Many would refuse to eat food prepared by non-Muslims for fear of eating something *Haram* (forbidden).

Islamic sites are also very important. For men, mosques are a hub of religious and social activity due to the five daily prayer times. On Friday afternoons there is a special time of prayer similar to the Christian concept of attending church on Sunday. I remember driving past the Stoddard Road mosque on a Friday and seeing men in billowing white trousers and tunics (*khamiis*), many bearded and wearing Islamic caps (*koofiyad*). It could have been a scene from the Middle East

rather than suburban Auckland. For men, these gatherings at the mosque are also an important social event and provide an opportunity to spend time with other men. Women do not tend to attend the mosque, with most observing prayer times within the home. Somali women have however established a Koran class every Sunday which is designed to instruct women on the teachings of Islam. Somali children often attend Koran class after school for two hours between five and seven p.m. There is also a Somali Koran class (*dugsi*) aimed at religious and language maintenance. The class runs on Monday for boys and Tuesday for girls.

Religious occasions throughout the year are important community events. *Ramadan* is a religious time that unites the whole community. Fasting not only requires abstinence from eating and drinking during daylight hours, but is also accompanied by greater religious devotion and efforts to refrain from sinful behaviour. One respondent said to me that your fast could as equally be broken by wrongful behaviour such as lying as it could be by eating food during daylight hours. *Ramadan* is an important time with many programmes and community events such as the swimming and adult literacy programmes grinding to a halt. For the purposes of my research, I abandoned trying to interview during *Ramadan* as many people reduced daily activities to a minimum and had limited energy to devote to such tasks. One of the reasons for this was due to the preparations involved in fasting. For women in particular, particular kinds of food needed to be prepared when the fast was broken at sundown every night. Some stated that Somali *Sambusa* (similar to Indian samosas) were a good food with which to break the fast.

The end of *Ramadan* is marked by *Eid-al Fitr*, a celebration similar to Christmas in its spirit. This is an important celebration that involves the preparation of particular foods such as *xalwo* (similar to Turkish delight) and sweet biscuits. Children are treated to new clothing and are given envelopes containing money by relatives. Often families will attend the mosque in the morning and then have a celebration lunch with family and then visit other families. Some families take their children to Rainbow's End amusement park or the movies and make a big family occasion of the day. One participant stated that his family has a barbecue for *Eid* (with *Halal* sausages of course!).

Closely related to religion is that of gender roles. The Koran prescribes quite distinguished gender roles, with women being responsible for the raising of children and the taking care of the home while men are the head of the household and responsible for earning a wage. This however is not universal across all families. In Somali nomadic culture, the entire household unit was involved in maintaining an economic livelihood however, there does appear to be a fairly consistent gendered division of labour within the home. The refugee journey has thrown this order into disarray particularly with the large numbers of female lone parents who arrived in New Zealand under the 'Women at risk' immigration category (see Chapter Two for discussion of New Zealand's refugee quota policy). As these women are typically lone parents (often with large numbers of children) they are solely responsible for ensuring the family is provided for; this can be a significant burden.

One participant reflects on this time in her life while she was living at the refugee camp and the effect it had on her health:

Khalisah	I was pregnant and because I was the breadwinner I was working very hard selling building materials at a market. I had to do a lot of lifting as I tidied up and put things in piles. I then got jaundice and had yellow eyes...I was also seven months pregnant. Was doing physical work...
*Jody	And what about your husband, was he not around?
Khalisah	He was not around very much. Would visit. Was an army man so by this time was unemployed. Had another wife and family. Would come and be gone the next morning. I was living in my family's house where we grew up. Rest of family was gone. I had to support my children or they would starve. My husband did not help me at all.
*Jody	And did you have other family members to support you
Khalisah	No-one immediately. I did have other relatives who I could go to for advice or moral support
*Jody	So who looked after the children
Khalisah	Sometimes they would come with me and then Jabbar and Mahir would take them home and look after them until I got home from the market. Sometimes they would stay with me. It was very hard when one of them got sick.
*Jody	Gosh that must have been very hard for you
Khalisah	Yes it was.

During this conversation the family member who was interpreting for Khalisah remarked in surprise at her admission about the trying circumstances of her life. Apparently she had not acknowledged this outwardly before and the interpreter noted that it would have been difficult for her to talk about it.

Nevertheless, in most marriages there appears to be a relatively common gendered division of labour. Yet one surprising finding for me was the extent of women's independence. As discussed above, Somali women are often portrayed or conceptualised as oppressed yet I found that many were independent and assertive. In some families women were in charge of the finances with men having to hand over their earnings to their wife each week. At a 'Preventing Family Violence' education programme run within the Somali community one community member recounted how it was his wife who used physical force in the family and that he was the one who was oppressed.

Gender roles have been greatly transformed during the process of resettlement. Yet it is important to acknowledge that the experience of women is greatly varied. While some are indeed independent and have control, others are more rigidly bound within strictly defined gender obligations with limited opportunities to socialize and venture outside the home. These women

tend not to participate in community events and some were not permitted to join in my research project. Yet it is also important to consider the impact such gender role shifts have had on men. While the perspectives of Somali women have been documented (e.g. Jenkinson, 1999) there has been very little discussion of the experience of men. This remains one area of investigation that warrants further exploration. With women assuming more control, some international studies have noted that men have been feeling a growing sense of disempowerment (Fangen, 2006). Some even note that this has contributed to high rates of domestic violence amongst Somalis living in Norway. During the course of my research there was an education programme designed to make people aware of the issue. However I was not personally conscious of any instances of such violence although that does not mean it does not occur. Suffice to say, as in any community, it is a topic that is not often publicly discussed.

As has been discussed, the process of resettling in New Zealand has resulted in the transformation of Somali cultural and identity practices. One of the key social structures that have formed since the arrival of Somali refugees in Auckland is the ASCA. The following section describes the development and impact of this innovative community organisation.

## **The Somali community in Auckland – community structures and dynamics**

While it is important to acknowledge that the Somali community is neither homogenous nor shares identical resettlement experiences, the spatial clustering of Somalis in the Mt Roskill area has solidified a sense of community identity. Although this clustering originally occurred due to the large tracts of state housing in the area and the fact that quota refugees are allocated a state house upon arrival, since the arrival of growing numbers of Somalis (and other refugee and migrant groups) the built landscape of Mt Roskill has been transformed reflecting the diverse population who reside there. Somalis, and other refugee and migrant groups have had a profound influence on the physical landscape of Mt Roskill and surrounding suburbs (Friesen et al., 2005; Lawrence and Kearns, 2005). An advertisement from a real estate flyer (Figure 26 overleaf) promotes one particular Mt Roskill property as being close to the local mosque. This feature would never have been promoted twenty years ago and is testament to the changing population within the area.

Transformed religious, retail and consumption landscapes are particularly evident. The area now boasts mosques, *Halal* food outlets and butcheries, spice shops, Islamic clothing shops and remittance offices. The local Pak 'N' Save supermarket now has a large range of *Halal* meat in response to the religious needs of residents and according to one participant, two large fast food chains offer *Halal* chicken on the weekend. In Dyck's research with immigrant women in Canada she observed "sedimentation of place through daily activity, as memories, habits and practices – as well as goods brought from India – are brought to bear on daily life and the construction of

landscape features” (Dyck, 2006:6). A similar phenomenon is evident when considering the settlement experiences of Somalis living in Auckland.

**Figure 26 Real estate advertisement**



m. 027 496 4214 p. 620 6039 ah. 623 9118

**MT ROSKILL**  
**- WALK TO MOSQUE**  
**\$269,000**

**Capital Gain Material**  
Fabulous freestanding 2 bedroom townhouse. Just recently redecorated with new kitchen/carpet paint & paper. Lounge opens onto a deck then stepping down to large sundrenched gardens. Currently 2 bedrooms - but potentially could be added onto to make a 4 bedroom home. This townhouse must be viewed!

**VIEW:** 8A Denize Avenue,  
Sat/Sun 1:00-2:00pm  
[www.barfoot.co.nz/290856](http://www.barfoot.co.nz/290856)

**KAYE CASHMORE**  
m. 0274 786 578 p. 620 6039  
ah. 634 2282

**PETER HEYWOOD**  
m. 0274 523 523 p. 620 6039  
ah. 627 1138

Since the settlement of Somalis and other refugee and migrant groups in the area, Mt Roskill has started to become a social services hub. At the time a small study on the area was conducted in 2003, community leaders identified a range of social service organisations who were relocating their head offices and opening branches in the Mt Roskill area including, youth outreach programmes such as I Have a Dream Charitable Trust, HIPPY (Home Interaction Programme for Parents and Youngsters) and health facilities such as the Hauora o Puketapapa (HoP) health centre. Kearns (1993) notes how the clustering of such services contributes not only to the wellbeing of individuals but also to communities. He states, “While the direct ministering of professionals such as physicians and midwives usually enhances the health of individuals, in two further ways the presence of appropriate services contributes to the broader health of the population: first, a household or community may feel more positively about its place because of the types and styles of services available; and second, the particular configurations of service provision may enhance the level of interaction within the household or community (Kearns, 1993:144).

Part of the reason for the density of social service organisations is due to the high levels of need experienced by individuals living in the area. The area has a high relative deprivation score according to the index developed by Crampton et al. (2000). The Wesley, Walmsley and Akarana Census Area Units (CAU's) in which many Somalis live have a consistent score of ten in both 1996

and 2001, indicating it is one of the most deprived areas in Auckland. In addition to the clustering of general social services, a variety of refugee and migrant organisations are located in the area including Refugee and Migrant Service (RMS), Refugees as Survivors (RAS) and the Auckland Regional Migrant Service (ARMS). This too, reflects the types of people who are now resident in Mt Roskill.

One important dimension of the community is the establishment of pan-clan organisation, the Auckland Somali Community Association founded in 1996 to assist Somalis with resettlement and represent Somalis to government and NGOs. The ASCA has a quasi-governmental organisational structure with different community members holding portfolios based on their skills and experience. For instance, a Somali woman with midwifery and nursing experience was given the 'health' portfolio and made responsible for coordinating health related activities. The Association has annual elections where leaders are voted for by secret ballot. To date, there has been no research that explicitly focuses on the characteristics and experiences of the Auckland Somali community. The Association became an incorporated society in 1997 with the aim of assisting Somali people with the various challenges of resettlement. While membership data is not recorded in writing, leaders estimate that there are approximately 1500 members. One relatively unique feature of the ASCA when compared to accounts of other Somali associations (Hopkins, 2006), is that it is a pan-clan organisation. This is quite a feat given the deep-seated clan divisions which resulted in the Civil War. In the British context, only a few Somali-led organisations have succeeded in gaining enough funding to sustain full-time services due to their small size which not only hinders them from attracting large funding grants and leads to a duplication of projects which, in turn, makes them compete for the same target audience. Lack of co-operation with other Somali organisations is an additional deterrent (Hopkins, 2006:371). Some Somalis have set up community organisations as a means of creating their own employment opportunities; this is a feature that has increasingly started to occur within the Auckland context.

The first focus of the Association was to find a centre where various community activities could be based. After using various community halls, in 2001 the Pan African Centre at Three Kings was opened with the assistance of Ministry of Internal Affairs and the Auckland City Council. This centre was used primarily by the Somali community (although made available to other refugee groups) and became a hub for Somali activities such as the adult literacy school and for meetings and consultations. In 2005 the ACC advised that the building in which the Pan-African Centre was located was due to be demolished. As a result, community leaders have since rented a hall from a nearby bowling club.

Since becoming an incorporated society, the ASCA has become a significant service-provider (Table 7) with annual income increasing from \$600 in 2000/2001 to \$221,520 in 2003/2004 receiving grants from a wide range of government bodies, charitable organisations and private trusts (Office of Ethnic Affairs, 2005). Programmes implemented by the ASCA in conjunction with funding bodies include:

**Table 7 ASCA programme history**

	<b>ASCA Programmes</b>
1995	<b>Religion and language maintenance classes held from a privately rented house in Mt Roskill</b>
1998	<b>Sewing classes for women</b>
1999	<b>Homework centre for primary and intermediate school aged Somali students</b>
2000	<b>Summer holiday programme for young people</b>
2001	<b>Summer soccer tournament</b>
2002	<b>Health Promotion projects including TB, women's health, nutrition, HIV/AIDS and FGM</b>
2003	<b>Adult literacy programme</b>
2004	<b>Swimming programme for women</b>
2004	<b>Road Safety classes for women</b>
2004	<b>Small business training</b>
2005	<b>Parenting programme</b>
2006	<b>Family violence prevention programme</b>
2006	<b>Triangle television training initiative</b>
2006	<b>Study support centre for high school students</b>
2006	<b>Workplace training programme for young people</b>

Despite widespread support for the Association, it has not been without conflict. Two Somali individuals have established rival organisations 'Somali concern' and 'New Zealand Somali Women's Association', after concerns were raised about the direction and values of individuals in leadership. These organisations have, however, failed to attract any ongoing funding and resources. This has meant that only a few people have joined these organisations after various complaints and grievances with the ASCA. In many cases members have returned to the ASCA after finding that the other organisations have not been able to assist them.

In August 2004, a small group of Somalis sent a letter and petition signed by 53 individuals to various officials within government departments. The letter claimed that the ASCA was not being run fairly and that access to ASCA programmes was not equitable. This resulted in a bitter and lengthy conflict that lasted nearly two years between 2004 and 2005. In order to try and resolve

the dispute, officials from the Office of Ethnic Affairs (OEA) tried to mediate between the two parties. This heightened tensions as key personnel within the OEA already had strained personal relationships with ASCA leaders from a previous encounter. A number of issues also arose in terms of how the OEA attempted to resolve the conflict. Individuals whom I spoke with felt that the mediation process fell far short of a professional attempt at conflict resolution. There was also little effort put into determining the background and legitimacy of the allegations. The individuals who made the complaints were formerly involved in ASCA programmes but had become disenfranchised when their programme funding had ceased. Furthermore the validity of the petition was not examined. A number of those who had signed the petition were children and others had been told it was for education services rather than a complaint against the Association's business affairs. There was also an element of sub-clan element tensions involved. Unfortunately, rather than recognising that the allegations were a product of community and clan tensions and treating it as community conflict, the allegations escalated and were sensationalized by the OEA. Community leaders felt a sense of having to clear their names despite the fact that ASCA leaders are volunteers and are not paid for their community work.

The 'mediation' process concluded in mid-2005 having found that additional capacity building was required by the ASCA particularly in the areas of reporting, asset management and strategic planning. This is unsurprising given that the funding procured by the ASCA is short-term and focused solely on service delivery rather than investment in capacity building and skills of Association staff. The ASCA was cleared of any allegations of financial wrong-doing. This too was unsurprising given that the Association is audited annually by an independent auditor. Nevertheless the investigation process was a very draining and traumatic time particularly for community leaders who have invested so much into the organisation. It became an immense burden and drain on time which respondents felt could have been better invested in the running of the organisation and the assistance required by other Somalis.

In many ways the ASCA has become a central foundation of Somali resettlement in Auckland. It serves as a rallying point for political mobilisation both locally and further afield. This is one important feature of transnational organisation. The following section considers the degree to which the Somali Community in Auckland can be thought of as being transnational.

## **Somalis as a transnational community**

Refugee resettlement, according to Shandy (2001) "is a peculiar term because it assumes the end of the international migration journey" (Shandy, 2001:1). Internationally, commentators have started addressing the phenomenon of Somali transnationalism and the way in which Somalis are highly mobile and maintain strong links with other diasporic Somalis and fellow Somalis living back in Somalia (De Montclos, 2003; Koser, 2003).

In many ways, the Auckland Somali community can be thought of as a transnational community. It shares a number of similarities with the experiences of other diasporic Somali communities. Somali households are increasingly becoming transnational in nature with family members moving back and forth between different countries whilst maintaining strong family connections. One indication of Somali transnationalism is the way in which members maintain strong relationships with family and friends living abroad. As is in the case with Nielsen's respondents in Denmark (2004), Auckland Somalis report frequent phone contact with friends and relatives throughout the world. For instance one community representative stated:

*Jody	Are your family all in Somalia?
Akram	Mostly they are in Somalia. Some of them in Somalia, some of them in Emirates, some of them maybe in Europe but I have friends, all of my friends call me in the morning from USA, and so I have friends all over the world, all of the globe.

Communication is largely by telephone which is unsurprising given that Somalis are an oral-based society. Community members use phone cards to help reduce the cost of the international toll calls. These information networks are dense, giving rise to what some participants call 'close community' where gossip and rumours circulate at break-neck speed. Dyck (2006) observed a similar phenomenon in her research with immigrant women from South Asia and contends that "Social networks of the women of the study, built up through day-to-day activity, are critical to their ongoing 'processing' of knowledge and experiences as they navigate and construct their embodied subjectivities in place" (Dyck, 2006:6). One research participant with TB spoke about how her sister living in the UK was harassed by other Somalis about her sister's illness even though she had not disclosed her illness to anyone in New Zealand (see Manderson and Allotey, 2003). Some participants also utilise the internet as a communication and information medium, although this is less prevalent than the phone in part due to cost and its reliance on written language. The internet is however becoming an increasingly important communication tool amongst the younger generation.

Another form of communication and information sharing that I observed during my fieldwork was the circulation of wedding videos. At nearly all the home-based interviews I attended, on my arrival a wedding video of a relative or friend living overseas would be showing in the home. The videos tended to be watched repeatedly as a form of entertainment and, in line with the notion of transnationalism, as a form of cultural maintenance. Viewers would point out to me their relatives and comment on the style of dress, mode of interaction and the differences between weddings here in New Zealand and those held overseas. According to community members, these videos are circulated freely throughout the community. One community member who was married during the time of my fieldwork told me that she was anxious about videotaping her wedding as she knew

it would then be circulated throughout the world and that people would comment about her and her wedding.

Another form of cultural maintenance and keeping in touch with events touching the lives of family and friends was through Arabic television. While access to this is dependent upon income (those able to afford satellite television), it was cited as a means of cultural maintenance. This practice reveals how Somalis strongly identify with Arabic culture based on the importance of Islam in their lives. In many ways, for Somalis living in Auckland, all things Arabic are a best-fit in the absence of Somali equivalents. In Hopkins' (2006) research, she found that many Somalis identified more strongly with Arabs rather than Africans and resented being aligned with other African/Caribbean population groups.

A further feature of transnationalism evident in the Somali diaspora is that of frequent movement of Somalis. This tends to more be between co-ethnics in other countries although some do return home to Somalia. Visiting Somalia is somewhat complicated as there is still political unrest and it is an extremely expensive journey. Throughout the course of my fieldwork, participants were highly mobile both within the city, the country and also to other countries. This was similar to the findings of Griffiths (1997) work with Somalis living in London. I observed that Auckland Somalis not only frequently changed residence within Auckland but also moved to other parts of New Zealand. It is fair to say though that there is an overall Auckland-drift for Somalis living in New Zealand. The main migratory flow is the migration of Somalis to Australia where there are much larger more established Somali communities. This secondary migration from New Zealand to Australia shares some similarities with the findings of Nielsen (2004) in regards to Danish secondary migration from Denmark to the UK. There, Britain was characterised as a country of freedom, tolerance and opportunities compared with Denmark which was constructed as a society of control, racism and discrimination in employment opportunities. One community leader estimated that thousands of Somalis have migrated to Australia. According to community members, Somalis experience better life prospects in Australia compared to New Zealand and find it easier to find work. This tended to be the main motivation for migration to Australia. The motivation for this movement is similar to that in nomadic times where people would always be searching for the best opportunities such as the best grass and water supplies to keep their stock alive.

There was also some evidence of using New Zealand as a temporary stop on the path of moving to Australia. Some waited in New Zealand to gain a New Zealand passport before moving onto their ultimate goal, Australia. Apparently many tried to migrate to Australia initially but found the immigration rules a lot more stringent than New Zealand. Interestingly, the decision to migrate is often made quickly. I was surprised by one research participant who decided to move to Australia and had sold all her household possessions to fellow community members within a matter of days. She spoke to me about her decision to move and said that if life was not better for them in Australia that she would move back to New Zealand.

While movement to Australia from New Zealand was the main migratory flow, Somalis also make intermittent trips to relatives living abroad and in Somalia although the incidence of these trips appear to be less frequent than for other diasporic Somalis (De Montclos, 2003; Koser, 2003). From my experience, there are few Somalis who make regular business trips between New Zealand and other countries and most movement tends to be for family or personal reasons. For many, these visits overseas are for the purposes of maintaining family relationships. Interestingly, the cost of these travels tends to be borne by other family members who have raised funds to permit the travel to take place. These trips tend to be finite in length and result in the individual returning to New Zealand.

Another important migratory movement also takes place for Somalis when searching for a spouse. While many Somalis marry within the Auckland community, often spouses are selected by family members within the extended family living overseas. This frequently means that the wife is required to move to live with her husband and less often, the husband comes to New Zealand. A number of women I met during the course of my research have since moved to the United States, Canada or the United Kingdom to join their husbands.

Despite the financial challenges of resettlement, remittances remain an important feature of Somali life. There are two remittance agencies operating in Auckland, Dahabshil and Amanna both located on Stoddard Road in Mt Roskill. Although there is no verifiable data, it seems likely that de Montclos' estimates are also relevant to Auckland (De Montclos, 2003). As discussed in Chapter Three, Somalis throughout the world are renowned for high remittance levels of up to 20-30% of household income, despite being in tenuous financial situations themselves (De Montclos, 2003). Remittances are an important link with family back home and are one way of maintaining contact and providing assistance to those who were not fortunate enough to be resettled. One teenaged Somali girl found a job working in a factory after school in order to be able to remit money back to her relatives still living in Somalia. This fascinated me given that many teenagers whom I know work in order to buy clothes or pay for entertainment, yet this girl was working to support her family in Somalia. This is not an isolated incident as teenagers/young people frequently appear to have a higher success rate in obtaining employment with their wages forming an important part of the household budget.

Yet remittances can place quite a burden on individuals who are struggling with resettlement themselves. One individual hoped to study when he arrived in New Zealand in order to obtain a good job but had to abandon this dream out of the necessity of sending money home back to his family as indicated by the interview transcript below:

*Jody	What did you hope to do when you arrived in New Zealand?
Akif	I would have liked to study and to learn English

*Jody	Why didn't you?
Akif	Because I had to establish myself and send home money to support my family back home.

For many participants their remittances are the sole source of income for their families back in Somalia. One participant recounted how her remittances supported her mother and eight siblings living in Kenya, one of whom was disabled. Another participant talked about how his remittances were the only form of income for his family members. When asked about remittances he stated that he sends home 10% of his income. As noted in the following transcript:

Adil	Ten percent. Well it depends where they live and life is not that expensive but Somali people can be different from each other. Some people pay to their families 80% of their income and all that depends on is where their family lives
*Jody	So like the cost of living?
Adil	Cost of living is right
*Jody	And do your brothers in [Ethiopia] also send money to the family?
Adil	Not at the moment because their income is not enough for themselves
*Jody	Sure. That's the thing, sometimes it's hard to survive yourself
Adil	...Breads, bills and everything, petrol and ten percent I save for them monthly
*Jody	Is that all, is that the only money your family lives on?
Adil	Yes. There is no other financials
*Jody	You'd have to be very careful wouldn't you
Adil	Yeah, yeah
*Jody	With every dollar
Adil	You have to cut.

Yet remittances are also a source of conflict. A number of times I was told of the conflict between a husband and wife over the amount of remittances to be sent to the relatives of each spouse. This is particularly troublesome for women who have married a man from a different sub-clan as they are torn between supporting relatives of their husband's clan and their own clan family members. Often, New Zealand Somalis remit to a wide range of relatives including distant cousins. One young Somali girl was phoned by a distant relative who she had never heard of asking for some money to be sent. She put the phone on hold while she asked her Aunt whether this individual was really a family member or not. Another community representative described how his wealthy father had rung him up and requested money to be remitted. According to the individual his father did not need the money but was testing his son's commitment and obedience.

In line with Vertovec's typology discussed in Chapter Two, another feature of transnationalism is the way in which transmigrants experience dual or multiple identities identifying with both their country of origin and resettlement and the way in which these are blended to produce new

hybridized identities (Vertovec, 1999). This feature is particularly evident in the relationships between parents and children where children relatively quickly take on values and behaviours of the host society which can often clash with the traditions and values upheld by the parents (Tilikainen, 2003). It is particularly striking in cases where the parent(s) may be socially isolated from wider New Zealand society whereas children are forced to interact with other children and with wider society through the school system. The situation is often exacerbated by the fact that the children are the only family members with English skills and are depended upon as interpreters. Throughout the years I was involved with the Somali community there were a number of cases where parents and children came into conflict. One central issue is that of rights. This particularly arises in the area of disciplining children. In New Zealand there is a strong notion that children have rights. This clashes with Somalia where the authority of parents is absolute and children are considered the property of their parents. In countries such as New Zealand however, children are told that they have rights and to call the police if anyone hurts them. A number of parents report that their children have learnt this very quickly and threaten to call 111 whenever they are asked to something they do not like. This is particularly a problem for female-headed households who have to discipline their children. A number of mothers with whom I worked felt that their sons were out of control and that they were unable to discipline them anymore. It has also created issues surrounding the appropriate use of force during discipline. In 2005 there was a parenting programme designed to improve awareness of a variety of discipline and parenting skills beyond that of physical punishment. According to respondents, physical punishment is widely accepted in Somalia and not policed. Yet in New Zealand the laws and values regarding punishment and the rights of children are vastly different. One parent felt that the programme was very helpful and found the concept of talking with one's children a novel one, yet one that he wanted to use with his own children as his own father had never spoken to him on a personal level.

On a more general level, parents expressed concern at the rate at which children were adopting customs and practices of New Zealanders with the concomitant loss of Somali identity and values. At the various consultation exercises I attended, a frequent request from participants was for the establishment of Somali schools or Somali language classes to ensure that their language be maintained. Some parents were concerned at how their children were refusing to speak Somali and only wanted to speak English. Somali parents also bemoaned the adoption of negative cultural practices such as swearing, bad language, smoking and mixing with the opposite gender. Young people in particular showed signs of cultural hybridization with a strong affinity for black African culture, music, dress and language. In addition, there is evidence of cultural inter-mingling of Somali youth with other refugee youth and young people from the Pacific. According to community members there have since been a few inter-marriages which have facilitated this formation of intertwined cultural identities.

While there was ample evidence of transnational activity in the form of communication, transformed cultural identity, the exchange of knowledge and ideas, frequent visits and remittances; there did

not appear to be the levels of organised political and humanitarian activity observed amongst Somalis living elsewhere (De Montclos, 2003). It is difficult to speculate why this is the case, although it may well be due to the considerable amount of effort and attention that is devoted to being involved within the Auckland Somali community coupled with the high remittance levels, suggesting that Auckland Somalis are focusing their efforts at a more individual level rather than collectively. Furthermore, while there is evidence of migration and visits to other Somalis in the diaspora, this movement does not appear to have the same regularity as noted overseas. Yet, as Levitt rightly points out, frequent movement is not the sole prerequisite for transnational activities and that transmigrants may be located in one particular place, but are deeply involved with people who are spread throughout the world (Levitt, 1996:179). This indeed appears to be the case for Auckland Somalis who, for the most part, are situated within one particular place but have strong involvements with other Somalis throughout the world.

## **Summary**

Although there are many factors that result in refugee flows, the refugee journey is one that invariably involves grief, loss, hardship and disadvantage. While many hold onto the hope of returning to their homeland or being resettled elsewhere in a safe and peaceful nation, the scars occurring from the refugee process are slow to heal and influence individuals' ability to carry out everyday life. Using narratives from Somalis I interviewed in this research, I have endeavoured to put a human face on the Somali civil war that has otherwise been documented in historical or political terms. The human cost of the civil war is indeed profound, and nearly all who I have come to know through this research have paid, and continue to pay, a great price.

Such experiences have come to influence the resettlement outcomes for Somalis in terms of employment, income, education, social support. Not only do Somalis have to deal with grief and loss from the past but also with challenges related to resettling in New Zealand. Many face discrimination and exclusion at a variety of levels which include political discourses through to the racist attitudes of local employers. Nevertheless, despite these structural constraints in opportunities to participate fully in life in New Zealand, Somali refugees are survivors. They have endured incredibly harrowing circumstances and their resilience is a resource that continues to be drawn upon during the challenges of resettling in a foreign land. The people I interviewed described various ways in which they exerted agency in order to secure a better quality of life for themselves and their families. Efforts to obtain and maintain social support are an example of this. The establishment and development of the ASCA is another example of the mobilisation of a group of refugees to meet the needs of their own community. Nearly all Auckland Somalis belong to the ASCA and have benefited from the efforts of leaders and elders who have sought to improve the lives of its members.

The resettlement process has also profoundly influenced Somali social organisation and culture particularly in terms of religion, family relationships and cultural practices, as Somalis continually seek to maintain and preserve traditions and values from the past in an ever-changing environment. Somali transnational activity is one expression of such efforts. Although residing many thousands of kilometres away, Somalis maintain close contact with family and friends scattered throughout the world by the use of communication technology such as phones, faxes and email. There is also a high degree of mobility amongst Somalis although this is tempered by the financial constraints of such mobility. The sending of remittances is one remarkable attribute of the Somali community in Auckland and is an important part of Somali identity and values.

The Auckland-based Somali population faces multiple and overlapping layers of disadvantage, factors which have been linked to the prevalence of TB. More generally both the refugee journey and the process of resettlement have a profound influence on wellbeing (and the subsequent development of TB). With this in mind, the following chapter considers the literature on refugee health and then discusses the different ways in which Auckland Somalis think about health and illness.

## Chapter 7: Somali health beliefs and experiences

*“The data and conclusions about refugee health that we have in the literature are exclusively negative. Absent is the study of refugee health or of healthy refugees. Yet refugees present perhaps the maximum example of the human capacity to survive despite the greatest of losses and assaults on human identity and dignity”  
(Muecke, 1992:520)*

Forced migration is a major life change with a profound impact on health. Not only do refugees have to deal with the upheaval of fleeing their homeland but also the difficulties of resettling in a new environment. The challenges refugees face in resettling are enormous and they frequently occupy an “often-marginal position in the new society which can create a condition of disempowerment and alienation, which in turn can affect their ability to achieve life goals in a foreign land” (Danso, 2001:3). This section aims to set the context for later discussion of specific TB experiences by considering the overall health and disease experiences of Somalis living in Auckland. Firstly, I offer an overview of the physical and mental health issues faced by refugees before exploring the ways in which the process of resettlement influences health. I then consider these issues from the perspectives of Somalis who were interviewed in the course of this research. Where applicable, I endeavour to highlight the different ways in which Somalis actively seek to enhance and maintain wellbeing. Narratives will be used throughout the section to consider participants’ experiences and views on these topics. I then shift my attention to consider Somali health beliefs and practices in order to address Aim Three. I argue that Somali health beliefs and practices are heavily influenced by Islamic teachings and Western medicine. I also examine the relationship and interaction between these models using accounts of the everyday health experiences of Somalis. My contention is that gaining a greater understanding of Somali beliefs about health and disease aids in understanding the ways in which individuals experience TB. This notion will be further explored in Chapter Eight.

### Refugee health

Due to the often-horrific experiences in their homeland and the challenges of resettlement, refugees have some of the worst health outcomes in society. Asylum seekers are often at an even greater disadvantage than refugees due to the stress of the asylum-seeking process and limited access to health and social services. In the United Kingdom, studies have shown that the health needs of asylum seekers are similar to the health needs of deprived or excluded groups including ethnic minorities (Bardsley and Storkey, 2000). In Australia, asylum seekers have also been

identified as one of the most disadvantaged groups in Australia in terms of access to affordable health care (Smith, 2000-2001:21). Closer to home, the Health Needs Assessment Report compiled in 2001 by the Auckland District Health Board describes the health status and health needs of refugee peoples (Auckland District Health Board, 2001). Key health indicators for the country of origin of many of New Zealand's refugees are very poor compared to the national population. For example life expectancy at birth for the New Zealand population is 77.8 years while for people from Ethiopia, Afghanistan and Somalia the figure reduces to 43.3, 45.5 and 47 years respectively.

In New Zealand, refugees have particularly high and complex needs in part due to the fact that the nation specifically creates places on the refugee quota for high-need groups such as women at risk, refugees with high medical needs and/or a disability and UNHCR priority referrals (n=600). Other countries such as the United States actively refuse entry to refugees with particular medical conditions such as syphilis, leprosy, and HIV (Adams and Assefi, 2002). In addition to quota refugees, there are also asylum seekers who apply for refugee status at the border when they arrive or at some later time. Health screening for asylum seekers is voluntary with evidence suggesting only one-third of asylum seekers undergo a health screen (Hobbs et al., 2002). One reason for this figure may be that asylum seekers fear that the results of their screening may jeopardise their application for refugee status. The third category is family reunification refugees who are required to undergo medical screening prior to immigration. However the reliability of this screening has been contested as, in some countries, favourable test results can be 'purchased' (Auckland District Health Board, 2001).

Despite the three different immigration categories, commentators suggest there is good evidence that quota refugees, asylum seekers and family reunion refugees have similar health status as all three groups come from similar countries (Solomon, 1999; Smith, 2000-2001). Yet it is important to remember that health experiences amongst refugees are diverse. A number of commentators have begun to resist the assertion that refugees universally have ill-health and have suggested that the process of labelling refugees as such can reinforce and perpetuate disadvantage. Van Ewijk and Grifhorst (1997) suggest that refugees have been constructed as the contagious and diseased 'other'; a threat to public health that needs to be 'treated'. Janice Kopinak's (1999) study of the health of Bosnian refugees in Canada, sought to break away from the assumption that refugees universally have poor health status. Using a definition of health utilised by the participants themselves, Kopinak found that the participants were in good health despite the health challenges posed through the process of war and resettlement.

### *Physical health*

A number of studies have investigated the physical health status of refugees upon arrival and have produced varying results. Most studies paint a picture of overwhelming rates of disease (Uba,

1992; Sinnerbrink, Silove and Manicavasagar, 1996), mirroring rates of disease in the home country, although circumstances during the refugee process can modify this such as the conditions in refugee camps.

In New Zealand research by Martin Reeve at the Mangere Refugee Reception Centre or MRRC, high rates of health problems among newly-arrived quota refugees were found (Reeve, 1997). Seventy percent of the 687 refugees screened in the year ending June 1996 required referral for further assessment or treatment to at least one secondary health care service. The findings of this study were,

- 42% of refugees infected with one or more intestinal parasites
- 54% of refugees experienced iron deficiency to varying degrees.
- 1.7% of refugees tested positive for HIV
- 13% reported experiencing torture, imprisonment, beating in country of origin
- 7% referred for further psychological services

(Auckland District Health Board, 2001:216)

Another study also demonstrated high rates of infectious diseases in refugee peoples. Research by Hobbs et al. (2002) into the health status of asylum seekers in Auckland found that during the 1999–2000 period, approximately 900 asylum seekers received health screening from Auckland Regional Public Health. The prevalence of TB amongst those who were screened was 1,333/100,000 while the prevalence of active TB in the New Zealand general population was 12.4/100,000 in 1999 and 9.9/100,000 in 2000. Just over one percent of screened asylum seekers tested positive for HIV.

A review of health screening results of the 2,992 refugees who were screened at MRRC between 1995 and 1999 revealed that 35% were being treated or monitored for TB/TBI, 26% had prior experience of malaria, 2% with HIV infection and 21.9% with schistosomiasis in addition to the presence of chronic conditions such as hypertension and diabetes (McLeod and Reeve, 2005). A study conducted in the Auckland region revealed that children from refugee and migrant backgrounds are at risk for vitamin D deficient rickets (Blok et al., 2000). Other issues include anaemia (7%), iron deficiency (22%), being underweight (14.5%) and overweight (28.2%) (Reeve, 2004).

In the evaluation of the Muslim Women's Swimming programme held in Mt Roskill since 2004, musculo-skeletal concerns were the main health issue identified by those interviewed. This includes muscle and joint pain in the shoulder, knee, back and neck. Other common health concerns related to mental health, specifically depression, stress and 'too much thinking' followed by social health concerns such as isolation, boredom and unemployment.

In another Auckland study of issues relating to refugee health (Lawrence, 2003), one general practitioner described how refugees face long-standing, multiple medical issues and partially attributed this to underlying stress. Using rhinitis and conjunctivitis as an example, this practitioner stated:

*"It seems so intractable. They just can't seem to get rid of it..... I mean you know it just goes on and on and on. And whether that's a reflection of their sort of general stress levels and irritability....some of the time that's what the problem is. You get these problems that seem to go on and on and on and on and I think it's more a reflection of an underlying stress level more than anything"* (Lawrence, 2003:15)

In many cases, these physical manifestations of stress and bodily pain are a reflection of the profound sadness and psychological distress experienced by refugees.

## ***Mental health***

In addition to numerous physical health issues, studies have revealed that refugees have high mental health needs (Gerritsen et al., 2006). Many refugees are exposed to torture, violence and rape which can result in significant psychological distress. Sinnerbrink et al. (1997) interviewed 40 asylum seekers attending the Asylum Seekers Centre in Sydney, 1994. Seventy-eight percent reported exposure to at least one major trauma prior to migration with the most common experiences being murder of a family member or friend, being close to death and forced separation from family members. Keyes (2000) reviewed 12 published papers on the subject of refugees and their mental health status. All of the articles concluded that refugees have negative mental health status, suffering from conditions such as depression, anxiety, posttraumatic stress disorder, psychosis and dissociation. Since 1984, the refugee mental health focus has shifted to post traumatic stress disorder (PTSD) (Muecke, 1992). According to Adams and Assefi (2002) "PTSD describes the patient's recurrent and painful re-experiencing of the event, emotional numbing and withdrawal, hyperarousal, and avoidance of trauma-related memories and situations" (Adams and Assefi, 2002:214). Mollica et al. (1999) found that between 18-53% of Bosnian refugees in treatment were diagnosed with PTSD.

There are however concerns at the ways in which psychological distress is measured and reported. Keyes (2000) argues that mental health diagnostic tools fail to incorporate cultural dimensions of health which influence the responses refugees make and the meanings attached to these responses. Keyes points out that within the Western medical framework, refugees may appear to be exhibiting symptoms of psychological distress yet these symptoms may in fact be "forms of resilience in adapting to a new environment, signs of grief, or natural parts of the mourning process" (Keyes, 2000:407).

Zarowsky (2004) challenges the widespread application of diagnoses such as PTSD to capture the distress and trauma experienced by refugees. Zarowsky argues for the need to consider distress and trauma in the socio-political context in which it occurs. Based on fieldwork with Somalis in Ethiopia she contends that Somalis' primary concerns were for justice, survival and being able to live a decent life. While the majority of her participants had experienced the loss of close friends and relatives, they attributed the cause of their suffering to the inability to maintain an adequate livelihood and the injustice of what had happened to them.

Summerfield (1999) suggests that the PTSD label 'pigeonholes' refugees rather than exploring their perceptions and interpretations of distress and their choice of treatment. He suggests that refugees typically feel that social and economic assistance would improve their situation rather than psychological help. Others have critiqued the use of the PTSD label as it medicalises what some commentators see as completely 'normal' reactions to trauma and war. Eisenbruch (1991) suggests that 'cultural bereavement' may be a more applicable 'diagnosis' for those whose "condition may be a sign of normal, even constructive, rehabilitation from devastatingly traumatic experiences" (Eisenbruch, 1991:141).

In New Zealand there are few studies of the mental health needs of refugees. In part this is due to the fact official mental health data is only a partial snapshot of the true burden of mental health and is often only analysed in terms of Maori, non-Maori and Pacific people (Abbot, 1997). Nevertheless, in comparison with migrant groups, refugees have poorer resettlement and mental health outcomes. For instance, Pernice and Brook (1994) assessed levels of psychological disturbance among community samples of adult Khmer, Lao and Vietnamese refugees, Pacific and British immigrants to New Zealand. Clinically significant levels of depression were found in 29 percent of the refugee group, 18 percent of the Pacific migrants and 8 percent of the British migrants. Locally, a 1999 study at MRRC found that 20 percent of refugees had suffered significant to severe physical abuse. About 14 percent reported significant psychological symptoms and seven percent were diagnosed as having post traumatic stress disorder (PTSD) (Reeve, 1997). Another study of asylum seekers in Auckland reported that 38.4 percent had symptoms or history of psychological illness (Hobbs et al., 2002). McLeod and Reeve (2005) found that psychological issues are particularly prevalent, especially amongst asylum seekers whose immigration status is not confirmed.

In one study conducted by an elder of the Auckland Somali Community, widespread depression was reported among Somalis resettled in New Zealand. Families find it extremely difficult to adjust to their changed circumstances and prolonged unemployment. Family breakdown is an increasing concern for the Somali community as families become trapped in a cycle of social and economic exclusion. Without timely intervention this cycle will greatly affect social outcomes for future generations of Somalis living in New Zealand (Auckland Somali Community Association, 2006).

In research exploring barriers experienced by refugees in accessing New Zealand health services, differing cultural understandings of health and illness were particularly evident in terms of mental health (Lawrence, 2003). Medical practitioners noted how refugees commonly present with somatic complaints such as body ache, tingling and one-sided body pain. As one doctor commented:

*“You know quite commonly you’ll get a one-sided body pain which really automatically you know sort of straight away isn’t a physical problem. It’s a reflection of something, stress or mental” (Lawrence, 2003:15)*

In addition, Lawrence notes how ideas held by refugees about mental health are quite different from the Western medical model, resulting in distinct challenges for health providers. Unlike in Western culture, there are no shades of grey between being mentally sound or psychiatrically unwell. Those with relatively minor mental health issues are put in the highly stigmatised latter category. Furthermore, in some refugee groups, mental health issues such as depression tend not to be medicalised (Karasz, 2005). There often is no medical system of counselling for mental health issues (though there is social counselling between the family and elders for family problems). When asked if refugees accepted counselling as a valid form of treatment for mental health issues, one participant laughed and said:

*“That’s funny....because people in our country, just crazy people is going to counselling so we feel, they tell us to see counsellor if crazy” (Lawrence, 2003:12)*

This situation obviously places health providers in New Zealand in a serious predicament given that mental health is one of the main health issues faced by refugees. Some clients refuse to accept they are ‘sick’ and feel their symptoms are not abnormal. Others may attend one appointment and never return while others withhold information from their counsellor.

One health initiative in Auckland that was initially designed to improve levels of physical activity has delivered unexpected mental health gains. In an evaluation of health needs at the beginning of the Muslim Women’s Swimming Programme many women experienced a variety of mental health concerns including depression, anxiety and a sense of loneliness and isolation. After participating in the programme for a year, women identified improvements in their mental health including a greater sense of happiness, relaxation and reduced stress levels. One individual noted that after attending the swimming programme, she slept through the whole night without nightmares for the first time in ten years (Lawrence, 2005b).

## **Resettlement and health**

While there is a wealth of literature detailing the high health needs of refugees, the “post-migration literature of geography on the health of refugees and their integration processes is scant” (Warfa et

al., 2006:503). In addition to existing research on the physical and psychological health status of refugees, commentators are increasingly calling for research on the health impacts of the resettlement process itself (Watters, 2001). Sinnerbrink et al. (1997) found that difficulties with the asylum-seeking process caused the greatest stress for asylum-seekers: over 80% were fearful about being sent back to their country of origin. Other resettlement issues included concerns about processing of refugee applications, separation from family, unemployment and accessing health care.

In a study conducted with nine refugee community representatives in Auckland, one theme that emerged was that health outcomes and a sense of wellbeing for new settlers were not so much determined by traditional medical inputs, but on wider resettlement factors such as immigration, employment and housing (Lawrence, 2003). One individual stated:

*“A lot of what I’ve observed has been like depression, anxiety, stress from actual resettlement in New Zealand” (Lawrence, 2003:10)*

Kizito (2001) concurs with the view that resettlement issues pose significant problems for health and wellbeing and suggests that asylum seekers face considerably more stress upon arrival in New Zealand due to the procedure required in order to apply for refugee status, the uncertainty of such an application, length of time required before claim outcome is known, lack of awareness of entitlements/lack of access to government assistance and fear of deportation. These stressors can not only aggravate existing symptoms but also lead to mental ill-health symptoms long after resettlement in New Zealand (Anstiss, 2001). Pernice and Brook (1996) investigated the mental health status of three refugee/immigrant groups in New Zealand. They found that demographic variables such as age, gender, educational level and marital status had little bearing on mental health status while resettlement issues such as discrimination, unemployment/underemployment and having a limited social network have a critical influence on mental health wellbeing. Discrimination was indicated as the key factor associated with high levels of anxiety and depression. Unemployment is also an important factor influencing levels of anxiety. Forty-three percent of refugees, 40% of Pacific Island immigrants and 80% of British immigrants to NZ who experienced considerable emotional distress were unemployed (Pernice and Brook, 1996:517).

I now shift attention from general refugee health issues to the specific health experiences of Somalis living in Auckland, New Zealand.

## Being healthy in New Zealand: Somali health concerns in Auckland, New Zealand

*Yeah. Health means too much for me, especially because if you are not healthy you are not, not existing. You cannot do anything...so you are mentally, physically you are not existing if you are not healthy. So healthy is the first priority of human being you know. That's why it's too much (Fakhir)*

As the preceding section indicates, refugees have high and complex health needs. This assertion was borne out in the range of health issues cited by participants I interviewed during the course of my research. Health issues range from problems with joints and muscles through to heart, respiratory, neurological and gynaecological issues. Some of the most common complaints were musculo-skeletal conditions, similarly documented by Lawrence (2005a). These, affecting women in particular, occurred in a range of places most notably joints and muscles in the back, neck, knees, shoulders and legs. Many attributed this pain to arthritis or rheumatism, although one interpreter confided that she had been present when a doctor had ruled out such diagnoses. Nevertheless, women ascribed bodily pains to such syndromes. This may be the case as “Somali lay models of health more typically expressed in terms of bodily complaint than emotional or mental distress” (Warfa et al., 2006:512). Regardless of causation, this bodily pain was a ‘thorn in the side’ for many women, restricting mobility and movement. This is one reason why so many women experienced benefits from participating in the swimming programme as exercising reduces stress, promotes restful sleep, improved circulation and mobility of joints and muscles (Lawrence, 2005b).

A number of participants also face chronic conditions including diabetes, heart problems and elevated blood pressure. Although refugees from developing nations are often associated with infectious disease, many also have chronic conditions (Palinkas et al., 2003). Diabetes was a frequently mentioned condition that some individuals struggle to keep under control. Poor nutrition and lack of exercise is commonly linked to the development of such conditions; these are illnesses which are most frequently associated by Somalis with life in New Zealand.

When discussing the health issues faced by Somalis living in Auckland, participants would frequently talk about New Zealand as an intrinsically unhealthy place compared with the health promoting properties of their homeland. For instance one participant noticed that prior to coming to New Zealand her health had been good but that since arrival she became unwell:

*Jody	Thinking back to when...before you got, before you came to Mangere, how has it changed your views on illness, sickness?
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Abir	I came to New Zealand, yeah I started to get sick, before I didn't notice that I had it. I was fine before...
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More often than not, such comparisons centred around climatic differences which have a range of flow-on effects in terms of health. An excerpt from one interview transcript demonstrates this:

Ulfah	In Africa 100, climate is good, 100 percent in Somalia or Africa, is good climate, no sick, for ever I am not sick my country.
*Jody	Really?
Ulfah	No. Really. No go doctor, no infection not anything. I am come to New Zealand maybe some time now...this muscle is sore, many many sore, see my doctor this is Ulfah muscle sick. Go in some scientist, Auckland hospital admission for sciatica because many years I am living in New Zealand.

In Somalia, the climate was ascribed with a number of health-promoting properties. Although there is climatic variation between different parts of the country, the weather was very hot and sunny for most of the year. One outcome of Somalia's hot climate is that it causes people to sweat. This is seen as a necessary and healthy thing as the quote below indicates:

Husniyah	Yes sweating is good because it releases toxic. In Somalia we used to walk everywhere, walk to the market everyday, except the rich people who had cars, but everyone used to walk. It used to make you feel healthier and lighter. Here there is a supermarket where everyone goes by car once a week only.
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South Asian women interviewed by Dyck (2006) similarly constructed the activities of daily village life in India as being a healthy and natural form of exercise.

For a number of participants, sweating is seen as one way of eliminating harmful impurities in the body. In addition, another person felt that sweating helped burn off unhealthy food types. For instance:

*Jody	What things can you do to keep healthy?
Wardah	Exercise and don't eat junk food. Sweat out fat and sugar. Fat and sugar are destroyed by body heat in Somalia - in New Zealand it just sits in your body.

New Zealand's climate in contrast, is characterised in entirely negative terms with numerous detrimental health impacts:

*Jody	How do you think the climate, the weather, what does that do to <i>Caafimaad</i> ? [health]
Ulfah	<i>Caafimaad</i> , yes. Weather in New Zealand 100 times is change. Weather in New Zealand is 100 times a day is change. Because 24 hours and one minute cloudy, one minute cold, one minute summer, one minute winter, 24 hours change. Climate, bad climate really, really is bad climate
*Jody	Is it bad for your health?
Ulfah	Yeah. Bad yeah for health, for children, or for old women, me too, because sometimes, this morning, so cold, oh no go toilet. Sometimes I am going in park, you know park because weather no good really in New Zealand. Maybe Australia weather is good and Africa is good. Even in Fiji weather is good. Hotter, hotter sunnier. But New Zealand I don't understand.
*Jody	<i>Caafimaad</i>
Ulfah	Yeah, yeah. <i>Caafimaad</i> bad. You coming coughing. You coming asthma. Some people in rash, the rash, sometimes children sick no go school today, the 'flu, the closed nose it is changed in 24 hours. No good health yes, no good health, no <i>caafimaad</i> .

As the above account indicates, the variability of weather conditions in New Zealand is linked with ill-health. One focus group respondent stated that because temperatures vary so greatly, body temperature goes up and down frequently which is not good for health. Other respondents suggested that changing weather can make people sick causing illnesses such as flu, hay fever, tonsillitis, rheumatism, sore joints, knee pain, dry skin, headaches, asthma, allergies, blood pressure problems and osteoporosis. One participant stated that the climate caused urine problems amongst the elderly as they were too cold to get out of bed at night to use the toilet meaning that the urine was remaining in the body and thus causing contamination.

Not only is the New Zealand climate variable, but much colder than that of Somalia. As the following account depicts, some Somalis feel that the skin is a porous layer through which the weather can penetrate and thus make you unwell, a similar finding to Helman (1991). As one interview transcript reveals:

*Jody	What about the weather, how do Somali people think that affects your health?
Husniyah	The cold, sometimes they think that the cold makes them sick. It can get in their lungs and make water and make them sick. One time I went swimming with my mother and sisters. When we left the pool it was quite windy. That night mum became sick and after that she refused to go swimming ever again. She thought that because she is old, the wind got inside her pores and made her sick.

Not only is there the idea that the weather can cause illnesses within the body but that the climate itself carries pathogens. For instance when asked about the cause of influenza, one focus group participant stated:

Shakirah	Caused by the weather which carries viruses or bacteria. Easy to transfer...
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This idea was echoed by a number of other participants who also believed that the weather transfers viruses.

The lack of sunshine in New Zealand is also a problem. One participant was diagnosed with rickets/Vitamin D deficiency. This is a common health concern amongst refugees with 80% of children and 98% of women screened at MRRC found to be suffering from rickets/vitamin D deficiency (Reeve, 2004):

*Jody	So tell me about the last time you felt unwell?
Akif	I felt weakness, feverish aches, and bones. Had blood and urine test. Vitamin D low. One of the causes is because Somalis are used to bright sun. Not enough sun in New Zealand. Because where I work there is not much sun.
*Jody	What did you suspect your illness might be?
Akif	I knew I wasn't having enough sun. I didn't know it was vitamin D though. Two months of vitamins. Also calcium.

There was also the idea that because the climate in New Zealand is so different to that of their homeland, that the body needs an adjustment period:

*Jody	How does the climate affect health?
Rashidah	If your body is not familiar with the climate you can get the 'flu. Your body needs to get used to it.

Another participant described how her body was unfamiliar with the cold:

*Jody	How does the climate affect health?
Almas	If you are born in a cold country your body is used to it. Same with a hot country. You need to wear the right clothes. When I came to New Zealand I didn't know what clothes to wear. I felt cold and unhappy. I saw other people wearing few clothes but didn't realise they had warm singlets underneath. I was too cold to do the housework.

Participants also repeatedly claimed that the Somali climate facilitates a healthy lifestyle. Back in Somalia people would walk great distances on an everyday basis including daily shopping at the market and children walking to school. The climate was felt to be supportive of good health and healthy lifestyles. This is commented on by one community member:

Fakhir	Yeah, if you go to one kilometre it's enough for you. So the climate is supportive so people, because we don't have these common diseases in Western, New Zealand, for example you have blood pressure, diabetes something like that, not common in Somalia, really, yeah. People are fit and even they not use the diet, particularly they are fit because the climate is very supportive.
*Jody	Do you think that's a large part due to the climate?
Fakhir	Yeah, yeah, because every body has his own exercise. Children when they go to the school they walk, the women are going to collect something from the market they are walking. So they are always sweating so they get the exercise. So around Somalia especially in the capital Mogadishu you don't even see physical clubs something like that, more than one or two, people they don't need.
*Jody	They don't need?
Fakhir	Not really, they have got their own natural physical [exercise].

In New Zealand however, participants noted that most people used cars and were not engaging in any form of physical exertion. The diet of Somalis here in New Zealand is also constructed as being less healthy of that of Somalia. This is due to consumption of foods high in sugar, fat and preservatives. One individual commented:

Bayan	People don't walk, don't sweat and eat lots of sugar. New Zealand food got sugar and fat.
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Similar to the findings of Australian research (Burns, 2004), a nutrition health promotion programme conducted with Auckland Somalis found that many had adopted New Zealand dietary patterns that tend to be high in fat and low in fruits and vegetables. This contributed to the occurrence of anaemia, constipation, poor dental health, allergies, diabetes, obesity and rates of cardiovascular problems amongst the Somali community (Lawrence, 2005d).

When asked about what individuals did to maintain good health, food was universally mentioned. Dyck (2006) notes that South Asian immigrant women she interviewed also considered healthy food as a prerequisite for living a health life. Somalis I interviewed advocated regular consumption of fruit, vegetables, milk and meat in order to ensure good health. Although people knew this, this did not always occur as described below:

*Jody	So what things do you do to keep your body healthy?
Ishraq	To eat more of you know food.
*Jody	What kinds of food?
Ishraq	Vegetarian, fruits and meats and keep you like strong, the body strong, to be strong. Yeah.
*Jody	So to keep yourself healthy you eat fruit and vegetables?
Ishraq	I'm not, I'm not eating. My food is only rice and pasta but I don't like fruit, vegetable and I'm not eating but my grandmother told me if you didn't eat like vegetable or fruit you're going to be dead because your body is not stronger. I'm not eat fruits, maybe fruits sometimes like one a month, I'm going to eat like one lemon only. My favourite thing is Coke.

One issue that was raised by participants and nutritionists alike is the Somali love of meat. This is particularly true for men who tend to consume large amounts of meat. One community member described how his ideal meal was one that consisted solely of meat. He was not sure why this was the case but did state that back in Somalia consuming meat was a sign of wealth. Camel meat was the meat of choice while fish was disdained as food for poor people.

A nutrition-related issue that is very widespread amongst the Somali community is that of constipation. This everyday issue is an interesting one as it also highlights important points about how Somalis think their bodies work. I was greatly surprised at the ease with which this condition was discussed within public settings with no sense of shame or embarrassment. In one conversation I had with a health worker who had worked extensively within the Somali community, she recounted how she was talking about feeling unwell only to have a Somali male enquire whether she was constipated or not! When I asked about the main health concerns amongst the community, constipation was frequently cited, as demonstrated in the narrative below:

*Jody	What would you say are the most common ones? [health issues]
Ghaniyah	Really the most common in my community is constipation and that is created for not eating, you know, not eating vegetables or not drinking plain water or something. They always say constipation. I have this myself.
*Jody	And what do you think, why do you think it is so common?
Ghaniyah	Mostly they because the area they live now and their home is different and their home is tropical, they drink a lot of water. Here you can't drink unless you use like a medication. The water, you don't need to drink cold water but in my home you need always to drink a lot of water because the water you need yourself. You perspire you losing a lot of fluid and then you need water to drink and it doesn't make, you know hard for constipation. But here it's quite cold and not going to walk. You can walk and go everywhere in Somalia, you know, and everytime you can go but here unless you have a transport you can't go somewhere and also

	walking is an exercise, the best exercise you can do is walking and here they don't walk so much.
*Jody	Why do you think that is?
Ghaniyah	Because in New Zealand always raining and sometimes the area you want is far away from the place you want, you need vehicle to go with and that makes you know obstacle to walk freely because you can go friend's house which is not far away but maybe ten minutes walk is quite good again back ten minutes walk and it will be twenty minutes and every day twenty minutes or more if you go is quite good.

This quote is interesting as it highlights a number of issues discussed in this section. Firstly the narrative indicates the way in which the climate in Somalia is attributed to healthy behaviours such as drinking water. In contrast, because of New Zealand's different climate, individuals tend not to drink as much water which in turn can contribute to constipation as the lack of liquid can harden stools. The lifestyle in New Zealand is also portrayed as being less healthy than that of Somalia due to the rain and physical accessibility of the city which inhibits physical activity. The other interesting point is the way in which the respondent felt comfortable to acknowledge they have constipation within a group setting. I did not observe such openness in terms of any other health concern.

For many Somalis, constipation is believed to make you feel 'dull' and cause a number of health problems including headaches, influenza and fever. At one of the focus groups I asked about what people believed caused headaches. One respondent replied:

Wardah	Constipation causes headaches. Need to get medicine or eat extra. If you say you have a headache people assume it's because of constipation. Causes by thinking a lot, hereditary reasons, dizziness, nausea or eye pain. You need to rest a lot, eat, drink lots of water and take aspirin.
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Being constipated was also seen as a health concern as it pollutes the body:

Ghaniyah	It can cause because if you constipated always it will affect your healthy because you keep all, everything you eat and you need the waste to go. If you keep your waste it will pollute your body and then your health will affect.
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This quote highlights the way in which Somalis tend to associate good health with 'flow'. In this context, an interrupted flow of waste is seen to pollute the body, something that was also raised in terms of elderly people not going to the toilet during the night and thus retaining contaminated urine in their body. Ideas about flow also arose when discussing sweating and the way in which it

enables the body to release toxins and burn up food. Another participant also advocated going to the toilet a lot in order to “reduce the ‘flu by getting it out of the body” (Wardah).

In order to remedy constipation, individuals spoke about consuming lots of vegetables and water and avoiding heavy foods such as meat, milk and Somali bread. Although using laxatives is quite common, one person felt it was not helpful as one can become reliant on them.

## *Mental health*

While Somalis discussed a wide range of physical health issues, during the course of my research it became apparent to me that the greatest health issue amongst the community relates to mental health. This has been documented internationally amongst other Somali populations (Palinkas et al., 2003; McCrone et al., 2005). Yet as this section discusses, mental health is a complex area as it is based on a Western biomedical construct premised on the idea of a mind/body dualism. Such a concept does not feature within Somali health and illness traditions (Warfa et al., 2006). As a result there is considerable dissonance between the explanatory models employed by Somalis and New Zealand health practitioners alike (Kleinman, 1987) when tackling the burden of psychological distress amongst Auckland Somalis.

A number of individuals I encountered had experienced profound sadness. Although I am not medically qualified to make such diagnoses, it appeared that emotional and mental health issues affected an extremely high proportion of the community. Such experiences ranged in severity with most attempting to manage their problems themselves although a few individuals required hospitalisation. I remember one occasion where I was scheduled to have an interview with a woman and arrived at her home to find the house in utter disarray. The participant was wandering from room to room, crying out and murmuring to herself, clearly in a state of distress. An ambulance arrived shortly after her seven-year old child had dialled 111 complaining of heart problems. The little girl had tried to get an appointment at her GP but there were no vacancies. As she had been admitted to Starship Children’s Hospital on a previous occasion she rang emergency services. When asked why she had done this she replied that they had been kind to her in the past. What was interesting is that the child had not shared her health concerns with her mother who was unaware of her complaint or efforts to seek medical care. This family was clearly under considerable stress with the mother sole-parenting a large number of children.

The suggestion that Somalis experience a high burden of mental illness was supported by a number of community members, one of whom stated:

Fakhir	Most of our society or other community they have a lot of stresses, depressions because they are, they lost everything behind them so they come to a new country, new environment, new climate, new society, so even though they are
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physically health but emotionally or mentally they may affect so it's very difficult to understand whether that person healthy or not, so me myself, I cannot say now I am healthy because still I am missing something.

Yet like other population groups in New Zealand, mental ill-health remains highly stigmatised (Jackson, 2006). As has been discussed in the previous section, Somalis along with other refugee groups originate from societies that do not recognise concepts of 'mental illness' and treatment such as counselling, apart from at the severe end of the spectrum in terms of psychiatric asylums (Mohamed, 1999; Guerin et al., 2004a). According to Warfa et al. "Culturally determined ways of talking about health may also explain some reluctance to speak freely about mental health problems, not necessarily because respondents consciously avoided discussing mental illness, but because there was an absence of language or concepts in Somali culture that formulate mental distress as a health problem worthy of seeking treatment from health care agencies" (Warfa et al., 2006:512).

It is important to acknowledge the points raised by those who have critiqued the way in which psychological trauma and distress have been overly-medicalised, ignoring the social, political and economic contexts in which it occurs. For many individuals, ongoing grief, sadness and loneliness are a dominant part of their life. While this can be partially attributed to experiences from the past, these issues are compounded by difficulties in resettlement (as elaborated upon in the preceding section) which are firmly rooted in social, economic and political issues. Of the people I encountered experiencing profound distress, only a small handful were currently receiving pharmacological treatment for their complaints with the majority attempting to manage the distress by themselves or use the Koran to assist (as will be discussed in the next section).

When asked about the main health issues faced by the Somali community, one focus group participant spoke about the range of health problems Somalis experience and connected it to wider resettlement issues as depicted below:

Almas	Bone problems, osteoporosis, muscle pain, neck pain, shoulder pain, sore knees, back pain, heartburn. Sometimes the people think too much and that causes illness. People thinking of back home and not happy. They realise they are not like people here. Don't have family and friends here. They miss where they are born and their neighbourhood. Makes them unstable. We're physically here but not mentally here. We do try to make ourselves happy but because we don't speak the language, know the rules we are scared to do anything. Scared about the neighbours and what they might think. We feel very different in every way. Different food and culture. We have to ask about everything – "Is this Ok, how do I do this?" We don't feel comfortable in ourselves. In my country all those things
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are easy. I have my family. Everything back home was very easy. All those things we don't have here so it makes us unhealthy.

This quote touches on a number of themes that have been identified such as physical health problems, lack of social support and discrimination but also raises the idea that most Somalis have to deal with the enormous amount of change with many finding it quite an uncomfortable and overwhelming position to be in. Everything is different including the language, neighbours, food, housing and culture. The participant above links this sense of discomfort to health. This idea was also raised by another participant during a group discussion, as they explain:

Kadar	Also when you change your, your way of living, in any way, affects your diet, the food you used to eat, if you change it at least, you feel something different again. Yeah. Even emotionally like Nuwwarrah and Fakhir said. It's when you change from what you used to do, you feel maybe you're not yourself or not very comfortable
*Jody	Especially so many changes
Kadar	So many changes
Fakhir	So many changes
Akram	Those are the physical. For psychological, mental health, you are not in worry, but never happen, you always you have some worry.

As this exchange demonstrates, Somalis are being forced to deal with many changes at the same time. The participants also touch upon how worry has a big effect on mental health, signalling how many people worry about their families back in Somalia and uncertainty over immigration status. One medical practitioner interviewed by Lawrence (2003) noted a direct link between the health status of asylum seekers and their bid to gain refugee status:

*"You know if they come up for an immigration review and it gets declined, they deteriorate. And then they, you know if they get their immigration status resolved then they are perfectly alright after that - straight away just about" (Lawrence, 2003:11).*

Of the individuals who disclosed their immigration status to me, most were quota refugees or family reunion refugees. There were, however, a number who had arrived in New Zealand under a false identity, a situation that became incredibly complex and stressful to unravel. There was only one individual who recounted how they had arrived in New Zealand with the assistance of a smuggler. The journey to New Zealand using forged documentation was a very risky and stressful trip. New Zealand was selected as being a less risky option than the United States which was the individual's preferred destination. After arriving at the airport, this person applied for refugee status. The application took over two years to be heard and was a stressful time particularly through the appeal

process. Obtaining refugee status was of utmost importance and it was not until this was achieved that this person could truly establish themselves, feel secure and carry on with life.

One quest that was common to nearly every Somali I encountered during my research was that of family reunification. Under immigration provisions, refugees are able to apply to have direct family members brought to New Zealand. This has become an all-consuming quest in many cases as for Somalis, the absence of family means that wellbeing is not possible.

One individual recounted how he was endeavouring to bring his wife and children over to New Zealand. He has been battling immigration officials for over five years. Another community member described how only he was given a place on the refugee quota as his wife and children were away from the camp at the time UNHCR officials made their official visits. As a result, he was the only one who was resettled in New Zealand.

Coping with family separation is a difficult task. As the transcript below indicates, the only way this individual manages is through hope – hoping that they will one day be reunited:

*Jody	How many children do you have?
Akif	Four
*Jody	How old are they?
Akif	The eldest is 12
*Jody	It must be hard being so far away from them
Akif	It is very hard. Very tough
*Jody	How do you cope?
Akif	Hope. I hope we will be reunited.

The costs of such separation are high and have a profound influence on wellbeing and the ability to cope in a new environment. Most of the Somalis I interviewed had a pervasive sense of sadness due to the fact that family members were still suffering back home in Somalia. Families must also bear a financial cost. Each year, the New Zealand Immigration Service organises a lottery of family reunion places which costs \$70 to enter each year although one participant stated that the worst thing about this was the loss of hope. One individual who successfully sponsored ten relatives to New Zealand was required to pay \$1,400 plus the costs of medical and police checks and flights. In addition, this person was required to be solely responsible for his relatives' welfare for the first few years of settlement as they had restricted eligibility for social support services and entitlements.

One of the most common health impacts of family separation is that of worry. Many participants described how they were greatly worried about their relatives and felt that 'too much thinking' had a detrimental influence on health. Time and time again worry was linked with poor health as noted by one community representative:

Akram	...you always you have some worry especially the nervous people who came to visa, get the new life, new culture, new way of life. Very stressful...
*Jody	And how do people deal with that stress, that worry, what do people do?
Fakhir	Yeah yeah, mostly they are worrying [about] their families, or their relatives back in Somalia or any other countries so what they do is always contact, contact their families back home
*Jody	So contact is one way to make worry less of a problem?
All	Yes
Fakhir	Even though they are far from them if they talk to them. At least they know what is going on there, so then they maybe get a relief, yeah, yeah, it's more clear.

As the above account demonstrates, frequent contact is one way of alleviating worry. Another participant listens to religious tapes to help alleviate her worry and anxiety.

One individual strongly agreed that worry damages health and described the hardships he has faced being isolated from his family and how worrying about them had influenced his health:

*Jody	How do you think worry damages your health? What does worry do to you?
Adil	Personally, worry damages my health. It makes me...it really affects me, getting worried, like without family, like parents, mother, it quite affected me. I think it's one of the things.
*Jody	So do you think your life will change when your family comes?
Adil	I think it will definitely be changed yeah, it will be different because you will feel more secure I think so, yeah, it's too hard to be apart. Because when I just remember when I was there, with family around, friends that we grow up together, you know a bit more...that kind of stuff.

These ideas are supported by another person who recounted:

*Jody	What things do you think damage your health?
Hiyam	When person has problems, left children behind, worry about relatives. Now I'm still new, I'm struggling to settle. Sometimes people get mental illness.

As will be discussed at greater length in Chapter Eight, one participant even linked her worry with the subsequent development of TB.

As the foregoing account indicates, stress and worry due to a lack of social support has taken a toll on her health. In addition her narrative demonstrates the extent to which some Somalis were

wealthy in their homeland and live with continual regret that they have lost the assets and resources they formerly enjoyed. For Somalis, material resources are particularly important for overall wellbeing (Zarowsky, 2004) with many respondents expressing ongoing sadness that they no longer had the income and assets (cars, houses, clothing and jewellery) they formerly enjoyed. Such concerns with material resources are compounded by the difficulties many Somalis have in finding a job in NZ, let alone meaningful employment. The difficulties faced by refugees in gaining meaningful employment in a competitive labour market have a considerable effect on confidence and psychological wellbeing, as summarised by one participant in earlier research:

*“No job for the parents. Mother has not job, father has not job, stay at home. After a while, after one month, five months they are getting depressed and the family getting sad.....sad is affecting the children. The children going to school...child be isolated at school, no support and in the end child....cannot do their education properly....everything really is affecting their health and the mental health” (Lawrence, 2003:11).*

One consequence of difficulties in finding employment is that many families struggle financially. This, according to one community representative has a variety of implications on health:

*Jody	What things damage health?
Ghaniyah	Really financial
*Jody	Financial things can damage your health?
Ghaniyah	Because you could not get a good food, you cannot get a good quality of house, you cannot get everything you need so it depends your financial and also it needs to be active, always if you are active it will help your healthy, activity. To do something.
*Jody	So are there any other things that damage health. You've mentioned financial
Ghaniyah	When I say financial as you know, for example if you have no ability to rent a house which your family can be suitable and you live in a overcrowded house you can, it can damage your health. If you have no financially, a good food to buy you know what everything you need and you can easily become you know imbalanced and you can be you know malnutrition and will affect your health. Yeah. So every place has a special treatment. You know but money we need all of us whether we are in a middle class or a high class or the lowest, everyone needs something to survive. But another thing is if the person is emotionally sick you can't treat money or any other thing.

Financial difficulties also restrict peoples' ability to obtain what then need to maintain health and treat illness.

## *Accessing health-care*

While Somalis have high health needs, international research has demonstrated that they have low health service utilisation rates (Comerasamy et al., 2003; McCrone et al., 2005). For many Somalis, difficulties in accessing health-care services can be an important resettlement challenge. This includes difficulties navigating the health system, communication, cost, transportation and cultural expectations of health-care (Lawrence and Kearns, 2005). One of the greatest barriers refugees face in accessing health services is communication. Communication issues make every part of the practitioner-patient relationship problematic, from enrolling with a GP through to understanding the instructions on the label of a medicine bottle. Most Somalis have limited English language skills and are required to navigate their way through a complex health system. The language problems experienced by refugees are epitomised by an excerpt from a paper by Burnett and Peel:

*“If not otherwise exempt, those on low income can apply with an HC1 form for an AG2 exemption certificate in order to receive free prescriptions, dental treatment, optician services, and hospital travel costs. The form, however, is 16 pages long and available only in English, and the certificate itself is valid for only six months” (Burnett and Peel, 2001:487).*

Somalis within the New Zealand health system face similar experiences.

The 2001 Health Needs Assessment report published by the Auckland District Health Board also identifies a number of barriers to accessing health care (Auckland District Health Board, 2001). As most refugees rely on some form of income support, cost can act as a barrier for many refugees particularly those with multiple, complex health problems that require a variety of medical interventions. Even those who hold a Community Services Card can find the costs of attending a GP prohibitive let alone paying for the costs of prescriptions.

While refugees are eligible for all publicly provided health services in New Zealand (Minister of Health, 2003), there are considerable barriers to accessing health care. The New Zealand health system is, in general, not well adapted to respond to the health needs of refugees. For instance, the use of interpreters is often limited to secondary and tertiary health care services and is not available to many community and primary health care organisations (Lawrence, 2005c). There is a low level of knowledge and skill in the New Zealand health care workforce with respect to the experiences of, and resettlement challenges for, refugee families (Mortensen, 2007).

However, while many Somalis experience difficulties within the health system, people told me how grateful they were that they were living in a country with good medical services and resources. As I will discuss with regard to TB (see Chapter Eight), the free availability of medication in particular is

frequently mentioned and is in contrast with Somalia where patients and their families are required to bear the cost of treatment.

## **Somali health beliefs and practices**

Having considered the health issues faced by Somalis living in Auckland, I now turn to consider the ways in which they think about health and disease. Health is a socially constructed phenomenon and is understood by different people in different ways. For instance, biomedical views of health see it as an absence of disease. In contrast, The World Health Organisation definition of health refers to a state of complete physical, mental and social well-being. Different cultural groups also have varied understandings of health and disease and these have been widely researched by medical anthropologists. While there has been some research conducted on the health issues facing Somali people, there are few accounts that address Somali health beliefs and practices.

One of the objectives of this thesis is to consider the way in which Somali health beliefs and behaviours have been carried with those who have migrated to New Zealand and modified in the new environment (Aim Three). During the course of conducting interviews and focus groups with members of the Somali community, I specifically asked a range of questions designed to elicit peoples' views on health and disease and the ways in which they understand and respond to bodily changes. This section describes the beliefs Somalis have about health and disease and their responses to these beliefs. As will be demonstrated, Somalis' models of health are heavily influenced by Islamic principles and thinking although this is closely intertwined with Western biomedicine. Before elaborating upon each of these influences I provide a background by considering health care in Somalia.

### *Health and healing in Somalia*

As I will discuss in the following section, Somalis have a broad all-encompassing view of the causes and nature of health and disease. These views are largely shaped by Islam and Western biomedicine. However in order to understand these influences it is important to consider them within the context of health and healing in Somalia.

Given the ongoing instability in Somalia, it is very difficult to obtain accurate and comprehensive data on the health of the Somali population. One of the only indicators available is that of life expectancy. In 2006, according to the United Nations Population Fund (UNFPA) Somali males' life expectancy was 46.8 years and females 49.3 years (UNFPA, 2006) which is extremely low compared with life expectancy in Western nations. Indicators from the New Zealand Refugee Healthcare Handbook estimate Somali life expectancy at 47 years (compared with 77.8 years for the New Zealand population), maternal mortality at 1,600 per 100,000 and an under-five mortality rate of 221 per 100,000 (Ministry of Health, 2001). Due to the dearth of official health and disease

data, much of the information in this section is derived from interviews with Somali-trained health professionals.

Prior to the Civil War, the Somali government had established a basic, but largely Western-based medical system including a medical school for training doctors. According to one Somali-trained health professional, health-care in Somalia was largely limited to secondary and tertiary care as the interview excerpt below describes:

*Jody	So does the Somali health care system have GPs like here?
Husniyah	No GPs. People go straight to hospital and wait in queues for the whole day. Wealthy people can go to the doctor whenever they want and go all the time. Most Somali people only go to the hospital when they are very, very, very sick. Especially mothers because they are so busy with the children that they come last.

Given the high burden of infectious disease, the department of health in Somalia had established a particular focus on public health. In Somalia, infectious disease was, and remains, a leading cause of death particularly from malaria, TB and syphilis. Other infectious diseases such as measles, whooping cough, tetanus, influenza and meningitis are also very common. According to participants, prior to the civil war rates of HIV/AIDS were very low compared with Somalia's neighbours (Ethiopia and Kenya) in part due to Islamic teachings on sexual relationships. Since the civil war however rates of HIV/AIDS have increased markedly (Guerin et al., 2004a).

To combat high rates of infectious disease, the government established vaccination programmes. One participant who worked in a Somali refugee camp after the war estimated infant mortality at around 50%. There were efforts to improve vaccination coverage and at the camp parents set up a 'jail' for those who did not vaccinate their children. These efforts were however, limited by the erratic supply of medicine. According to this informant, the Somali government did not want medical services to be unsustainable and as a result, doctors were only able to do what the government could continue. This was largely determined by the availability of particular medicines. As a result, doctors were not able to treat chronic conditions such as diabetes as they were unable to acquire the necessary medicines.

The Civil War which began in 1992 resulted in the collapse of a state-provided health system. Not only were hospitals, medical supplies and resources destroyed or damaged, but many of those who had staffed the health system were themselves part of the refugee flows who were later resettled overseas. In Auckland alone there are a number of Somali trained doctors, nurses and midwives. According to participants who have enduring connections with their homeland, the health care system in Somalia today is *ad hoc* and limited to the services provided by private operators and the few NGOs who remain in Somalia. Without a stable government, very little money is allocated towards health services.

Prior to the Civil War, health-care in Somalia was not limited to biomedical inputs. As Parr notes, “in places where conventional health care (doctors, hospitals and medicines) are scarce, it is important to think through different forms of care, to assess how care works within and between different groups (e.g., women and children) and how health care involves a mixture of modern and traditional practice” (Parr, 2003:218). Although the influence of colonisers from France, Italy and Great Britain saw the expansion of Western biomedicine, this was largely limited to the main urban areas and the wealthy who could afford it. Most Somalis managed their illnesses themselves or sought assistance from traditional folk-healers. According to respondents, Somali traditional healers tend to be concentrated in rural areas and were mainly used by those who were unable to access the services of any other health providers. According to Elmi (1999) traditional healers are still widely used in Somalia in part due to the fact that it is the only medical care available for the vast majority of Somalis who reside in rural areas.

### *Interaction between health systems*

When talking about health beliefs and practices with research participants, I was interested in the degree to which individuals’ health beliefs were infused by both Western biomedicine and Islamic medicine. Mass-Islamization occurred in Somalia between the 11<sup>th</sup>-13<sup>th</sup> centuries and has come to influence every aspect of life ranging from teachings on ethics, business, interpersonal relationships and health. In other words, Somali models of health are firmly situated within wider social, political and economic contexts such as the resurgence of Islam since the Civil War.

Yet research participants also expressed a high degree of trust and familiarity with Western biomedicine. In many ways the two models of health appeared to sit alongside one another and operate simultaneously. This idea is supported by Adib (2004) who notes that Islamic teachings on health do not represent a cohesive, stand-alone medical system and that “Islamic medicine fails to depart from the biomedical, ‘Western’ model’s concepts and practices” (Adib 2004:699). Rather than being an alternative to Western medicine, Islamic medicine is in addition to and offers considerable comfort and benefits to those who follow the teachings of the Koran and Hadith (sayings of the Prophet Mohammed). Adib thinks of Islamic medicine as “a pious garment which Muslim doctors and patients are expected to don as they approach an otherwise Western medical model” (Adib, 2004:701). This metaphor is a useful one in that it highlights the extent to which Muslims’ see their world through the lens of Islam and are exhorted to be aware and cognizant of the spiritual dimension of life. For instance as noted by one person:

Almas	Koran says if you are sick you have to do whatever is good for your health. Read the Koran, go the Imam and get advice. Also go to GP.
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In the case of illness, the decision about which medical provider to attend tended to be influenced by the type of complaint that was being experienced. For instance in a focus group discussion about health issues, one Somali woman made the following comment:

Almas	Koran says if you are sick you have to do whatever is good for your health...Try whatever you think is good for health. The Koran doesn't just say read the Koran. If you have cancer or broken arm, go to the doctor. If you have mental problems or see devils or are anxious then it is better to go to the Koran side.
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As this person indicates different types of conditions needed to be treated in different ways. Acute physical health concerns, such as cancer or a broken arm in this example, are the domain of Western medical doctors. Spiritual and psychological concerns are the domain of Islamic healers. Things do get a little complicated in that those who have been affected by black magic may also suffer from physical ailments. I asked one individual how you can tell what has caused your headache – whether it's magic or medical. The respondent stated that religious healers are able to instantly tell the cause of people's afflictions although people tend to turn to religious healing after trying western medicine first:

Akram	Mostly the people they go first to the modern [medicine]
*Jody	The modern medicine
Akram	The modern medicine. If they don't respond they go to the religious.

When I asked another person the same question they underscored the importance of the spiritual dimension regardless of which option they selected:

*Jody	And so how would a person decide whether to go to a religious healer or a western doctor, how do people make that decision?
Ghaniyah	Everyone who goes to the Western doctors believes that the spiritual is very important and some people they go before they go to the doctor they go to get spiritual healing and after that they go to the doctor.

Another participant felt that the decision on who to seek help from when unwell depended on financial resources:

*Jody	So when people are sick, who do they see first? Or do they try all three types of healing at the same time?
Husniyah	They try religion first, then traditional medicine then western doctors. But wealthy and educated people go to doctor first.

Nevertheless, all participants agreed that psychological issues were spiritually rooted and required assistance from trained healers in order to resolve them. This is similar to the findings of Edginton et al. (2002) who observed that amongst rural South Africans, people believed that diseases caused by breaking social protocols could only be treated by traditional healers not by Western medicine.

Traditionally, Somali medical practitioners tended to be older men in the community whose skills were passed down through previous generations. These traditional doctors treat illnesses caused by spirits using herbs, fire-burning and healing ceremonies. According to one person:

Husniyah	There are also traditional medicine men who mix plants together to remedy illnesses. Sometimes costs thousands of dollars. They make you take a drink or have a bath. Sometimes use burning on place of pain to make it go away e.g. burn on temples for headaches, on back for backache, on wrists for hepatitis. Mainly done by rural people. People can get relief and feel better.
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Fire-burning is one method used by traditional healers to help treat conditions such as malaria and jaundice. A stick from a special tree is heated until glowing and then applied to the temples, elbows, ankles and abdominal regions (Jackson, 2006).

There are three main problems for which traditional healers are thought to be most effective. Firstly, the 'evil eye' is misfortune or illness caused by a person wishing harm on another person (Elmi, 1999). This can be done on purpose or accidentally. According to one source, some Somalis believe that lavish praise can bring on the evil eye (Cross Cultural Health Program, 1996). The second problem is that of black magic or curses. These can cause a range of diseases with curses from ill-treated or disregarded parents being seen as among the worst (Elmi, 1999). Somalis also believe in evil spirits known as *jinni* as one individual notes:

Husniyah	There are also the <i>jinni</i> . These are demons/spirits. Medicine man will bang on drums and slaughter animals, use expensive perfume, dancing and eating to get rid of <i>jinni</i> .
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According to Lewis et al. (1996) Somalis believe that spirits can reside within each individual and can cause illnesses such as fever, headache, dizziness and weakness when *jinni* become angry. When someone is possessed by a spirit they might talk strange languages or in a different voice. More often than not, the recipient is incoherent, shaking, crying and out of control. They say and do unusual things. There are a number of reasons why people may get a *jinni*. One individual thought it occurs if the *jinni* likes the person or if one makes someone with a *jinni* angry. A person can be cured of *jinni* through a healing ceremony designed to appease the spirits involving special rituals, eating special foods and burning incense.

As these three problems are seen as being spiritual in nature, they require a spiritual solution. Consequently, those who suspect they might have a spirit inside them, or that someone has given them the evil eye, will visit a traditional healer rather than a medical doctor. According to research participants there are no Somali traditional healers living in Auckland. This is possibly due to the fact that traditional healing is prohibited by Islam and the practice has become less and less popular over time particularly given the resurgence in Islam in Somalis' lives. While Somalis still strongly believe in *jinni* they now seek assistance from Islamic healers rather than using Somali traditional healers. According to one individual:

Husniyah	The Koran says that jinni exist but tells you not to believe in it. If you do you go to hell.
*Jody	Oh really?
Husniyah	So you are supposed to treat with Koran healing only. The sheikh will read Koran. Sometimes he will use a long stick to hit the person and the jinni will cry out "Please don't hit me, don't make me go".

Nevertheless, although traditional healing practices have been outlawed within the Koran, healers still operate in Somalia, particularly in locations that have no other health services. Some people found that folk-healers helped them greatly when nothing else worked:

*Jody	Oh Ok. So why do people go to the traditional healers then [given it is forbidden by the Koran]
Husniyah	People recommend it to others if it works for them. Some of it's psychological. If people think it's going to help then it does. My aunty had schizophrenia. They went to religious healer but still the same. Then went to traditional medicine man. They charge every time you go and sometimes make you come back seven times so they can make money from you. My aunt spent all her money on it and it didn't help her because she had schizophrenia. Then we took her to hospital and they gave her psychotic medicine which helped her.

This quote is particularly interesting as it highlights the way in which this individual engaged the services of multiple health providers in order to find relief. It also highlights another important point which is that most Somalis tend to believe that mental health concerns are primarily resulting from spiritual forces. As a result, they tend to seek spiritual healing.

The Auckland Somalis I interviewed unanimously agreed that spiritual afflictions such as *jinni* and evil eye could be remedied through Koran faith healing. In Somalia there were big religious centres where individuals would pay to be treated. In New Zealand however religious healing appears to be the domain of individuals who are well-versed in the Koran. According to one respondent:

Husniyah	There are also sheikh who do religious healing for young, elderly and women. They make you drink special water 'samsam', holy water and read out the Koran. Sometimes people become healed and feel relief. Sometimes people take outside showers with holy water.
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Although there is no formal Islamic medical training system, there are Koranic healers who have studied extensively and will often specialise in particular conditions such as jinni or the evil eye.

Some verses of Koran (such as Surah Yasin, Surah Baqara, Surah Musafat, Surah Muawadteen, Surah Falaq, Surah Fajar, Surah Ahad) are believed to make one healthy when one reads them in times of sickness. People can either read them for themselves or get a sheikh to read the Koran over their body. Alternatively some people read the Koran over some water and then drink it. One person told me that the Koran states that every disease can be healed except death.

The Koran also gives advice to about isolating individuals with infectious disease. Men at one focus group recounted how the Prophet Mohammed said that individuals should keep away from people and places affected by cholera or leprosy and that people with those illnesses should not travel. One respondent accentuated the fact that any person can use Koranic healing:

*Jody	So what does spiritual healing involve? What do you do?
Ghaniyah	It involves we treat the holy Qatar, the holy Koran, the holy Koran that's how we heal. We read them the holy Koran and so many religious people who believe they will read the holy Koran and the person if he believes then it will heal.
*Jody	And who does, who does the healing?
Ghaniyah	People who knows the Koran
*Jody	And who would Somali people go and see
Ghaniyah	Usually we teach our children when they are young but some people like, when you study schools every child he needs to learn special subject you know. We teach a certain verses but the whole book, the whole holy book. You know some people they specialise even to memorise and they know by heart all of it and the people who really specialise for religious people mostly that people heals...Because it's not something else, it is the Koran and anyone can read. Even I myself I can read it. I can read to my children, they can read to me. I can, they do it themselves. It is not important to go someone else even you can do by yourself.

There were however some individuals who saw Koranic healing as the domain of individuals with special training and knowledge.

## *Explaining disease*

Islamic belief systems also provide a framework for the way in which Somali people understand and explain disease. According to Islamic teachings, disease originates from a “lack of attention to the spiritual dimension of human beings, and to estrangement from the will of Allah. However, little attention is given to intermediate causal links between these attributions and disease outcomes” (Adib 2004:699-700).

One of the themes that emerged when talking about this topic was that of Allah’s will. Most believed that their lives were pre-ordained and that:

Falak	God created everything that happens to you before he even creates you.
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As a result, most felt that there was a sense of fate or destiny in terms of health and disease.

*Jody	So why does God make some people sick
Akif	Destiny. Fate. From conception to 120 days, your journey has been pre-destined. You're complete
*Jody	Does sickness serve a purpose?
Akif	Only God knows...

This same respondent also acknowledged that Allah was in control when it comes to health and disease:

*Jody	What things do you do to keep healthy?
Akif	To be aware and conscious about my health/wellbeing. If any changes I go to the doctor. Religious people will say you get sick. Depends on God's will. You can try to do everything but if God wants you to be sick you will be sick no matter how hard you try. What is important to western people is not for Somali people. The most important thing is God's will. Next is hygiene, food, sleep but these things don't really mean much to us. It's cultural. They know it but people don't do it.

For one person, it was important to be patient and not complain or try to resist God’s will (also documented by Elmi (1999):

*Jody	So did you see your sickness as coming from God?
Adil	My sickness
*Jody	Your TB?

Adil	Yeah. My TB, at that time, actually yes it came from God but when the thing happen to me comes from God, but that does not mean that, like I have to be angry or I have to complain or I not supposed to go and look for medicine. It's just an Allah thing that can happen,
*Jody	So it's part of life?
Adil	Yeah it's part of life.

While individuals felt it was important to accept ill-health as God's will and not to fight it, there was a strong sense that individuals were still responsible for their own health and obtaining the treatment they need to become well again. For some this meant:

Falak	You have to cure yourself and read Koran. Thank God for everything include sicknesses and health.
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Nawal	Need to be patient, ask God's sovereignty, praise God and go to the doctor.
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When I asked about the reason why God gives people sicknesses, one individual reinforced the idea that everything both good and bad is God's will. Rather than viewing bad things as punishment, he saw them as a test and a chance to prove his devotion:

*Jody	So why do you think that God would give people sicknesses? What are the reasons for that?
Barir	The Koran says, from God saying, "I will, I will give you everything, human being whether it's bad or good" and I would say for example if someone go to die, he said all the world will come together to try and save that person, they can't. So it's the religion.
*Jody	So it is like God's will?
Barir	Yeah. God's will yeah. Everything, I think Muslim believe that everything that can happen to you, it happens so you try you can defend it but sometimes there are things you can't control, yeah.
*Jody	Do you believe that God gives some people sicknesses as punishment? Do you think that's true?
Barir	In the war, we are in the war, this is a test. It's not punishment it is test. God will see if you will take this, and will say 'thanks God' and be patient or whether you cry or what's happened these things, it's a test. He will test your capacity to say 'God forgive me' or yeah, 'thanks' ...Yes that is true. It says in Koran he will give you everything and then he will give back to us for praying and asking and this, this, this, this. And God's saying we'll still test you, like what happened in Somalia, some kind of disaster you know, volcano, the big thing, everything happen. So

water coming or you know, he will test you. So we will see those who will accept that test or those who will cry and jump around and say “this things happened to us”. We have survived we have to say “thanks to God” and move forward. So some people will always blame, blame, blame, blame.

While many felt that diseases were ‘supernatural’ things that could happen to anyone, there was also the belief that there were particular diseases that affect those who openly flout Islamic laws and teachings. For instance:

*	What does the Koran say about health?
Almas	Koran says things are <i>Haram</i> [forbidden] or <i>Halal</i> [permitted]. If you do bad things such as drugs, alcohol or prostitution you will get diseases. Two types of diseases. One type is mysterious and happens for no reason such as broken arm or cancer. The second type is brought on yourself such as AIDS. If you have clean food, water and good sleep everything will be good. If you are in a bad place it makes your health bad. You just buy disease.

This idea was particularly evident in terms of HIV/AIDS which one individual thought was punishment from Allah for those who do not obey his rules. In the eyes of this person:

Almas	AIDS is not our disease - not a Muslim disease. Happens if you go somewhere else such as a nightclub. If you go there you are buying disease. TB is like AIDS.
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While there was a sense of fate about illness experiences, individuals did a number of things to try and maintain health. I sought to explore this by asking interviewees “What is health?” Apart from one Somali trained doctor who recited the WHO definition of health, all other participants struggled to understand what I was asking. Frequently I would be told that ‘health is health’ and that it was very important but many were unable to define the term any further. Participants wondered why I even needed to ask such a question because in their eyes it was so self-explanatory. I realised that part of the problem with answering the question was that it was very abstract. I refined the question for later interviews to be more grounded in everyday life. When I asked “What things do you do to keep healthy?”, participants were better able to understand and respond. This is similar to the experience of Dyck et al. who found that among the immigrant women they interviewed, “The women talked in concrete terms about how they were dealing with their illness, and attempts by a research assistant to draw on personal experience in more depth were not always taken up. Our exploration of the contextual features of the illness experience sometimes did not make sense to the women” (Dyck et al., 1995:622).

When asked to describe the ways in which individuals thought about health and endeavoured to keep healthy, a variety of responses occurred. The first response involved being faithful and

reading the Koran, praying and following Islamic laws in order to live a morally upright life. A number agreed that being healthy meant avoiding those things prohibited by the Koran:

*Jody	What does the Koran say about health?
Huma	Healthy people need to stay away from bad things - drugs and alcohol.

Almas	Smoking, alcohol, drugs. Women have to be careful about men who have disease. Men also have to be careful about women who have disease if they are unfaithful.
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Part of this is watching the places you inhabit. Individuals who frequent immoral places such as night-clubs were seen to be bringing ill-health upon themselves. For most participants, a state of health is one which individuals are complete and clean. Participants mentioned that health involved wellbeing both physical, emotional and spiritual wellbeing. For example:

*Jody	Every culture thinks about health in different ways. How do Somali people think their bodies work?
Husniyah	I'm not really sure. To be healthy means to have good money, to be kind, to have a faith, to not be into bad things like drugs and alcohol, no sinning. It's holistic like physical, mental and spiritual.

This quote touches on both socio-economic determinants of health, moral and religious values in addition to physical and mental aspects of health. A number of participants indicated that to them health could be thought of as a state of completeness across the range of spectrums including physical, emotional and spiritual dimensions. One individual mentioned that for him, being complete meant having his family with him. Currently he is the only member of his family/sub-clan living in Auckland and that as a result he doesn't feel able to settle well or feel comfortable. He states:

*Jody	Do you think that worry about your family has influenced your health?
Adil	Yes it actually did it was major part. If they were here I would get more emotional [support], it affects, being lonely is no good
*Jody	No
Adil	Lonely is bad. You should at least have someone.

Completeness also refers to having adequate material resources to maintain a satisfactory life. One interviewee stated that:

Akif	Having no job means there is not enough money which makes you sick.
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For another person, health meant being able to live the life they wanted to and achieve their goals:

Ghaniyah      When we are healthy that is the time we can do our own life what we want to do. Unless we are healthy we can't work, we can't study, we can't do anything for ourselves so the life of the person the most important is the healthy.

For Hala, one's mindset was also important. As the narrative depicts, by dwelling upon and worrying about certain diseases, a person can actually cause the disease to happen:

\*Jody            So what things do you think damage your health? What things make your health bad?  
Hala              Sometimes I'm healthy but if I thinking mentally "oh I'm sick, I'm sick, I might got that disease, I might got that disease" later on some people they got real disease  
\*Jody            So one thing that can damage health is, are you saying thinking?  
Hala              Yeah.

There was also a strong focus on self-responsibility. Participants' emphasised the behaviours required in order for individuals to maintain health. A quote from one focus group participant highlights this:

\*Dahaba        What things can you do to keep healthy?  
Almas            Keep clean, eat good food, keep busy, find a job. Make friends, do exercise and learn the language. Try to make happy, get enough sleep and go on holiday with family.

One of the first things mentioned by participants is having enough food and eating the right kinds of food. Given their refugee background where food was in short supply, this is an understandable priority. In particular fruit, vegetables, milk and meat were mentioned as food that needs to be consumed in order to be healthy. One individual noted:

\*Jody            So what things do you do to keep your body healthy?  
Ishraq           To eat more of you know food  
\*Jody            What kinds of food?  
Ishraq           Vegetarian, fruits and meats and keep you like strong, the body strong, to be strong. Yeah.

On the other hand, eating too much food, the wrong kinds of food or not having enough food is associated with ill-health:

*Jody	What things are bad for your health?
Huma	Overweight, not exercise, eat unhealthy food or not eating enough food.

*Jody	What things are bad for your health?
Falak	Not eating regularly, if you don't have three meals you get sick.

Eating the right kind of foods is associated with bodily fitness and strength. This appears to be the main way in which individuals recognise health in others both in terms of appearance and demeanour. For instance:

*Jody	How do you recognise health in others?
Hiyam	You can see her face. You can tell straight away by the face, like you. Smiling. Healthy person friendly. Unhealthy, sad, need help...

*Jody	What does it mean to be healthy?
Akram	To be healthy means the person should be strong, fit, physically healthy, no worry.
*Jody	No worries.
Akram	No worries. Healthy, his body will be so fit, strong, healthy also his mental and emotions, fit and healthy.

Another important means of maintaining health relates to hygiene. When asked about what the word health means one participant suggested:

*Jody	So what does the word 'health' mean to you?
Akif	The word health is...the cornerstone for health is hygiene.

This was frequently mentioned, and according to one individual, maintaining a clean and tidy home is a specific Somali trait:

*Jody	How do you, what things do people do to keep healthy?
Akram	...They have to live very good, very healthy place you have to live for example the accommodations. Especially the Somali people they always like their house to be clean
*Jody	Clean. Do they?
Akram	Absolutely, yeah
*Jody	Why do you think that is?

Akram	Because it's naturally....I think it's their attitude, they always like their house to be clean...then their dress clean and so on....they live for a clean place and also they are healthy.
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By failing to have good hygiene or spending time in places that are not hygienic, ill-health can result. When asked about what things damage health, one respondent said:

Falak	Bad hygiene and lots of people sharing one room or small house.
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As the narratives included in this section demonstrate, Somalis have a wide range of views about health and disease. By and large these ideas are rooted in Islamic teachings and prescriptions for living. There is also a deep sense of Allah's will in determining health and disease although there is a strong focus on specific behaviours required by individuals in order to maintain health and prevent disease.

### *Islam and Western medicine*

One of the reasons for the mutual inter-dependence between Western medicine and Islamic medicine within participants' accounts of health and disease is due to the exhortations of the Koran and the Hadith (the Prophet Mohammed's sayings) for individuals to seek treatment for their illnesses. As noted by one individual:

*Jody	So what kind of relationship is there between western medicine and this religious medicine? Are they, do they go together well or do they sort of conflict?
Akram	They always go together. Yeah. Of course, according to our Koran say, always, order to us, there are a lot of diseases and there is a lot of medicine to treat that. So you always have to take your medication, our Koran says that. The disease or illness and there treatment, so you have to treat the appropriate one. So according to that even the Koran accept the modern medicine, it accept it, yeah and order us, this religious.

This point was raised by a number of individuals who indicated that the first thing they do when they become unwell is to search for medication as described below:

*Jody	So what do you do when you feel sick?
Akif	I have to look for medication.

This approach to health is also consistent with health practices back in Somalia prior to the civil war. According to community members, the most common course of action in the case of illness

was for individuals to visit the pharmacy in search of medication. Only if the illness was very serious would a doctor be consulted. This is in part due to the high costs of seeking medical attention in Somalia meaning that medical care was largely the domain of the wealthy and those living in main urban areas. According to information gathered from participants, the medical system was largely private with a user-pays system as highlighted in the excerpt below:

*Jody	And so, so does it cost to go to a medical doctor in Somalia?
Akram	Yes, it costs. For example the surgical costs maybe five dollar or ten dollar, US dollar. Maybe twenty dollar or forty dollar in New Zealand dollar.
*Jody	Ok
Akram	It's a lot of money
*Jody	Yeah. How do families pay for it?
Akram	Mostly, maybe one of the parents they work, they pay the doctor of the family.

One participant recalled an encounter where she visited a doctor in Somalia complaining of stomach pain. He examined her and then without another word handed her a prescription. As she was about to leave she queried whether the prescription was for tablets or for syrup. Khalisah then recounted:

Khalisah	I realised he was angry so I left because sometimes they take the prescription and rip it up even after you have paid for an appointment.
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Khalisah explained that visiting the doctor cost a lot of money and she was worried that if she returned the prescription to the doctor that she would walk away with nothing.

This narrative highlights one of the expectations Somalis have when seeking medical care. Patients nearly always receive antibiotics and expect to receive such medicine from any medical visit. According to Lewis et al. patients feel disgruntled when they travel some distance and at some cost only to receive no medication (Lewis et al., 1996). This sentiment was expressed a number of times by participants who were frustrated that they had visited their New Zealand doctor and left with a prescription for Panadol which they could have procured themselves without a doctor's appointment. The idea of value for money seemed to be determined by whether medication was prescribed or not.

One idea which repeatedly emerged was Somalis' unswerving faith in the power of medication. This was universal apart from one person (Ghadah) who expressed hesitation at the use of antibiotics as they 'dry everything up'. This view of antibiotics was however the exception in contrast with the opinions expressed by the majority of participants who consistently repeated the idea that when they were sick it was their responsibility to secure the necessary medication. This issue arose when discussing religious healing with one individual. They noted:

*Jody	So do people still go to religious healers?
Husniyah	Yes but they go very often to doctors. Sometimes the people get frustrated when they go to the doctor and he won't prescribe medicine i.e. for a virus where medicine won't help. They go to different doctor until they get what they want. They now go to the doctor all the time because they have the community card. Sometimes they go every day of the week. The doctors talk to me and ask me to educate the community about it.

This is an interesting comment and one that was supported by a wide range of participants. In my experience, Somalis are very assertive and enterprising when it comes to securing something they need. Whether it be for food, housing, income or health care, they tend to 'shop around' exploring multiple avenues or possibilities until they are able to secure what they need for their families. This has given rise to the perception that Somalis are very persistent and demanding (Lawrence 2003), however such an attitude of persistence is understandable given the people's backgrounds where they are required to fight for what they need in order to survive in a refugee camp. However such attitudes do come into conflict with New Zealand service providers who are operating within a limited funding environment. As a result, community representatives such as Husniyah have been enlisted to 'educate' the community about what is 'appropriate' behaviour and expectations in terms of medical providers.

Another interesting point from this narrative is the way in which Somalis appear to be presenting frequently at the doctor. This is in contrast with the findings of McCrone et al. (2005) in the UK but consistent with ideas put forward by Guerin et al. (2004a) for NZ. According to participants, frequent presentation is a feature of the fact that for those with a Community Services Card, attending a doctor may be free or very cheap at some clinics such as Hauora o Puketapa (HoP) in Mt Roskill. As a result Somalis often visit a doctor for minor complaints such as colds and headaches.

In addition to Somalis' embrace of medical intervention, many expressed great faith and trust in their medication. As will be discussed in relation to the stigma associated with TB, because medicine is freely available in New Zealand, a number of Somalis believe that the disease is no longer to be feared. This sentiment appears to stem from the shortage of medicine experienced in Somalia. In addition, in New Zealand most medicines are free or heavily subsidised. This is in contrast with Somalia where individuals often had to pay an enormous amount of money. Furthermore, since the conflict in Somalia, participants report that the quality of medicine had deteriorated. As noted by one individual:

Falak	Since the civil war, medicine in Somalia comes from Pakistan. They give us expired medicines or fake powders that look like medicine. This causes diseases.
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As a result of this suspicion over the quality of medicines, newcomers to New Zealand were suspicious of the origins of their medicine:

Husniyah	At Mangere [Mangere Refugee Reception Centre] people would be given medicines and throw them down the toilet because they don't know where they were imported from.
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Over time however, Somalis' trust and faith in medicines in New Zealand appears to have been restored.

When discussing issues relating to health and healing, participants expressed a high degree of trust and belief in Western biomedicine. Most of the participants I interviewed were very familiar with Western medical concepts and systems due to their exposure to it in the past. There were, however, a few concepts such as primary care, prevention and the referral system that were novel. Childbirth is another example. One Somali trained doctor commented to me how most Somali women were not familiar with the concept of ante-natal care, as rural women tended to give birth at home with the assistance of a midwife, while urban Somalis would only visit the hospital at the time of delivery. The concept of disease prevention and primary care were also quite unfamiliar. A number of individuals were unfamiliar with New Zealand's system of referral and wanted to see a cardiac specialist immediately rather than deal with their GP.

Of interest to me was the number of respondents who indicated that the main way they knew they were healthy was based on their doctor's verdict as opposed to their own assessment of their wellbeing. For instance:

*Jody	And how do you recognise health in yourself?
Abal	I know I am healthy through the doctor, going to, you need to be connected with the doctors and hospitals yeah...

*Jody	How do you recognise health in yourself?
Adil	Results from the doctor tell me I'm healthy.

As a result, regularly visiting a doctor is seen as an important way to keep healthy as Ghadah and Ghaniyah describe below:

*Jody	What things do you do to keep healthy?
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Ghadah I have to check several times with my family doctor. You have to go to doctor for different issue. If pregnant, go every month. If sick, go for check up. For women's issue, go every three years.

\*Jody And so what does a person have to do to keep healthy, what things do they need to do?  
Ghaniyah He needs to keep his healthy to eat good food, do exercise, and always check up.  
\*Jody You mean a doctors check-up?  
Ghaniyah Yeah, check-up once a six months or once a year, yeah, always be sure what is your situation because sometimes some kind of disease before it become too late you can not notice if you are healthy and check up yourself if something comes immediately you can treat it.

One individual felt it was important to have regular contact with doctors just in case there was something wrong but unrecognised:

\*Jody So what does the word 'health' mean to you?  
Akif ...Good to have regular contact with doctor. Sometimes you might have something wrong with you without realising...

In the case of illness, most male participants indicated that their primary course of action would be to visit a doctor. For example:

Adil I think the first thing I supposed to do is go and see a doctor, a family doctor  
\*Jody Anything else?  
Adil Anything else, actually no, that's all.

\*Jody So if you had a problem with your body in Somalia. What would people do first of all if they recognise they had a problem in their body?  
Akram They go straight away to the doctor.

When I asked these participants how long they waited until visiting the doctor, most indicated that they would arrange an appointment straight away. For instance:

\*Jody After what, three days, four days, two days? How many days would you wait  
Adil To see a doctor?  
\*Jody To see a doctor

Adil	I think I don't wait. Straight away. If I become sick last night and then I know what kind of sick because, and then I will go and see the morning.
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On the other hand, another informant contradicts this by claiming that men delay visiting a doctor until they are very unwell:

*Jody	You mentioned that the young and elderly and women go to see religious healers, what about men?
Husniyah	No, men are stronger. They wait until they are really, really sick before seeing someone. Would go and see the doctor.

While women also mentioned that they would seek advice from a medical professional this typically tended to occur only after a variety of home remedies were attempted:

*Jody	And how long would you wait before going to the doctor?
Ghadah	For first three or four days give the soups. Then come OK. If not OK then go to family doctor.

These home remedies largely originate from the Koran which provides a number of teachings about managing illness particularly in the form of herbal remedies and faith-healing.

The use of home remedies appears to be consistent amongst all women I interviewed and was also observed in Dyck's (2006) research with South Asian immigrant women. Somali women whom I interviewed said that their knowledge of home remedies had been passed down from their own mothers and these women are now in the process of passing such knowledge onto their children. Men I interviewed hardly ever mentioned the use of home remedies, which may be in part due to the fact that women are ordinarily responsible for the health of their families.

What is interesting is the way in which most individuals think of these remedies as 'Somali remedies' when in fact it emerged that they originated from the teachings of the Koran. This highlights the way in which Islamic principles and teachings have been so closely enmeshed with Somali culture and identity that they are seen as being one and the same.

The use of home remedies is part of the way in which Somalis feel a sense of self-responsibility in keeping healthy and treating disease. For instance Hiyam and Hala suggest:

*Jody	From which sources did you learn about health?
Hiyam	My parents. So I'm now mother I have to teach my children.
*Jody	What sort of things do you teach them?

Hiyam	Wash your hands before you eat, cut your nails, clean your clothes, wash after toilet, don't eat food left out, use clean water, clothes, bed, make sure dishes are clean. Have more to teach in New Zealand because cold country, socks, jumpers.
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*Jody	And whereabouts did you learn from health? Whereabouts did you learn about health? Who taught you about health?
Hala	Mum she teach me and she tell me about
*Jody	What kind of things did she teach you?
Hala	When you are sick what kind of food you can eat, when you got the fever you have to drink like a lot of water or something, what do we call in Somali, because sometime if you are constipated you come headache or flu and some fever so we have to eat like soup, beans, a lot of beans, yeah.

The widespread use of home remedies existed within Somali families long before the arrival of Western biomedicine into Somalia but was reinforced due to limited access to doctors and the high cost of attending a doctor. As a result many individuals managed their illnesses themselves. For most participants there were a range of common remedies including soups, honey, garlic, black seeds and a special massage with oil. For example, Ghadah describes the remedies she gives her children for influenza:

*Jody	Are there any traditional Somali treatments you give your children when they are unwell?
Ghadah	For 'flu I give honey and lemon. It works like antibiotics. For 'flu we don't like going to doctor straight away because we don't like antibiotics. We feel if we take antibiotics they will dry everything up. We give soups and stuff. Soup with milk and veges and black pepper and garlic. Skim the fat off the meat. Also give milk with black pepper to drink. For fever, take off clothes and do massage with oil and lemon. This cools down the fever.

I then continued by asking this respondent how the treatments work. She was astounded that I did not know as the narrative below reveals:

*Jody	And how do these treatments work?
Ghadah	You mean you don't know? You've never used them? Soups keep things clean. When you get constipated the 'flu will come. Black pepper good for blocked nose. Also good for adults. Lemons have vitamin C. My daughter puts lemon on everything, eats lemons whole!

Another mother said that when someone in her family is unwell she gives them various home remedies and if there is no improvement after a few days, she will visit the doctor:

Hala	I try first for lemon and honey. I beat and I gave it to them and panadol and I've got at home a Panadol so I give it to them and soup
*Jody	Soup
Hala	Yeah. Then when I feel it's not working, all those stuff I take them to the family doctor.

Another remedy is the use of black seeds known as *xabad sooda*. These seeds can be added to drinks or food and are also beneficial to health. According to two participants:

*Jody	When I was talking to other people they mentioned that they take black pepper in soups and black seeds
Husniyah	Yes, the Prophet Mohammed said in the Koran that black seeds, <i>xabad sooda</i> are very good for you. I can't remember what they are called in English but you can buy from Indian shops. You drink them or mix them with oil and put on your body.

*Jody	And are there any Somali medicines or Somali things you do traditional things you do if you are sick?
Ishraq	Yeah...the black things
*Jody	Black?
Ishraq	Yeah. It's like sugar
*Jody	Oh like little seeds
Ishraq	Yeah like it's black...and you put them with tea or milk for the kids
*Jody	Yeah. And what does it do for your body?
Ishraq	It's like, when you're sick like you know it like makes it, it stop like you know if you coughing or something vomiting and little bit it stop for you.

According to the Koran, honey has a number of health-promoting properties. As one individual describes:

Husniyah	Other things are honey. Prophet Mohammed said that honey is the best medicine. There is a story of a mother whose son is sick. She asks what to do and he says give him honey. She comes back again and says he is still sick, and he says give him honey. She comes back a third time and he says give him honey. The third time the boy became well. It's not shop honey but real honey straight from bees.
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According to one individual, following Koranic teachings on eating honey and black seeds can have dramatic effects:

Shakirah	Need to eat black seeds with honey. Have it every morning. Good for your health. The Koran says this can cure every disease except death.
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Soups are a frequent remedy for a variety of illnesses. Soups often involve cooking meat with black pepper and then drinking the liquid. This liquid is believed to be able to cure influenza and other minor ailments. One respondent believed that individuals with backache need a special kind of thin soup made from goat meat and black pepper to treat back-pain:

Wardah	People with back ache need soup - goat meat, black pepper - very thin soup.
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One individual did acknowledge that soups were a traditional treatment for influenza in Somalia but that times have changed now in New Zealand. When asked about the causes and treatments of the 'flu she replied:

Huma	You get flu from other people, crowding and cold weather. To treat the 'flu you have soup in Somalia but kiwifruit in New Zealand.
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Another remedy is massaging oil into the skin. This is helpful for aches and pains as well as other illnesses as described below:

*Jody	And what about for things like flu or cough or sore throat or headache what things do you do if you're feeling like that?
Hala	Sometimes we use, I put in my hair olive
*Jody	Olive oil?
Hala	Yeah
*Jody	And what does that do?
Hala	Sometimes you woke up
*Jody	Water?
Hala	Cold water, yeah cold
*Jody	What does that do?
Hala	Because very headache, because I feel when I've got the very bad headache, I feel that when I use that oil or cold water I feel I will come down you know like my headache is gone.

*Jody	And you put the oil on here [head]
Barir	Yeah I put on here and then massage. You put evening

*Jody	You put the oil on and then massage it. And how often would you do that?
Barir	Every week, one night
*Jody	One night every week. And did that make any difference?
Barir	...the pain is gone instantly.

As these accounts depict, Auckland Somalis draw on a wide variety of health beliefs and practices within the context of their everyday lives.

### *Summary*

This chapter has addressed Aim Three by documenting Somali health beliefs and practices. While a wide range of ideas has been discussed in this chapter, reflecting in part the breadth of Somali ideas about health, there are a number of common threads that run through the diverse range of health beliefs and experiences. The first is the degree to which Somali notions of health and disease have been strongly influenced by the social, economic and political contexts in which they are situated. One of the dominant influences is that of Islam which has been a feature of Somali life since the 11<sup>th</sup> century, albeit to varying degrees. These contextual factors are also important in terms of Somali health experiences both in terms of physical and mental health and in the challenges experienced in the process of resettlement. While these dimensions have been discussed separately they are highly inter-connected as evidenced by Somalis' understandings of health and wellbeing. Resettlement in New Zealand has transformed every aspect of life and as a result Somalis are interacting with the Western medical system on a greater basis than previously. As noted by Dyck (2006) migrants' conceptions of health and illness are modified and deeply embedded in their experience of place both materially and socially. Somalis have a high degree of faith and trust in Western biomedicine although this is tempered by a keen awareness of the spiritual teachings and principles by which they live their lives. While this spiritual dimension is of utmost importance, there is a strong sense of individual responsibility as demonstrated in the wide array of behaviours that participants listed as health promoting or health damaging. Yet it is important to remember that ideas and beliefs about health and wellbeing are not static or an entity unto themselves but are constantly being re-formed and re-negotiated within evolving social, economic and political contexts. Understanding Somali health beliefs and practices does however aid understanding of the ways in which Somalis make sense of TB and they way in which they respond when affected by the disease, as will be discussed in the following chapter.

## Chapter 8: Understanding TB – A dreaded disease or just like the ‘flu?

*...TB it become historically some kind of big disease in our society, its shameness. So people come here and still they have that belief. The second thing was that people have problem with public health nurse. They come to houses so other neighbours or other members of the community will see you are having the TB. So that's the most thing they hate, that's the thing a big issue that stigma. You have TB, you can't get married, it's going to be heritage [inherited], your children will have that TB, that's the image that is there, yeah (Namir)*

*In New Zealand we heard that TB is like 'flu. At wintertime you get 'flu. It is like 'flu, I'm not worried. It is easy, nothing to worry' (Hiyam)*

This chapter outlines the different ways in which Somalis living in Auckland think about TB. Beliefs about TB have a profound influence on the way in which individuals understand and respond to the illness (and those suffering from it). As documented in the review of TB literature within Chapter Four, in light of the resurgence of TB rates, there has been a strong push to better understand the ways in which different people think about the disease (Carey et al., 1997; Tulsy et al., 1999). The primary focus of such efforts is to understand peoples' attitudes towards TB so that incorrect views can be remedied, thus improving treatment outcomes (Kocs et al., 1995).

This push to understand and correct erroneous attitudes has also filtered down to communities themselves. Throughout the course of my fieldwork, I have encountered a sense of pressure to provide 'correct' responses when talking about TB beliefs. When I asked one individual what she thought causes TB she requested that I turned the audio-tape off and expressed concern that her answer wasn't 'correct'. I assured her, along with all other participants, that I was interested in all the different ideas people have about TB and that I was not there to judge participants' views as being correct or not. This urging on my part potentially explains the enormous range of ideas and beliefs about TB that emerged during interviews.

While such concerns with correctness may, in part, be due to the way in which participants viewed me as a medical authority figure (see Chapter Five for further discussion of this issue), I believe this response also reflects the activities of public health practitioners in Auckland. In the face of high rates of TB amongst Somali refugees, high levels of stigma and perceived low levels of knowledge of the disease, the Auckland Regional Public Health Service (ARPHS) conducted a

'train-the-trainer' TB education programme in 2002. This programme trained six Somali community representatives to undertake TB education activities within the community. As I will discuss, educators encountered resistance when attempting to broach the topic of TB while seeking to provide information on causes, symptoms, treatment and transmission of the disease.

Historically, TB has been a highly stigmatised disease. Stigmatisation is an inherently social process whereby people with characteristics perceived as objectionable are discriminated against and ultimately rejected. Sociologist Erving Goffman's 1963 classic *Stigma: Notes on the management of a spoiled identity* is frequently cited in research on stigma. Goffman describes stigma as an attribute that is deeply discrediting, leading to a spoiled identity (Goffman, 1963). He continues by suggesting that stigma arises from three broad categories: (1) physical deformities, (2) character blemishes, and (3) ethnicity, nation and religion. Goffman argues that stigma prevents individuals from full social acceptance and becomes the dominant identity by which that person is known. In order to deal with this situation, individuals tend to manage information about themselves through selective disclosure or concealment in social interactions (Riessman, 2000).

Social scientists have extensively documented how stigma plays an important role in the experience of certain illnesses e.g. venereal disease (Brandt, 1985), mental illness (Rosenfield, 1997), HIV/AIDS (Schneider, Snyder-Joy and Hopper, 1993), sexually transmitted infections (Gilmore and Somerville, 1994) and leprosy (Volinn, 1983). Frequently, stigma has been linked with diminished social standing and support. Furthermore, negative reactions from other people can hinder coping and recovery (Schulte, 2002). Nevertheless, there are a number of commentators who have documented how stigmatised individuals exert agency in their efforts to resist stigma (e.g. Riessman, 2000; Link and Phelan, 2001; Camp, Finlay and Lyons, 2002).

Compared to other diseases, there is a relatively small literature on the stigma of TB with researchers tending to focus on erroneous beliefs and community fears (Macq et al., 2005). Some recent examples include research by Long et al. (2001) in Vietnam who found that the social stigma of TB is highly gendered in line with existing gender relations. Stigma was experienced socially and economically, with a number of participants reporting that having the disease had a profound financial impact beyond issues relating to cost of treatment. Jimenez (2003) examined the occurrence of stigmatisation during a TB outbreak amongst individuals enrolled in a drug treatment centre while Kelly (1999) considered perceptions of stigma amongst individuals with active tuberculosis and reflected on the way in which these come to influence treatment outcomes. Within the TB literature, stigma tends to be frequently cited as something that needs to be overcome in order to improve treatment outcomes and compliance rates rather than emphasising its meaning and impact on the lives of individuals. This latter emphasis is a key foundation for this research.

Issues surrounding stigma emerged at many levels throughout the course of this study both in terms of the way in which the research was carried out (as discussed in Chapter Five) and the results that emerged. When asked about what Somali people think of TB, words such as shame, danger, fear, stigma and death were frequently cited. As discussions continued, two interesting yet somewhat contradictory narratives emerged. The first narrative is associated with the past in Somalia and includes ideas that TB is a highly stigmatised disease with significant implications for the social identity and wellbeing of the individual. As this section deals primarily with TB beliefs and attitudes, individuals' experiences of the disease will be considered in greater depth in Chapter Nine.

The second narrative minimises the seriousness of the disease by comparing it alongside other less stigmatised conditions, typically influenza. This conceptualisation of TB was associated with Somalis living in New Zealand today. It was difficult at first to make sense of these two conflicting narratives and I was required to "...listen to silences as well as words, to attend to what people are not saying as well as what they say" (Cassell, 2002:179). As my fieldwork progressed, it appeared that these two accounts tended to reflect the 'public' versus 'private' divide. This interpretation of these conflicting accounts was confirmed by two Somali focus group facilitators who believed that group members' comparison of TB with influenza was a 'public' account of the disease and that people would not share their private views and experiences of TB in a public/group setting. According to Cornwell (1984) public accounts are those offered when individuals are concerned that what they say is acceptable to others, whereas private accounts occur when the need for acceptance is not as strong. In other words, the socially acceptable 'public account' of TB is that it is a treatable disease that is no longer stigmatised. Privately, however, participants acknowledged that in fact TB is still highly stigmatised and has had a profound impact on their social standing and identity. In some examples, I was told by particular individuals that TB was not a major issue for them, however in subsequent interviews, the true extent of their isolation and marginality was revealed. It was only as I became trusted and spent time with participants that the true extent of the impact of TB on their lives became apparent.

This chapter describes the TB beliefs of both general community members and individuals who have personally experienced TB themselves. While Somalis living in New Zealand suggested that their knowledge and understanding of TB is different from that of Somalis still residing in their homeland, individuals' beliefs about the epidemiology and impact of the disease are firmly rooted in the social context of health (as discussed in Chapter Seven) and TB in Somalia. This section begins by considering the way in which TB is understood and experienced within Somalia drawing upon the concept of stigma. I then shift to the New Zealand context and address the way in which TB knowledge and beliefs have been transformed by Somali new settlers. I then outline the different ideas respondents reported as holding concerning the causes, symptoms, transmission, risk factors and nature of TB disease.

## TB in Somalia

According to participants, TB was (and is still) a very common disease in Somalia and a leading cause of death. Although accurate data is lacking, prior to the Civil War, it was estimated that 80% of the adult population were infected with tuberculosis (Agutu, 1999). Since the Civil War, commentators suggest that widespread poverty, malnourishment and lack of health services have worsened the TB situation (Peltola et al., 1994; Agutu, 1999). According to Agutu (1999) the availability of over-the-counter TB drugs in urban areas is also a concern given the increase in MDR-TB internationally.

Nowadays, lack of data collection remains an impediment to estimating fully the extent of TB in Somalia. In 2005, the total TB burden in Somalia was unknown (World Health Organisation, 2005) as is the total size of the Somali population. Incidence rates (per 100,000) in neighbouring countries are 619 in Kenya, 353 in Ethiopia and 744 in Djibouti (World Health Organisation, 2006d; 2006b; 2006a; 2006e). Somalia's incidence rates are likely to be similar or higher than those of its neighbours. This issue with data collection is highlighted in a study of Somali medical practitioners in Northern Somalia (called Somaliland) in which 60% of practitioners had treated a TB patient in the last 12 months but only one had submitted this notification to the National Tuberculosis Programme (Suleiman, 2000).

Regardless of the true extent of the TB burden, it has long been a highly feared disease that has "traditionally meant a lifetime of illness and stigma" (Citrin, 2006:4). Italian doctor Annalena Tonelli established a TB hospital in Boorama after working as a teacher in north-eastern Kenya and observing that TB often went "untreated and led to social ostracism, gruesome deformities and finally a painful death" (UNHCR, 2003a:1).

According to those I interviewed, TB was a common affliction in Somalia and frequently associated with death. As noted by the following interview excerpts:

*Jody	And so in Somali culture, what do Somali people think about TB?
Abal	They think it is a serious disease which causes death. Anything could happen to you. They believe that TB is one of the baddest diseases.

*Jody	And Khalisah, what do Somali people think about TB?
Khalisah	They think it is very bad. Anybody who suffers TB, it's terminal, they just die. They don't think that medicine makes a difference. It's not curable. They don't believe that medicine can cure TB.

*	What happens to someone if they get TB?
Falak	In Somalia the TB goes to your lungs and you die. Not enough medicine to treat it.

Frequently, participants said that in the past, TB used to be thought of like HIV/AIDS is today – an incurable disease resulting in certain death (similar to Kelly (1999)). For instance:

Kadar	Somebody who has TB is like somebody who has AIDS, yeah, so scary.
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As touched upon in the accounts above, one idea that repeatedly emerged was that many felt that the fear of TB stemmed from the shortage of anti-TB medication. Two focus group individuals mentioned that in Somalia TB medicines were expensive, of questionable quality and not readily accessible. One person said that they were often expired. For example:

*Jody	In Somali culture what do people think about TB in the past in Somalia?
Nawal	People were put in a room by themselves. If there was no medicine they would die. Might get expired medicines.

Non-completion of treatment regimens was apparently quite a problem. While this tended to be attributed to a lack of education on the patients' behalf it was often dealt with quite strictly:

Akram	...medication in Somalia was restricted because some people discontinued treatment so we always get their elders or parents who will sign the form and then they will take the responsibility if he discontinues or sometimes they call the police and the take to jail if he discontinues the treatment.
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One participant recounted how she purchased TB medicines on the black market for a relative with TB when she was living in Saudi Arabia. It was a sensitive situation and meant that the family had to hide the illness from outsiders due to fears of deportation.

Yet prior to the war, TB treatment was very limited in Somalia. Those in remote villages and rural areas were often undiagnosed. One Somali trained health worker described how doctors in remote areas without access to x-ray or laboratory facilities often diagnosed patients according to appearance and other symptoms. Treatment was, however, problematic given that medicine was inaccessible and unaffordable.

As a result most nomadic Somalis treated TB using home remedies. According to two respondents this involved giving nourishing soups and food to help build bodily strength:

*Jody	So what would have happened if I had got TB and I lived in a rural part of Somalia
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Mahir            The Somali tradition in rural areas was to treat that person like an animal - to try and fatten them up. Give them rest, good meals, well cared for. Give them extra food the rest of the family doesn't get.

\*Jody            What kind of special food  
Yaminah        Food to gain weight like fatty food, meat, milk, meat with soup. Something with vitamins.

Then if the soups and food did not work, some would seek help from traditional healers who would use fire burning to help alleviate the illness:

Ghaniyah        The cultural treatments is sometimes they if they have a TB they thought you know this person is maybe it's like a bad cold or 'flu and they try you know to give out lot of, a lot of soup, animal soup and that soup they put you know some kind of spices and they thought it will heal and stop his coughing  
\*Jody            So they gave a special kind of soup?  
Ghaniyah        And then it doesn't assist if TB because TB germ needs medication and sometimes they try you know to make some fire  
\*Jody            Oh yes like...  
Ghaniyah        Fire  
\*Jody            Sort of like burning  
Ghaniyah        Burning.

While the availability of biomedical TB treatment was limited to those in urban areas with the financial means to pay, the primary response to tuberculosis was isolation. According to one individual this isolation occurred as people were afraid of getting TB. Isolation occurs in a number of different ways both physically and socially. For instance, according to one participant:

Abal             In Somalia when they had a TB they used to take them away from the family and you know, they used to think that person is like dead or something, dead person.

This isolation meant that individuals with the disease would sometimes be forced to sleep outside the family home and use separate eating utensils rather than sharing a communal meal. Mealtimes and food are a particularly important element of Somali family life. According to two participants:

Yaminah        ...In the country, people with TB have a different room they have to separate from the family, especially not sleep together. Even have to cook them special food.

Akram	Yeah, for example, twenty years ago in Somalia a person who got the TB was always stigmatised by the community and always the people they, they hard because according to the person who know the TB, the TB change their physical feature of the patient, the patient always look...very skinny, eyes sunken, malnutreated. They always isolate him, the keep him apart from the people and they, they don't treat very well.
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Nearly all community representatives who were interviewed had memories of living in Somalia when relatives from nomadic areas with suspected TB came to stay. Families tended to struggle to balance the need to show hospitality to family members and the desire to protect the health of their family from this 'tubercular' risk. The parents of one community representative used to deliver newly-arrived relatives to the hospital to be tested for TB before allowing them within the family home.

In some cases, those with TB were sent to the national TB hospital in Mogadishu. One individual mentioned how this hospital was located alongside the psychiatric hospital and she used to remember feeling scared when driving past it:

*Jody	In Somali culture, what do people think about TB?
Hiyam	...I just heard we have got hospital for TB. No one will visit because scared of catching.

One respondent who worked within the health system in Somalia had slightly different memories of the TB hospital:

Husniyah	There was also a very good TB hospital with very good Somali doctors and also doctors from Finland. Very high rates of TB in Somalia. Patients would get free medicines, x-rays and accommodation. The staff would also do health promotion and health education for patients and their families because of the isolation and stigma of the disease. People think only bad people get the disease. Sometimes patients would stop their medicines. The doctor likes the patient to stay in the hospital so he can watch him. Some people would even deny they have TB, would say they have a bad cough. They are afraid because of the stigma. Nurses would visit patient's houses. Staff that worked in the TB hospital would have do extra training.
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According to this person, for some people the TB hospital was a place of refuge rather than a place of fear as it meant they were able to obtain treatment outside their home village and thus prevent others finding out about their illness.

Those with tuberculosis were not only physically separated from others but also socially isolated as demonstrated in the following two accounts:

Kadar	...They feel outcast. They don't...especially in Somali culture. Somebody who has TB, is, like somebody who has AIDS, yeah, so scary. People in the community they are very afraid of it. They try to isolate the person who has TB.
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Fakhir	They say, oh look that is the man or the woman who has got the TB, so please don't eat with me, don't go with him, don't grow with him, don't talk to him, that's the way they are isolating the people, yeah, so the person who has got the TB is scary for that, all social thing...so it's really very difficult.
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Yet despite these accounts of stigma and shame, a number of respondents suggested that attitudes towards TB have improved with time, and that today in Somalia, people are more educated and aware of the cause and nature of the disease, and that stigma is now not so severe. For instance:

Jody	And if I had TB in Somalia, how would people act towards me?
Jabbar	Now you could lead a normal life. But in old days it was scary. People would ostracise you.

Namir	Most people now believe you can't get TB if that person having the medicine. But before it was, you couldn't eat with him or they couldn't sit with him or they couldn't marry to that person.
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There were however some who felt that the situation had not really improved. One individual felt that the reason why the stigma associated with TB had not reduced was because access to medicine was still difficult:

Yaminah	In Somalia medicine is still hard. People worry because lack of medicine and medicine is expensive.
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Another person was dubious about whether understanding and stigma of TB had improved, believing that the fear of TB was a deeply entrenched Somali trait:

Jody	So, do you think that Somali people living in New Zealand still think that TB is a bad disease?
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Tibah	Yes, it is bad disease because it is my culture. Little better is coming.
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Another person agreed and added that this was particularly pronounced amongst nomadic Somalis who were constructed as lacking awareness and being ill-educated about the disease:

*Jody	And do you think that, do you think that it's still the same in Somalia now [had just talked about how TB in Somalia was a feared disease]
Barika	Yeah, we never change
*Jody	Really?
Barika	Yeah
*Jody	Still the same
Abal	In Somalia we have a problem. In the city they not think like that but the rural people they still think.

This rural/urban divide was apparent through many discussions relating to health and disease. For instance, one individual recounted how nomadic people do not understand illnesses compared with urban people and try 'cultural treatments' such as soups or fire-burning rather than attending a Western doctor. As Ghaniyah explains:

Ghaniyah	Yes, yes they are because the town people when someone feels sick immediately they go to the hospital and they treat and nomadic people immediately they don't understand what the sickness is or they don't immediately seek, you know, professional people but they try first to treat, you know, cultural treatment.
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Although the social context of TB in Somalia has a profound influence on the way Somalis understand and respond to the illness, migrating to New Zealand has not only involved the movement of bodies but also of ideas, values and beliefs.

## **TB in NZ**

Since coming to NZ many participants indicated that TB beliefs and knowledge have changed profoundly and that TB is no longer a stigmatised disease. A number of reasons were given for this transformation including the free availability of medical resources and improved education levels. Somalis living in New Zealand today are constructed as being well-educated and knowledgeable about the disease and hence no longer fearful of the condition. According to Fakhir:

Fakhir	But nowadays it's ....normalising the TB...because the people they are realising that TB is curable, it's not killer disease as AIDS or anything like that and now they
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are encouraging to do, or to share their problems with families or friends or doctors, so yeah. So nowadays is come quickly.

Frequently I heard individuals comparing TB with influenza and constructing it as a normal, every-day illness that is treatable and easily cured. For instance:

Hala            It's normal. I tell many people. Because sometimes people TB no problem. TB is very easy. Same as 'flu.  
Jody            Are there some people you wouldn't tell  
Hala            Like my friends it's ok but some other people they know I was sick but they don't know why I was sick. But yeah, at least I feel in NZ that it's like the 'flu, so it's nothing to worry.

Hiyam            In New Zealand we heard that TB is like 'flu. At wintertime you get 'flu. It is like 'flu, I'm not worried. It is easy, nothing to worry.

In part the heightened awareness of TB is due to the activities of community TB educators. Initially educators encountered great resistance in attempting to talk about the disease. Some community members wondered why only bad things such as HIV/AIDS, FGM and TB were being talked about in the community. One educator commented that the only worse subject than TB to broach is that of HIV/AIDS. When asked about the challenges faced in delivering such messages, one educator noted that stigma remained strong.

\*Jody            And what was the greatest challenge that you found educating people about TB?  
Namir            I think that be, that, the stigma and the worry about TB. A lot of people believe that TB was like the way HIV is, the AIDS and they know, you're not going to die but people who believe there is no cure, it will come back again, it will come back again that's the belief of their...

The main aim of the education sessions according to one educator, was to spread the idea that TB can be treated:

\*Jody            And so what were the main messages you were taking out to your community members?  
Durar            We were, we were thinking two things. How to prevent TB some, one member has a TB, how to prevent TB and the other message was it's ok to have TB and there's a cure and it's simple, it's just like 'flu or sometimes easier and you can get early treatment and that's it. There's a lot of taboo and a lot of, there's a lot of

misunderstanding and taboo in TB culturally so we had to educate them about all of that.

Educators themselves discussed how their own views and beliefs had been drastically changed through receiving the ARPHS training. For instance, virtually all the educators believed that TB could be spread through sharing utensils. Unsurprisingly, when educators ran the sessions they found that many people also had misconceptions about the disease:

\*Jody ...How do you think the programme impacted the community?  
Kadar I think was learn more about it and they familiarise with it and just when they see it's not that scary as they used to think. I think they have ....improved, especially how they used to think about TB.

While broaching the topic of TB was incredibly difficult and threatened the credibility of some educators at times, it was felt to have had a positive impact on the community. Educators noted that there is much left to do but that their contribution had at least opened people up to talking about the disease:

\*Jody And just the last question is how do you think the TB education programme impacted the Somali community at large, at large?  
Durar I think it gave them an insight into what TB is actually it's...and that they can have TB, they could be cured, and I can't think what was the other thing. It's like any other disease. I think still some of them, yeah, sceptical about this, but mostly, they have changed, change of attitude.

The other main reason why individuals suggested that attitudes towards TB have improved is due to the availability of health services and TB medicine in New Zealand. One person said that she had never dreamed of having such easy access to medicine before. Medication and treatment is a very important component of Somali health and wellness beliefs (as discussed in Chapter Seven). The belief in the power of medicine is also relevant in terms of TB and has been attributed with the reduction in stigma. As noted in the following interview transcripts:

\*Jody In Somali culture what do people think about TB in New Zealand?  
Almas Treatment is free. Nobody scared or hide it. In the refugee camp the public health people used to come every two to four weeks and they would come and check people's rooms. We would ask for Mantoux tests. In New Zealand everything is free, hardly anything. Nothing to hide. Free doctor, free medicine. Not to worry. Less TB in Somalis now. In 1993-1995 someone in every Somali family had TB.

The attitude to TB has changed because it's now common. Like the 'flu. People used to hide because it's a bad disease. Like a common thing now.

\*Jody Who have you told about your TB?  
Hiyam I haven't discussed in anyone because I've only been here 3 months. I haven't met many Somali. But I think it's ok to discuss. I don't think people in New Zealand scared to talk about TB like in Somalia. It is very easy because there is medicine. Once you have treatment you are ok. Why I think we were scared in Somalia is because infection in chest and people cough yellow stuff and make me feel uncomfortable.

Yet although participants put forward the idea that TB is no longer as stigmatised as the past, there still appeared to be a great deal of stigma surrounding the disease. As raised by Husniyah:

Jody So now in NZ do you think the stigma to TB has changed  
Husniyah No not really, it's still the same  
Jody Do you think Somalis in New Zealand have a better knowledge and understanding of the disease?  
Husniyah Yes but you can still have knowledge and not do it  
Jody Yes I guess that's true of everyone isn't it. So TB is still seen as a scary disease?  
Husniyah Yes. But second to HIV. HIV is the worst. Cancer is fine and even syphilis is fine. But not TB.

Another participant stated that although people with TB were able to be part of family life, many still endeavoured to hide the nature of their illness:

Khalisah I have seen it where people with TB still share food with their family. No-one will ostracise them now  
Jody So if you have TB do you keep it secret or tell people?  
Jabbar People try to keep TB a secret. People claim they have bad bronchitis  
Jody Why?  
Jabbar Because of the stigma.

One respondent felt that stigma has not improved as stigmatised attitudes have migrated to New Zealand along with the people:

Namir ...TB it become historically it some kind of big disease in our society, it's shameness, so people come here and still they have that belief and the second thing was that people have problem was, public health nurse they come to houses

so other neighbours or other members of the community will see you, you are having the TB so that's the most thing they hate, that's the thing a big issue that stigma. You have TB, you can't get married, it's going to be heritage, your children will have that TB, that's the image was there, yeah.

Another person agreed stating that medical professionals need to be sensitive when raising the topic of TB with Somali asylum seekers and family reunion refugees:

*Jody	Do you have any suggestions of how medical people in New Zealand can provide better care for Somali people with TB?
Jalilah	Not to check family reunion and asylum seekers straight away for TB because the place where they come from, TB is still scary, bad disease so they will lie about knowing someone with TB. Mangere people ok, under control. Others need a lot of attention.

The continuing existence of stigma was noted by health professionals who worked with the Somali community when implementing the education programme. At the outset, individuals within the community refused to accept there was any TB amongst Auckland Somalis and maintained that it was no longer a problem. It took quite some time before it was even acceptable to discuss TB. The challenges faced by educators in discussing TB are also testament to the depth of feeling about TB. One educator described how community members wanted information on how to detect TB in *others* in order to avoid catching the disease. These individuals mentioned how they noticed some Somali families being visited by Public Health Nurses and speculated whether this visit was related to TB:

Durar	They ask you "If somebody comes how do we know they have TB? Somebody comes and we know some families we see the nurses coming to them so is that why the nurse coming to them"? So it's just like shame on the others and hiding so is it that the nurse coming to that family. Some families they saw, maybe even the nurses coming to children, you never know, but if you wanted them they said "We don't go to this families because somebody told us they have TB". So we know it's not that you can go there, you can see them, you can visit them, you can sit with them, you can eat with them as long as they are taking the medication, so it's 'ahhh', I thought there might be my friends taking the tablets so I thought I would get the TB.
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In addition, the assertion that TB is 'just like the 'flu' and is no longer stigmatised seemingly contradicts the challenges I experienced in trying to talk about TB in the Somali community (as discussed in Chapter Five). At nearly every stage of the research process, from participant recruitment through to the phrasing of questions, I encountered resistance to even talking about the

disease. For example, one individual I interviewed went to great lengths to assure me that her knowledge of TB was based on hearsay rather than first-hand experience within her family:

*Jody	So what are the symptoms of someone with TB?
Yaminah	I've never seen but I heard the person is weak, looks different, sick person, not strong, lose weight, lose appetite. I hear that, not in my family.

Other community representatives involved with social services also affirmed that indeed TB is still highly stigmatised. Kalilah recounted an experience with a Somali individual who became so distressed at her diagnosis that she had attempted to cut the TB out and was fortunate to be discovered and taken to hospital for emergency treatment. Some time later, this individual moved overseas to escape the stigma.

## **The nature of the beast: Somali beliefs about the etiology of TB**

In addition to considering the meanings Somalis attach to TB, I also surveyed people's understandings of specific aspects of the disease including causation, transmission, symptoms and the relationship between TBI and TBD. Participants were generally forthcoming about their views on the disease although a few said they were unsure. One individual was reluctant to answer my questions, stating that in-depth knowledge about TB was the domain of her doctor.

Before commencing interviews I anticipated that general community members' understanding of TB would be different to those who had personally experienced the illness. This however, appeared not to be the case. For example, when talking about the cause of TB none of those who had had TB attributed the illness to germs or bacteria. Instead participants generally provided multiple explanations for their illness including exposure to dust, a lung injury from a car accident and bad bronchitis. A theme that clearly emerged was that there was a great appreciation of the way in which poor socio-economic conditions contribute to the incidence of the disease. There was a generally good understanding of the mode of transmission, with refugee camps unanimously cited as an unhealthy place where infection occurred.

There was, however, a great deal of confusion about TB testing and treatment. While most people understood that the Mantoux test is used to test for TB there was a lot of confusion about what the results of the Mantoux test meant. One person equated a large Mantoux result with the need for medication, while another person thought that the Mantoux reaction was TB and described how she used various soaps and creams to try and wash it off.

The following section outlines the different beliefs Somalis have about the epidemiology of TB including the causes, transmission, symptoms and types of illness.

## Causes

Similar to Citrin's (2006) research, Somali participants expressed a wide range of ideas regarding the causes of TB including germs, heritage, moral retribution, worry, environmental factors, lung injury, worsening of influenza, climate and socio-economic conditions. Each of these will be discussed in turn.

The first type of causal mechanism mentioned was that TB is precipitated by a virus or bacteria (terms used interchangeably to refer to a mysterious micro-organism). Although this is the biomedical explanation of TB it was not commonly cited by those whom I interviewed. There was, however, appreciation of the link between humans and Bovine TB. One individual who was a community TB educator described how some community members were concerned about contracting TB from drinking cows' milk in New Zealand. This individual explained:

*Jody	Yeah. And so were people quite concerned about getting TB through milk?
Ghaniyah	Yeah. They say how can we know this milk whether it is safe or not and I said of course the New Zealand milk is quite safe because always professional people control and looking the meat and looking the milk and everything is safe.

According to this person, there was confusion about how cows became infected with bovine TB and the relationship it had with human TB. One participant also recounted how a friend who worked in an abattoir developed TB after he cut his hand.

Another cause of TB that was mentioned by a few participants was the idea that TB can be hereditary. Kwan-Gett (1998) conducted focus groups with eight members of the Seattle Somali community and reported that participants believed that TB could be hereditary for up to six generations. According to one Auckland Somali community TB educator, the idea that TB was hereditary was common. I similarly encountered this belief when interviewing individuals with TB. When discussing the horrible nature of the disease, one family member mentioned that Abir's future children would inherit TB from her. She then justified this belief by explaining how doctors always ask about family history of TB in order to determine who passed the disease on. I was then asked for my opinion on whether Abir would automatically pass on TB to her children:

Barika	No-one that you know like TB, horrible, you don't like
Furat	It's the worst disease ever
Barika	Yeah. And you know Abir, she had a TB, maybe the kids have TB, her family, you know, after, after, after they will have a TB [i.e. hereditary]
Abir	My kids
Barika	In the future, yeah
*Jody	You think so?

Abir	Yeah
Barika	I think so yeah maybe
Furat	My big brother believe that
Barika	What do you think? Even the doctor would ask you know the grandmother had a TB they said, if you say 'no' and then they said oh maybe this not TB', but if you say 'my grandmother used to have a TB', 'oh', they said, 'we maybe check the TB'. So if Abir had the TB, our kids will have maybe...

For a few individuals, TB was seen, in spiritual or moralistic terms, as a slight on the honour of the individual. Generally, community members tended to subscribe to this idea to a far greater extent than those who had/have personally experienced the disease. For instance:

*Jody	And what did people, what were Somalis attitudes towards TB?
Akram	They think about, it is a very shame disease, and they always, I forget the word it's called it. The people, they always thought that bad...they feel that maybe that person is different to the others because he get very bad disease or illness and little bit. The honour of that person is maybe affect if you get it, especially in the ancient time...

While Hala believed her TB had spiritual origins, Husniyah felt that the disease was retribution for immoral behaviour:

*Jody	And what do you think caused it?
Hala	I don't know. The gods just said, they gave it to me.

*Jody	So what are some of the beliefs that Somali people have about the causes of TB?
Husniyah	...that it can happen to someone who is bad or cruel and that TB gives TB as a gift to that person.

This retribution appeared to be particularly evident when there was the sense that someone had knowingly chosen to behave in a morally dubious way as indicated by one focus group participant:

*Jody	What kinds of people are more likely to get TB?
Bayan	People who always mix with other people. Go to nightclub, sleep in bad places get coughed on or in crowded places.

One idea that emerged in Somalis accounts of health and wellbeing (Chapter Seven) was the power of the mind. Worry is one example of the way in which the mind can have a powerful influence on health. Abal also mentioned that worrying about TB could cause it to happen:

Abal                    If we worry too much about the thing, if you say “Oh my baby might be able to get that thing” [TB] straight away the baby would get the thing you were worried.

When Abir became very unwell family members quickly suspected she had TB due to her coughing, night sweats and weight loss. Abir’s mother refused to believe it could be true and forbade other family members to even mention the word ‘TB’ for fear that it might cause it to happen. Interestingly, Hiyam believes that she developed TB through worrying about her family members back in Somalia and her inability to alleviate their suffering:

Hiyam                Sometimes I'm thinking too much so for example I had the TB. So I believe that TB attack me because I was thinking too much. I was worrying my family back home, a lot. Sometime I go to the toilet and I just sitting in the toilet but I was thinking my family. So I have got big family and I can't afford to fix their problems and I can't afford to send whatever they want so I was thinking, thinking, thinking a lot. So yeah, I thought that damaged my healthy...

Another cause of TB relates to environmental factors. As in the research of Edginton et al. (2002), who demonstrated that many rural South Africans believed that TB is caused by airborne dust, similar beliefs were cited in my research, particularly by men. These beliefs are potentially linked to male-dominated professions such as mining. Adil believes that airborne particles had potentially caused his TB:

Adil                    Yeah. The one thing I can't mistake is, I used to be spraying, spray painting  
\*Jody                Sorry?  
Adil                    For the work I used, the working.  
\*Jody                Yes, yes  
Adil                    Two jobs. My first job which I worked from August 1993 to 1995 was, spraying, spray painting. We used to wear a mask but that's not. There are two types of masks you know, the paper one and not that one, the paper one and we used to powder coat. I [read something] written lately that powder coating can lead you to have a TB from the powders because I used to spray different kind of powders...  
\*Jody                So there's possibly a number of ways  
Adil                    Because I've [read something] written somewhere, I heard those powder coating affect it. And I'm not quite sure...

Inhaling steam from working in commercial laundries was also thought to contribute to TB. This was an interesting finding as many Auckland Somalis work in a commercial laundry in Auckland.

To combat this, laundry workers in Somalia used to drink a lot of milk and special oil to wash out their chest and protect them from TB:

*Jody	Any other activities that can be more of a risk for catching TB that you can think of?
Barika	People who work the laundry cleaner, they make the iron using the machine, not iron like this
*Jody	Oh steam ones
Barika	Open it and then you know put the thing. Back home in Somalia if you use the iron, easily you get TB
Abal	TB, yes
*Jody	So you think the steam can make more of a risk
Abal	Yeah. In back home people used to work in the laundry in the things for the iron and they used to drink a lot of milk some oil that's this thing yeah...they drink the thick oil
*Jody	Oil?
Abal	And then they say it's going to wash the, it's going to be washed the chest
*Jody	So washes out the lungs
Barika	Yeah
*Jody	Did you try that?
Abal	No
*Jody	No
Abal	We never had that chance, we've been in refugee camp. In refugee camp, no oil. Special oil, oil...

Connected with the idea of inhaling airborne particles, there was also a strong association between smoking, chewing *khat* and TB. Smokers are thought to be particularly at risk of developing TB due to the lung damage caused by smoking:

*Jody	What do you think causes TB?
Shakirah	If you have a virus or injury to the chest. It then changes to TB. Can also be caused by smoking...

In addition smokers were perceived to be at risk due to overall lower health:

*Jody	But are some people more likely to get it [TB] than others?
Akif	Those who are heavy smokers, more than non-smoker who keeps health in better condition.

Chewing *khat* is another risk factor in part due to the long sessions that *khat* chewers engage in. One individual thought that *khat* chewers in particular were at risk because they did not tend to look after themselves:

*Jody	Because people who always chew the <i>khat</i> it takes a long of hours to sit and chew the <i>khat</i> . They chew the <i>khat</i> , and they forget to have the lunch or the dinner, to eat or to drink, they just...To chew <i>khat</i> for long, maybe 24 hours. Or maybe 48 hours, so they always become underweight people and they get infected with TB.
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Another cause of TB cited by a number of individuals is that it occurs as the culmination of an evolving chain of illness. Most commonly this comprised of a cough which becomes influenza which then turns into bronchitis and lastly into TB. For instance:

*Jody	What do you think causes TB?
Jalilah	Also if you get cold, 'flu, then bronchitis it worsens to TB.

Abal	If you get cough, 'flu and then you know, you know, you can TB easily.
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*Jody	What do you think causes TB?
Bayan	...If you get the 'flu and don't treat it it changes to TB.

As a result I was told that it is important to treat such complaints (cough or influenza) or otherwise they could turn into TB. This highlights the way in which seeking treatment and medication is a key component of Somali attitudes towards maintaining health and preventing illness (see Chapter Seven for further detail).

Another cause of TB that was cited by a number of individuals is that TB occurs as a result of lung damage. One participant believed her TB was caused by damage to her lungs as a result of a car accident. Husniyah and Akif suggest that:

*Jody	So what are some of the beliefs that Somali people have about the causes of TB?
Husniyah	That it's caused by an accident where the impact results in TB that a bad cough can develop into TB.

*Jody	What do you think causes TB?
Akif	...Also if you get lung injury and then the infection of the wound can lead to TB.

Individuals with extra-pulmonary TB also subscribed to the idea that TB occurs due to an injury. In most cases, people explained the location of their extra-pulmonary TB in terms of an injury that had happened to the particular body part. For instance, one participant who experienced TB in the back suggested it was caused due to an injury sustained after falling down the stairs and the epidural injection she received during childbirth. The idea of TB resulting from an injury was also shared by Khalisah who believed that TB could occur due to injuries sustained from heavy lifting. She explains this idea using a culturally specific context of camel herding, an important part of Somali culture:

Khalisah	Some Somalis say if someone is a manual labourer and lifts heavy things it can rupture and make a wound which then invites the TB to set up.
*Jody	And is that something you agree with personally?
Khalisah	Yes. We believe. We were told this. For example someone who herds camels away from the towns and when a female camel has a baby the herder has to carry the baby. The baby needs to stay in one place for seven days before it can walk. If the herder needs to move the camels before then he has to carry the baby. It is very heavy even as a baby. If the herder then starts coughing people think it's TB because of the heavy lifting for so many years.

The idea of the skin being a porous layer through which the weather can penetrate (as discussed in Chapter Seven) was also invoked when thinking about the lungs. This idea was also suggested in a focus group of Somali men who felt that living in a cold climate contributed to the development of TB as dampness could get into the lungs:

*Jody	What do you think causes TB?
Nawal	A chest/lung injury. In Nairobi they have very cold weather which can get into your lungs.

Yet despite this wide range of different causes of TB, there was an overwhelming sense that overall socio-economic conditions were an important cause, or determining factor in the development of TB. This is illustrated clearly in one individual's explanation of TB as being caused through a lung injury, prefaced by general living conditions:

*Jody	What do you think causes TB?
Khalisah	What I think causes TB when somebody did not have enough nutrition and been exposed to situation not enough to eat, become weak, easier to get infection like a cold, it persists because of circumstances, becomes worse, then bronchitis, person starts coughing which causes cracks in the lungs. TB germs can then invade and get into wounds and cause TB.

Poverty was commonly cited as an important risk factor in the development of TB. For instance Akram and Almas note how poor people were most affected by TB:

*Jody	And what kind of people get TB?
Akram	Usually very low economic level, and especially the large families that, who have a lot of kids and the level of economic is very low, illiterate people...

*Jody	What kinds of people are more likely to get TB?
Almas	People who don't get enough food or clean water or don't have a clean house. Often people who are refugees or are poor...

Nutrition and hygiene were two living conditions that were frequently mentioned as an important cause of TB. These tended to centre on a lack of food and lack of hygiene, two striking memories of the refugee experience. For instance:

*Jody	What do you think causes TB?
Akif	... Also if you get run-down, starvation you are more susceptible to germs.

*Jody	And what do you think causes TB disease?
Abir	Um, I don't know, I don't. I think, the hygiene, if you don't be clean and things and if you don't eat the healthy food and...

One individual who had had TB in Kenya that then reactivated in New Zealand believed it had occurred because he was not taking good care of himself. Due to exhortations from his doctor to lose weight, this individual began exercising for hours and hours every day. In addition he stopped eating food, only allowing himself a small breakfast and some fruit at night. When he was eventually diagnosed with extra-pulmonary TB, his family members tried to convince him to stop exercising and to start eating more food as they believed that this had caused the TB to reactivate.

Yet this is not always the case. One participant wondered why one of her relatives who was well nourished became infected with TB:

Barika	...my cousin wife she's the biggest of the family and she got the TB easily, why is this she's not protected?
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Other living conditions that were associated with the development of TB include lack of medicine, unclean water, stress and contaminated food. Refugee camps were unanimously cited as, not only

the place where people were infected, but also the cause as indicated in the following section on participants' beliefs about the transmission of the disease.

## *Transmission*

Despite the wide range of views on the causes of TB, nearly all respondents agreed that TB is spread when one infected person breathes on another. Typically, this act was associated with living conditions at refugee camps which were overcrowded, unhygienic and lacking in the necessities of life. For instance Almas stated:

*Jody	What do you think causes TB?
Almas	...Caused by sharing a room with too many people in refugee camps.

Typically, most individuals knew that this transmission occurred while being in a contained space with another person with infectious TB:

*Jody	What do you think causes TB?
Jalilah	If you meet someone with TB and share a small room with someone with the chest infection.

Nevertheless this belief was not universally endorsed with some believing TB can be transmitted during fleeting encounters. I remember one occasion when such a view was expressed in a public situation. As the excerpt from my research journal depicts:

*I accompanied one participant to a TB outpatient appointment at Greenlane hospital. Seated in the middle of the large waiting room was a woman with a baby. Ulfah approached the woman and said that the baby shouldn't be in the waiting room because of the breathing. Said that babies were weak and should be kept away from hospitals. A few moments later Ulfah looked at the woman and called out to her 'go into the corner with the baby'. The woman nodded and took the baby to the corner. I felt very embarrassed and wanted to approach the woman and explain Ulfah's actions. Ulfah said again that it wasn't good for the baby to be in here. She asked whether all the people in the waiting room were here for TB and I explained that the waiting room was for people attending the dental, dermatology and respiratory outpatient clinics. Ironically, a few minutes later the woman and baby were called by the respiratory physician. While Ulfah was trying to protect the baby from the people in the waiting room, chances are TB was already an issue for the woman and her family.*

In addition to the idea that TB is spread through close contact with someone who is infected with the disease, there were a range of other everyday behaviours that were thought to spread TB including eating together and sharing utensils, clothing and beds. Participants said that you should avoid doing all of these things with those who have TB. For instance:

*Jody	How can you catch TB?
Shakirah	If someone has TB you shouldn't eat the same food with them or share their clothing or bed.

One individual who became a TB educator recounted how she used to provide a relative who had TB with separate eating utensils and then wash his plates and cup with hot water and soap to try and avoid spreading the disease to other family members. She describes the surprise expressed by community members when she taught them about the ways in which TB could be spread, according to this individual people were:

Durar	...amazed when we told them that you cannot get TB if you eat with somebody or used the cup, used the plate and they couldn't believe it they said "No, no why isn't that's how you get TB from somebody?" and we said "No, no it's airborne, you just get it when from the breathing from the air". You can't get it from the eating utensils you use and you can't get it and so it's ok to eat with somebody that has TB, drink with them...
*Jody	So they were quite surprised?
Durar	Quite surprised that they say you can't get the TB that way.

As a result of these everyday behaviours, most participants advocated isolation and sterilisation in order to prevent the spread of disease. This isolation, as described by one respondent below, has contributed to the stigmatisation of the disease:

*Jody	What about beliefs about how TB is spread
Husniyah	Oh that they have to segregate. They think that the TB will be spread immediately if they are with the person. They don't eat with them, give them their own plates and food, make them hide in one room or outside. Very strong stigma and segregation. No-one will marry them.

Although some people thought that you could catch TB instantly upon contact with an infected individual, not all individuals develop TB even after close contact with those with active disease. For instance, in one family situation, a relative who shared a bed with Abir and spent considerable amounts of time with Abir never developed the disease:

Abal	Me and Abir used to sleep in same bed at home and TB she had it that disease and TB, I worried we used to sleep in one room, we used to share the food and I did not even get it, the infection because of my protection, my body...
Abir	And she doesn't believe she's going to get it ever.

Another reflected upon how TB was not automatically spread and that some family members catch the disease while others do not:

Ulfah	Today can you from four peoples you share food maybe some get, maybe some not get. Yeah. Because many peoples or family, Somali share. Some people TB, some people not TB for God can help peoples, I don't know, maybe...One mother is maybe TB, baby breast feeding, the milk she feed, baby not TB, mother is TB.
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While poor living conditions were frequently cited as an important determinant of TB, there were also particular groups of people thought to be particularly susceptible to TB. Elderly, young people and pregnant women were thought to be particularly vulnerable because they do not have the bodily strength or energy to fight off the infection. For Somalis, bodily strength is an important component of what it means to be healthy as discussed in Chapter Seven. Such ideas were raised by Ghadah and Ishraq who believed that they became infected with TB while pregnant. These participants felt that they were particularly weak during this time and therefore susceptible to infection. This idea was also raised during one group discussion in regards to young people and the elderly:

*Jody	And what kind of people do you think are most at risk of catching TB?
Barika	Kids or old people
*Jody	Kids or old people
Barika	Yeah
*Jody	Why?
Abal	Kids and person who just doesn't have enough energy
Furat	Weak person
*Jody	Weak person, ok.
Barika	And old. Why old?
Furat	Because they don't have any energy you know
Barika	Some old people they, don't have energy. Sixty one years they just walking and doing everything [imitates behaviour of elderly person], or sometimes...or eighty
Barika	If the person got you know, strong, maybe it takes four years the TB keep the body infection.

As this quote shows young and old people were thought to be at risk due to their limitations in physical strength to fight the disease. In the case of the strong person mentioned by Barika, they could fight the infection for a much longer period. Abal agreed that bodily strength was required to fight off TB:

Abal	If you get cough, 'flu and then you know, you know, you can TB easily. And then you breathe, you're not strong but if your body got strong you can protect maybe the TB...
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Although most individuals believed that particular groups of people such as smokers, poor people, old and young people were most susceptible to developing the disease, there were two individuals who felt that TB was indiscriminate in its choice of victim:

*Jody	So what kind of person gets TB?
Kadar	I think everybody gets TB, it doesn't specific kind of people.

*Jody	What kind of person gets TB?
Akif	Everyone has equal chance.

While there were two individuals who did not know how TB is spread, there was one respondent who doubted whether there was any spread of TB due to the infectious disease control practices of public health officials:

*Jody	Something I wanted to ask you about was how was TB spread between people.
Adil	In New Zealand or in Somalia?
*Jody	Yeah, how is the disease spread from one person to another
Adil	In Auckland? I think it's spread, I've never heard of any such case because here is, the authorities are very strict, if you have positive TB, active TB you can be isolated for two weeks. So it's hard to spread it. But some people actually, you don't know when they have the TB and they don't understand the TB because, for individual...so but I don't think intentionally someone would spread it. Like if I am totally positive I won't have a chance to spread it because of the rules that. But if I want to do it intentionally I can do because, it depends what TB, it's lungs I think it's very difficult.

One person emphasized that the way to prevent the spread of TB is to ensure that people take their medication. Once they were taking medication, they no longer needed to be isolated:

*Jody	So taking the medicine is really the most important thing?
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Akif	Yes. You could share food, sit together.
*Jody	So how did people know that the patient was taking their medication?
Akif	Those with knowledge and education they have that responsibility to take medication. They know how important it is. Those that lack, someone else would make sure.

As shall be discussed in the following section, the mode of transmission is also implicated in the type of symptoms experienced by those with TB.

## *Symptoms*

In total, interviewees had an extensive knowledge of the symptoms and development of TB. The main symptoms that were mentioned include weakness, weight-loss, coughing, fever, night-sweating and coughing blood as noted by one individual:

*Jody	How do you know if you have TB?
Jalilah	Fever, mostly night time, weight loss, not good appetite, headache, weak, no energy, night sweats...

Together these symptoms formed a powerful image of the TB sufferer and this has a number of implications particularly for those with extra-pulmonary TB.

For many, the tell-tale symptom of TB is weakness and weight-loss. When asked to describe someone with TB, the following description of a TB sufferer was typical of many accounts:

*Jody	So now what would a stereotypical TB sufferer look like?
Husniyah	Thin, tall, weak, weak raspy voice that has changed. Cough a lot. Sometimes blood. Not a strong cough but a weak cough. Because in Somalia we are like Polynesians in thinking that fat is good, that it is a sign of wealth and being healthy and beautiful. So whenever people see skinny people they think they might have TB.

This idea that TB is associated with thin and weak people was repeatedly mentioned. Jalilah suspected a house-guest staying with her has TB because he 'acts funny'. When I asked what she meant and she then said "weak":

Yet the equation of thinness and weakness with TB is being modified within a changing social context of health and disease. One individual mentioned how for some people, a thin and weak

person is now more frequently suspected of HIV/AIDS rather than TB, in part reflecting the changing attitudes towards the disease:

*Jody	So are you saying that in older days if you saw a skinny person you thought they might have TB, now it's AIDS?
Mahir	Yes. Now TB is normal. The big thing is AIDS. TB used to be very skinny. You can tell someone has AIDS because they are very demoralized. Have no more hope. It's an end. Person's outlook is dejected. You can tell. Someone with TB is not like that. There is hope after TB if you are treated.

As this account suggests, for some, the stigma of TB has been reduced due to the availability of medication. Some suggest that TB is now a normal, non-stigmatised disease and that HIV/AIDS has taken its place in terms of being the most-feared disease. Yet as the discussion in the following chapter reveals, this assertion is not universally accepted.

TB is also thought to limit the ability of the body to thrive and grow. In the context of children, one individual commented:

Kadar	For example, a child can't grow up. Growth is not compared to his age and his growth is, yeah, that's the main symptoms.
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Appetite was frequently mentioned particularly by those who had had TB themselves. They talked about how they lost interest in food and struggled to eat. One individual recounted,

*Jody	What happened when you started to get sick?
Abir	First time, I never eat anything, I started to hate food and you know.

This lack of appetite is an important factor as good food is such an important aspect of Somali notions of wellbeing and strength as described in the previous chapter.

Another individual agreed with the idea that weakness is one of the main symptoms of TB although these can vary according to the type of disease:

*Jody	What happens to your body when you get TB?
Akif	General weakness, depends on what type of TB you have as each type has its own symptoms.

When asked about the different types of TB, TB in the lungs was cited as the most common form of TB. A few also acknowledged that it was the most dangerous, based on the ability to spread the infection to others:

*Jody	And, do you think things would have been different if you had had TB in the lungs? Do you think things would have been different?
Adil	I think things would be different. I heard lungs are more serious than here (points to lymph nodes). Although my doctor tell me that if I not went for treatment, it could pass all the way to lungs. But I've just heard, especially from the doctor that lungs are more worse.

Yet there were also quite a number of participants who cited multiple places in the body in which TB can occur including lymph nodes, stomach, joints, kidneys, brain, tonsils and back:

Fakhir	It affects many parts of the body yeah. Not only the lungs but it can attacked the glands, and it can affect the brain, the stomach, it can affect the bones, it can affect everywhere of the body.
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The awareness that TB can inhabit many different parts of the body may be in part due to the fact that a high proportion of Somalis suffer from extra-pulmonary TB. Quite a few of these individuals stated that they had only just learnt this information in recent years due to the ARPHS TB education programme conducted in 2002. Ghaniyah suggests:

Ghaniyah	I get you know education of the TB I myself some, you know knowledge because I knew the glands or the lungs or other body but I didn't know...I knew that the joints maybe you have arthritis or you have rheumatism. I knew the TB glands, and TB lungs but I haven't had any idea for the kidneys and joints.
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Another individual echoed a similar sentiment when she stated that people attributed their illnesses to something other than TB due to limited awareness of the different body sites that can be affected:

*Jody	What is the understanding about the reasons for extra-pulmonary TB
Husniyah	No not really. They think it is something else apart from TB. They know about TB in the bones and lymph glands but not very familiar...

There was however a great deal of confusion about why TB inhabits various parts of the body. The following quotation highlights the uncertainty many participants had in providing additional detail beyond the body parts in which TB can occur:

*Jody	So what are the different types of TB that you can get in the body?
Ulfah	The different TB, is mainly the, maybe I don't know, I'm not sure, what sort what TB, I'm not sure my body TB, some people, other people maybe different TB. TB for bones, TB for ...here, TB for the stomach, TB or may be something is different. Yeah?
*Jody	Something different?
Ulfah	Yeah, yeah for the stomach, for body, for lung, for chest, things... Maybe people are different. Some coughing, some not coughing.

One individual speculated that the different types of extra-pulmonary reflected different modes of transmission. One community TB educator described how some individuals believed that drinking improperly treated cows milk results in intestinal TB. Another individual thought that lymph node TB was transmitted between husbands and wives or between a mother and her children:

*Jody	How can you catch TB?
Jalilah	Not sure. You can catch glands one between husband and wife. Also can pass from mother to baby or through coughing...

Another individual who had TB twice thought that it had crossed from one part of the body to another site in the body because the first instance of TB had not been properly treated. Yet while there was a generally high awareness of the different types of TB, some felt that pulmonary TB was the only type of TB. Others indicated that they were not sure of the different types of TB.

One commonly identified tell-tale symptom of TB is that of coughing and haemoptysis (coughing up blood) in particular. Coughing due to TB is thought to be different to that of influenza or a cold due to its length of duration and intensity:

Kadar	The main symptoms that the patient can feel is the coughing for a long time coughing not like 'flu that can be finished one week or two week, but the cough should be over a long time, a couple of months or years.
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Another symptom associated with TB is that of fevers and sweating. For instance:

Abir	Oh, I used to sweat all the night, yeah, I used to feel hot and hot and hot all the time...
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Yet because of the strong image of the coughing and emaciated TB sufferer, some individuals believed that they did not have TB as they did not appear to have the classic TB symptoms. For instance, when I asked one individual why she was reluctant to start TB treatment she stated:

*Jody	Why did you not want to take the tablets?
Khalisah	Because I was TB free. I didn't have it. We understand TB as being infectious TB people. Someone who is coughing, emaciated, weak and bed-ridden.

Khalisah then imitated the cough of a TB sufferer - body all bunched up rocking back and forward with a hacking cough. A similar situation happened for another participant, whose family disagreed with her TB diagnosis because she did not fit the stereotypical symptoms experienced by someone with TB:

*Jody	Why were your family opposed to the operation
Jalilah	We think people cough, weak, lose weight. They thought because I was not these things I didn't have TB.

Due to the firmly engrained ideas about the symptoms of TB, many of those with extra-pulmonary TB disease remained undiagnosed for a long time. This is in part due to the fact that the symptoms of extra-pulmonary TB are similar to other conditions. For instance, one individual with back pain and headaches was shocked to find out that the cause of his back pain was in fact TB. When those with extra-pulmonary TB were diagnosed, some were doubtful of the accuracy of their diagnosis due to the stereotypical image of the TB sufferer. Consequently, while education about TB has indeed increased awareness this can actually hinder the diagnosis and treatment of those with extra-pulmonary TB.

## ***TBI***

While a fairly consistent set of ideas about the causes, transmission and symptoms of TB emerged, there was a great deal of confusion about the relationship between TBD and TBI. One of the main aims of the Somali TB educators was to educate people that there are two types of TB. One participant who admitted that she had not realised that TBI existed and was distinct to TBD:

Hiyam	Because I don't know much about TB. I used to think if you had TB you die straight away. I did not know that TB could sleep. I was surprised I couldn't pass on to family. I took medicine to kill the germs. I'm still asking why...
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In many situations entire families were receiving TBI treatment. In these cases, I often observed that parents decided not to tell the children why they were taking medicines. One mother simply

told her children they were taking medicine to get rid of germs without ever mentioning TB. In another family, the children were unsure why they were taking medication with one child thinking it was for malaria.

Yet since commencing treatment for TBI, many people have gained greater knowledge about the difference between TBI and TBD. Frequently, people referred to having 'germs in their body' or that they had sleeping TB. What is interesting is that most of these people believed that by taking TBI preventative medication these germs would be killed and that they were protecting themselves from future attack. Such a view is in line with Somalis overall beliefs in the power of medication (discussed in greater length in regard to TB in Chapter Nine). This unquestioning belief in the power of TBI medication is potentially due to the lobbying of Public Health Nurses who frequently have to spend quite some time trying to convince clients to accept that they have TBI and to get them to begin treatment. One unintended consequence of this lobbying is that individuals have an elevated expectation of the effectiveness of the treatment.

Another common cause of confusion is the Mantoux test. All individuals I interviewed had received a Mantoux test when they arrived at Mangere Refugee Reception Centre or during voluntary health screening offered to asylum seekers. In general there was a high level of awareness that the Mantoux test is used to find out whether people are infected with TB or not. Both health professionals and community educators described how after the TB education programme, many Somalis lined up wanting to be tested. This according to one participant also occurred in the refugee camps where some families who were concerned at the disease status of fellow room-mates requested doctors perform regular Mantoux tests.

While there was good understanding of the purpose of the Mantoux test among participants, there was a great deal of uncertainty in interpreting the results of the test. One person equated a large Mantoux result with the need for medication and was confused as to why she had not been prescribed TB medication. Another person thought that the Mantoux reaction was TB and described how she used various soaps and creams to try and wash it off. One young person believed that he was taking TBI medication to prevent further itchy reactions produced by the Mantoux. One person said:

*Jody	So why are you now taking tablets?
Muhab	Because at Mangere I had an injection and it was itchy and then got big. It means I've got germs.
*Jody	And what will happen to you if you don't take the medicine?
Muhab	Maybe I will get lots of itchy.

This focus on the Mantoux test result is potentially due to the fact that for many, it is the only visible and outward sign of an internal and hidden infection.

## Summary

This chapter has described the different ways in which Somali respondents understand and make sense of TB in order to address Aim Four. Respondents had a wide range of ideas about the causes, transmission and symptoms of TB. These various ideas tended to sit alongside one another with many individuals subscribing to multiple explanations for their illness. Biomedical explanations did not tend to dominate views on TB which tended to be firmly grounded within a socio-ecological understanding of health that acknowledges the varying influences on health. Somewhat surprisingly, ideas about TB did not vary between those who have experienced TB personally and those that have not. Men were inclined to subscribe to environmental causes of TB in part due to the nature of occupations that these were associated with. General community members tended to frame TB in moralistic terms unlike individuals who have/had the disease who tended to explain the disease in terms of more external factors located in the everyday environment.

Talking about TB was not a straightforward process and the conflicting narratives that emerged highlight the extent to which people's constructions and understandings of the disease, reveal important insights into the social worlds in which we live. Many participants were eager to present a 'progressive' account of TB within the Somali community – that it was a disease of the past which had been overcome by medical expertise, the availability of effective medication and that 'modern-day-Somalis' were well educated and thus no longer fearful of the illness. Privately however, chinks in this public 'armour' emerged with accounts of shame, isolation and disadvantage. TB remains a highly stigmatised and dreaded illness.

Somali ideas about TB strongly reflect the social construction of TB in Somalia and in wider socio-economic and political constraints. There is evidence that TB beliefs have been modified in New Zealand in response to the greater availability of health care and medical resources and, to a lesser extent, efforts to raise awareness about the disease through educational activities. As a result of these factors, a number of respondents suggested that TB has become de-stigmatised in the face of enhanced access to medical assistance. While this may be true to some extent, TB remains a highly stigmatised and discrediting illness, the implications of which will be discussed in greater depth in Chapter Nine.

## Chapter 9: TB journeys

*They say “Oh look that is the man or the woman who has got the TB, so please don’t eat with him, don’t go with him, don’t grow with him, don’t talk to him”. That’s the way they are isolating the people, yeah. So the person who has got the TB is scary for that, all social thing...so it’s really very difficult. (Fakhir)*

This chapter charts the ‘journeys’ of Somalis with TB from the illness recognition stage through to their post-treatment experiences. While this chapter largely focuses on one illness, it is important to remember that TB is not experienced in isolation from the other health issues faced by people in the contexts of their everyday lives. While the delivery of medical services in New Zealand is compartmentalized into primary, secondary and tertiary health care sectors, individuals with illnesses such as TB are required to interact with a broad spectrum of health professionals and services across these institutional divides. For instance the assistance of GPs is typically sought at the beginning of the illness process. However the GP’s role lessens once patients enter the hospital system. What is often not recognised is the burden of responsibility placed upon the individuals themselves in managing and navigating the myriad of appointments, referrals, tests, prescriptions and visits. This requires an enormous investment of time and resources over a long period. For some who face many other responsibilities in terms of family, children and finances it is a significant undertaking.

In order to describe people’s TB journeys this chapter is organised chronologically, drawing upon participants’ narratives to highlight the inter-connections of the different stages of the process with their own personal experiences. I begin by describing the illness recognition process before moving to consider the way in which participants responded to illness. I then consider the diagnosis and treatment process and the different people involved in caring for those with TB. The final section of the chapter examines the significant impact TB has upon people’s lives particularly in terms of isolation, separation and the exacerbation of existing vulnerability.

### Recognising illness

For most individuals who were eventually diagnosed with TB, the recognition that they were ill hinged on the presence of two variables; unusual pain and/or the inability to complete everyday tasks. Localised pain occurred in those who were later diagnosed with extra-pulmonary TB and tended to be located in the same part of the body as the TB. One participant who had extra-pulmonary TB recounted how she developed pain in her side and stomach. Another individual had strong back pain. Most people attempted to reconcile this pain as being temporary and fleeting –

something that would go away with time. One woman who had experienced strong stomach pain in conjunction with fatigue described this idea:

*Jody	So tell me about the time when you first noticed you were feeling unwell?
Raha	I was feeling tired, very weak, couldn't walk long distance. Couldn't be active at all. Felt tummy pain. Thought it was normal and would go away. I lost my appetite, couldn't eat. I did not like people asking me to be active. Sleeping all the time, didn't want to go anywhere...

Those who experienced localised body pain tended to explain it within the context of their everyday lives. One person who had a sore back attributed it to working long hours at the office. Another with chest pain believed it was asthma while another person with a painful back thought it was connected to a fall that had occurred previously.

The second stage at which most individuals recognised they were unwell occurred when they found themselves unable to function normally. Illness is therefore seen as a deviation from a desired or 'normal' state of personal function. In the words of Khalisah "I felt like I couldn't do what I used to". For one young person, the recognition of illness occurred when she found herself unable to complete physical education classes at school while for another person, it was the inability to play a game of soccer. One mother became increasingly worried when her young daughter stopped wanting to play and do 'normal' childlike activities. For Ishraq, this involved overwhelming tiredness that prevented her from completing simple household tasks:

Ishraq	Like tired, and you can't do anything, you can't like pick up cups and put them in the kitchen and ...you feel tired and you can't do anything and you feel tired.
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This interference with daily life appeared to worsen to the point where many individuals were completely incapacitated and unable to function. As Tibah recounted:

Tibah	I live the bed and...I am not standing up, I am not sitting, I am not eating.
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In many cases, this restriction of everyday life was the starting point from which a range of other symptoms followed. One individual, observed that after feeling lethargic and tired, she noticed her appetite decreased:

*Jody	What happened when you started to get sick?
Abir	First time, I never eat anything, I started to hate food and you know it was so bad with me and then I became, you know, like too much cough and sweat and I was

not able to you know like be at school. When I run my heart used to beat a lot you know, yeah.

Abir I don't used to eat anything, I just used to hate and I never feel you know hungry, I never really eat any food. [My mother] tell me eat, eat, eat and then I tried eat and then when I eat little and I hate it...

This lack of appetite meant that many participants lost a great deal of weight:

Abir I become so skinny  
Abal Yeah skinny.

\*Jody So how has having TB changed you?  
Ishraq Yeah, to be a skinny  
\*Jody Skinny  
Ishraq Yeah I was fat before.  
\*Jody Why do you think that happened?  
Ishraq Lose the weight because you don't, you don't eat food if you eat the food you cough and vomiting and the food you know, not going to your body...

Another common symptom experienced by those with TB was the presence of night sweats:

\*Jody And what was the main problem it caused you, when you had TB infection  
Abir Oh, I used to sweat all the night, yeah, I used to feel hot and hot and hot all the time. Yeah.

While Adil put these down to environmental factors (hot summer weather), the occurrence of these sweats led many to start wondering what was wrong. One thing that interested me was the way in which most people tended to minimise their experience of lethargy, lack of appetite and pain as being something that would 'go away'. One male who had extra-pulmonary TB first recognised that he was unwell when he noticed a large growth in his neck. This was seen as a deviation from normal. While he had previously noticed weight loss and night sweats, it was not until this growth occurred that he began to wonder what was causing such things. For those with pulmonary TB, it was not until a cough began that the other symptoms were taken seriously in their own right. For Abir, it was only once she started coughing that she began to see her other symptoms (lethargy, lack of appetite and sweats) in a different light. This is described well in the following narrative:

Furat It was the cough  
\*Jody Were you coughing?

Abir	Yeah a bit. Coughing like middle of night you know
*Jody	And when did you start coughing?
Abir	After like when I became more and more, when I became really sick
*Jody	So after the night sweating?
Abir	Yeah
*Jody	You started coughing. And at what stage did you think it was TB?
Abir	At the cough, cough
*Jody	At the coughing stage?
Abir	Yeah. Also the losing weight, losing weight.

For this individual, these physical symptoms of lethargy, appetite and weight loss soon spiralled into a sense of depression:

Abir	I didn't even care about my life
Abal	Abir, tired, tired every time sick.
Abir	I was near to the grave, you know, near to die.

*Jody	And do you think, having had TB has changed your beliefs, your thoughts
Abir	Yeah
*Jody	In what way?
Abir	I was think I was going to die. I wasn't thinking that about, you know, the world or anything for, like now I actually yeah,
*Jody	And how did that make you feel, having that thought in your head?
Abir	Hopeless, yeah.

People's illness stories tended to be firmly grounded within their own life histories. The following account speaks to one woman's experience of the civil war, wider health issues, health system encounters and socio-economic hardship. It also raises points discussed in Chapter Seven on Somali health beliefs in terms of pregnancy being considered as a time of weakness:

Khalisah	I was sick and have never been as strong since. I was pregnant and because I was the breadwinner I was working very hard selling goods at a market. I then got jaundice and had yellow eyes. I was also seven months pregnant. Was doing physical work. Had fevers at night, jaundice, sternum pain, back pain. I wasn't getting enough food. Not only was there not enough but also what there was, was not nutritious food. I went to the doctor because I wasn't feeling well. I had chest pain, stomach pain and my urine went orange. I was also seven or eight months pregnant. That was another reason why I didn't want to take the TB medicine was because it is not good during pregnancy.
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Illness also impacted upon families. One mother recounted how worrying about her daughter's health had taken a great toll. She believed her daughter was close to death and worried that she would never recover:

Abir	Yeah, the whole family thought it's finished for you, you're going to hell, you're dead, bye bye. That's all. They thought I was going to die, and yeah...
------	--

When her daughter required surgery to accurately diagnose her illness, Abal became very distressed and concerned that her daughter did not have the strength to survive the operation given the toll TB had on Abir's health:

Abal	When they took her to the operation room, I just sit her bed and just keep crying...I didn't expect to see her [Abir] come back...I was crying two hour until I see she was fine...I had a operation, and I knew that the operation is no good and I had a big operation and I thought oh...she doesn't have that much energy and if she has the operation maybe she will die quickly...
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While Abir successfully recovered from the operation it was just one step in, what would be, a long and gruelling treatment process.

## Responding to illness

As discussed in Chapter Seven, Somalis place a great deal of emphasis upon self-responsibility in terms of responding to illness. Interviews with individuals with TB indicated that many attempted to manage their illness themselves using home remedies or Koranic healing. For instance, when one female participant became extremely lethargic, lost her appetite and began coughing, her mother began plying her with soups, meat and milk. As discussed in Chapter Seven, it is believed that these food types are particularly wholesome and good for building strength. Ghadah felt that her symptoms were due to influenza and began treating herself accordingly:

Ghadah	At Mangere X-ray and Mantoux, everything clear. Three years ago I become sick. High fever at night, coughing, headache, no energy, vomit. I thought it was the 'flu so I had honey, lemon and black pepper.
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As discussed in the previous section, a number of participants waited quite some time before they attached significance to their symptoms. This is true for Adil who noticed large lumps in his neck. He delayed visiting the doctor as the growths were not painful and seemed to come and go. He showed the lumps to a co-worker who said that the lumps were normal and that he had

experienced something similar in the past. It wasn't until the growths became much larger that Adil became quite concerned and visited an accident and emergency clinic late one evening:

Adil	I noticed enlarged lymph nodes. Would go down and come up at different times of the day. Would come up after work. I showed a co-worker the lumps, he touched them and said it was normal. Another co-worker of mine had lumps on his arms. The lump wasn't causing any pain. Then one day the lump was huge so I went with a friend to the emergency doctor at St Lukes White Cross. White Cross sent me to Medlab to take a sample but they couldn't [take one]. White Cross then sent file to family doctor who referred me to Auckland Hospital. They did an ultrasound and took a sample with a fine needle. After a few days they came back with TB diagnosis.
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While there were a variety of illness and TB experiences there were some commonalities shared by different participants. The first was the way in which nearly all participants repeatedly visited their GP during the diagnosis process. Most had a primary GP they usually visited although, due to high demand, many had to seek assistance from other GP practices when appointment waiting times were long. GPs tended to feature at the beginning of the illness process when individuals first noticed that something was wrong:

Within the literature on TB, the notion of delayed diagnosis is frequently mentioned in terms of the delay on the part of patients in presenting at their doctor. The opposite appears to be true in the case of my participants who visited their doctor very frequently in search of relief. One person stated that she visited her doctor between 10 and 20 times before she was diagnosed, a mother took her daughter to the doctor every day while another woman reported that she visited her doctor twice a week:

Ishraq	I was very sick and every one, every one week I go twice, twice a week I go to the doctor family and they told me you don't have TB it's pneumonia.
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Although people sought repeated assistance from their GP this often did not yield the outcome respondents were hoping for. Of interest to me were the accounts of the way in which the ideas and views of participants were dismissed by their medical practitioners. For instance:

Barika	And then my Mum keep saying to the doctor, she has TB, but the doctor didn't believe it...
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A small number of participants suspected they had TB before being formally diagnosed. Ishraq thought she might have TB due to the correspondence of her symptoms with those of the

'traditional' TB sufferer as outlined in Chapter Eight (i.e. someone who is thin, weak, coughing and experiencing night sweats). Her views were however rejected by her doctor in favour of the diagnosis of pneumonia:

Ishraq	I went to doctor family and I told them I need x-ray and they give me x-ray and then, like you know, the injection you have and they told me you don't have TB you got like pneumonia.
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Another person whose relatives were receiving treatment for TBI also believed she had TB. When she mentioned this to her doctor she was told that this was not the case based on her lay knowledge compared with the doctor's 'expert knowledge'. Although not formally diagnosed, Ghadah suspected she may have had TB in the refugee camp due to the similarity of symptoms with her current sickness:

Ghadah	Went to family doctor. Went to Greenlane x-ray. I was excited when I went there because I thought they might find something. X-ray clear. Family doctor gave me cough medicine. He gave me more medicine and cough medicine. I felt few hours of relief. When he listened he said chest was clean. Somehow I don't know why I thought I had TB. I told family doctor I thought I had TB because when I was in refugee camp I had same symptoms. In Africa and Mangere. And he said "No, you're not a doctor".
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Many participants felt extremely frustrated at the way in which their illness accounts were minimised or even dismissed by their GP. Abal became increasingly distressed when her doctor kept on saying that her daughter was "Fine, fine, fine". In another case, one mother discussed how she believed her daughter was sick but this idea was not supported by her GP. She returned with her daughter for many visits yet a biomedical cause of her illness was not discovered. After a number of weeks, Shafiqah's daughter was diagnosed with TB. As the narrative below shows, although Shafiqah holds the New Zealand health system and doctors in high regard, she believed that her doctor should have been able to diagnose her daughter's illness more quickly. Part of Shafiqah's frustration appeared to stem from her belief in doctors as the ultimate medical authority (as outlined in Chapter Seven):

Shafiqah	Everything in NZ is good. In NZ the pills are free, there is a hospital, they take you there, the nurse comes to your house - compared with Africa where you have to walk to the hospital and pay your own money for things. NZ very very good in that respect....but he [GP] should have known it was TB. I knew that my daughter was sick, I am her mother but he didn't think so.
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Furthermore, Shafiqah blames her GP for her daughter developing TB in the first place by not prescribing effective treatment for influenza. This draws on a health belief (described in Chapter Seven) that TB can occur at the end of an evolving chain of illness (i.e. cold, influenza, TB):

Shafiqah	Because family doctor didn't give medicine for the 'flu, it turned into TB.
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In response to these shortcomings, Shafiqah changed her GP.

Those with extra-pulmonary TB who presented with localised pain usually left their GP's surgery with a prescription for Panadol. This resulted in feelings of frustration of being prescribed an over-the-counter medication that did not assist them greatly. The following narrative refers to Barir's frustration at repeatedly being prescribed Panadol during his second and third visits to his GP:

Barir	Second time same. Third time I didn't take any pain relief because when he [doctor] went to give it to me I said "Look I already have the other two [prescriptions] you give me" and I left. I was upset.
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As a result of this dissatisfaction many individuals bypassed their GP's and directly admitted themselves to hospital after finding that pain relief did not alleviate their symptoms. This is explained in the following narrative:

*Jody	So when did you first start to feel unwell?
Haha	Sometimes hot, sometimes cold. One month, one month. One month I was sick, but I was just trying, I'm ok, because I had fever and sometime I feel cold, sometime I feel hot. And I went my family doctor and he said to me "Take the panadol, go home". Not feeling well. And then I went to the Auckland Hospital for emergency. My fever was very high and they couldn't find anything and then they take all my blood tests, urine test...nothing, everything was showing OK. And then they transfer to Greenlane. At Greenlane they decided to go back in to find out...

In a number of cases this decision to go to hospital was made by family members who were concerned at their declining state of health of their loved ones:

*Jody	So can you tell me about how you were feeling when you first noticed you were unwell?
Raha	Went to family doctor after three weeks. She explained and prescribed medication. The medication had not effect. Now had diarrhoea from medicines. Four days later had blood test and x-ray. Before I got the results I ended up in hospital. My older sister was very worried about me and convinced my other sister

to take me to hospital. Had headache, nausea - worse than before and pain in stomach. Next day in hospital they had suspicion of TB.

Ishraq            The next day my husband told me no you don't go to doctor family again and he called the ambulance and I went to Auckland hospital and I sleep all night there. Next day they told me you going to take you blood, urine and yeah they couldn't see anything and they take you know the sputum, spit.

Unlike others participants who bypassed their GP in favour of directly presenting at hospital, on Barir's fourth visit to his GP he was very assertive and demanded a referral to hospital:

Barir                ...he gave me pain relief and I go back four times and I said, 'I'm not going back'. and the family doctor send me to the hospital and when I go to the hospital they put me in the scan they see that there is something wrong here. And then so what happened after that, and then they put me some, they said it's liquid, it's very bright and they put me some kind of tablet...then I was two month in hospital...

For everyone I spoke with, presenting at hospital proved to be fruitful and was the place at which people finally obtained an explanation and the treatment they were so desperate for. It is important to note that many of these cases were especially complicated particularly given the wide-range of health issues participants were facing. Nearly half of my participants had extra-pulmonary TB that is extremely difficult to diagnose due to the similarity of symptoms with other illnesses. This is one of the reasons why Das et al. (2006b) urge health practitioners to have a "high level of clinical suspicion for TB" when dealing with refugees and migrants (Das et al., 2006b:1).

## **An explanation at last!**

\*Jody                Can you tell me about the time when you found out you had TB?  
Jalilah                I was the healthy person. I do not know how they found TB in me.

One issue that is frequently raised within the wider TB literature is that of delayed diagnosis due to late presentation at medical services. As mentioned earlier, those I interviewed presented very frequently at their doctors. However, many still endured a long wait before being correctly diagnosed. Of the 12 people who experienced TBD in NZ, eight were able to provide information about the dates at which they became unwell, visited a medical facility and were finally diagnosed (the remainder, such as those who had TB in Somalia, were unable to remember the timeframes of their illness). Of the eight people for whom such information was collected, the average length of time between first falling sick and being diagnosed was 4.4 months with a range of one to 11

months. The average time before diagnosis for those with pulmonary TB was 3.7 months and 4.8 months for those with extra-pulmonary disease. This is not surprising given that extra-pulmonary TB can be extremely difficult to diagnose due to its similarity with other common ailments.

Given the turbulent process of diagnosis, many participants were extremely unwell by the time they were admitted to hospital most frequently in the Emergency Department. For most individuals, the hospitals were described as a place of relief where the cause of their troubling symptoms was finally explained after many fruitless visits to their GP. Most people spent a few weeks in hospital until their overall health had improved and the course of treatment commenced.

For many, TB was the diagnosis of 'last resort' after every other possible test and explanation had been ruled out. This is depicted in the narratives below which highlight the wide array of tests carried out in hospital:

Ghadah	Three years ago I become sick. High fever at night, coughing, headache, no energy, Vomit...Coughing. Became pregnant, not eating, vomiting and very weak. Don't remind me, it was crazy. It was like two illnesses. I maybe caught it when I was pregnant when I was weak. Maybe neighbour gave it to me. Still not well. After baby born, another chest xray, xray clear. Two x-rays clear. After baby born bad stomach pain and still coughing. Gallstone. Sputum test. It took 40 days for answer, found TB and then started TB treatment...
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Hala	...And then I went to the Auckland Hospital for emergency. My fever was very high and they couldn't find anything and then they take all my blood tests, urine test...nothing, everything was showing OK. And then they transfer to Greenlane. At Greenlane they decided to go back in to find out
*Jody	Why did they transfer you to Greenlane?
Hala	They take everything. The blood test, the urine test, everything, the xray, scan, but they say no, we couldn't find anything, better to go Greenlane and they have to check over there.

Given the difficult diagnosis process, respondents' reaction to their diagnosis was influenced by their individual health and TB beliefs. Similar to the findings of Searle (2004) a number of participants were very relieved to find out they had TB because they were concerned that the cause of their illness was something far more serious such as cancer. TB was felt to be relatively straightforward in comparison with more serious heart and liver conditions:

*Jody	What were your thoughts and emotional feelings during this time when they were trying to find out what was wrong?
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Hala	I feel they might find a lot of bad disease, it's very bad, because I was very sick!
*Jody	Like what?
Hala	I was worried they might say oh you got a problem for your heart, for your liver, yeah. They found out it was TB I said "Thanks God, thank you God" because easy, TB easy, very easy.

Part of this relief seemed to derive from the fact that there is medicine to treat TB and that it is freely available in NZ, something that was certainly not the case back in Somalia. This emphasis on medicine is depicted in the narratives below:

*Jody	And what was your reaction when the doctor told you you had TB? What was your reaction, how did you feel?
Ishraq	...TB is better because the TB they got you know the medicine if you got 'flu and they don't have medicine they told you, drink only water but the TB is, they got a lot of medicine.

Ghadah	I don't know why xray clear and sputum not. Doctor didn't know. I didn't ask, I just wanted medicine. Spent seven days in hospital.
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The power of medication was a clear theme that emerged during the interview process. As described in Chapters Seven and Eight, Somalis place great value on medication. Part of this is due to exhortations from the Koran for each individual to obtain the treatment they need in the case of illness. Furthermore, medication forms an important part of Somalis health beliefs and practices due to the presence of a Western biomedical health system back in Somalia. Yet due to political and economic pressures, medication became scarce and highly sought after and eventually was only available to those with power and wealth.

While some felt reassured by the availability of TB medication, others' reaction to the diagnosis of TB reflects the long held stigma surrounding the disease. One individual said that it would be better to die than to be diagnosed with TB while another said that when her daughter was diagnosed with TB she thought it meant that death was imminent. There were also a significant number of individuals who were so unwell at the time, that all they wanted was relief. One individual said she was too sick to care about the diagnosis and wasn't entirely aware of what was happening around her. Another person put it this way:

*Jody	What was your reaction when you found out you had TB?
Raha	I didn't think anything. I just wanted medication. Doctor said it was curable. I knew I was sick. I didn't care, just wanted medicine.

There were, however, a small number of individuals who were uncertain about the accuracy of the TB diagnosis. One person did not believe she had TB due to the large number of health checks and screening she had undergone since arriving in NZ. Because she was a family reunion refugee and had not lived in a refugee camp (a place which she associates with TB) she felt that she couldn't possibly have the disease:

*Jody	So why did you not believe him when he said "It's TB". Why did you say, No, not TB at the start?
Tibah	Yeah, because I think it is not, TB for my body. Because if they, I couldn't even this country, every sick, everywhere is check my health the doctor and the clinic. And a lot of times I live, I come to New Zealand in '97, July and he checked all my health, alright. Where come from this TB? Yeah. Where it comes from this TB? Because I am not refugee camp, I'm not..., you know where it comes from this TB? My thinks this could be. I think maybe it's not TB because I know I'm not TB. I am not, I'm sure it's not TB.

A similar idea was expressed by one participant who also felt that she did not fit the stereotype of the typical TB sufferer. Interestingly, she framed the disease as something that had been placed on her externally, something that wasn't internal or an innate part of who she is:

Jalilah	I was the healthy person. I do not know how they found TB in me.
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On a similar note, Yaminah was also surprised at the diagnosis and began questioning where and from whom she had picked up the infection from. Adil was also shocked and found the diagnosis hard to accept given that he had always had good health and had not been sick during his adult years.

Another interesting finding was how those who had previously received TBI medication (Raha, Abir, Ishraq) and went on to develop TBD some time later did not appear to connect the two events. In some cases, people did not even mention to me that they had had TBI treatment in the past and I only picked it up when browsing through their Public Health medical notes. In participant narratives, these appeared to be two discrete and unrelated events. One individual who mentioned his previous experience of TBD in Kenya believed that the TB had moved from one location in his body to another because the treatment course was not very effective. While he received TBI treatment as the result of a large Mantoux reaction when he arrived in NZ, he later developed extra-pulmonary TB. Khalisah who also had TB previously in Somalia had not undergone treatment due to the fact that she disagreed with the doctor's diagnosis, the cost of treatment and concerns about the effect of the medicine on her unborn baby:

Khalisah	...My reaction was nuh-uh I didn't want medicine so I left the pharmacy
*Jody	Why did you not want to take the tablets?
Khalisah	Because I was TB free. I didn't have it. We understand TB as being infectious TB people. Someone who is coughing, emaciated, weak and bed-ridden.

Despite Khalisah's view that the diagnosis of her Somali doctor was incorrect, subsequent testing and feedback from Public Health officials in New Zealand has led her to re-evaluate this medical encounter and accept the diagnosis of TB.

## *Hospital*

While hospitals were described as a place where an accurate diagnosis was made and a source of relief in the form of effective medication, it was a place from which most individuals soon wanted to depart. The reality of spending long periods of time within the TB ward was compared with a prison due to the fact that windows were not able to be opened giving a sense of feeling trapped and separated from the outside world:

Abir	Yeah but I didn't like it you know it was like a prison, you can't go outside you know
*Jody	So you couldn't open the window?
Abir	No you can't...They didn't even have a window
Barika	You can't open it the window
*Jody	It would've been like a prison
Abir	Yeah it was, you just stand at the window and just watch outside, they said you can't open, they just keep only the TB and nothing else
Barika	The TB place, TB ward, that's why.

One individual described how she was required to stay in hospital much longer than she wanted to:

Ishraq	...they told me I have to stay like one month until you clear everything and I say "No I can't stay one month and I'm going to take my medicine at home" and they say no you should stay one month in here.
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This institutionalisation was problematic particularly for those with other young children to care for. One mother who had only recently had a baby, wanted to return home after commencing treatment. In the end her husband had to care for their newborn child at home, placing a great strain on the family.

There were also interesting patterns in the way in which hospital staff were described. Unlike GP's, the doctors that participants encountered at the hospital were overwhelmingly portrayed in a

positive light with superior medical knowledge and were able to accurately and effectively treat their complaints. For instance:

*Jody	What has been your experience with doctors?
Jalilah	They are my friend. I like them.

*Jody	What has been your experience with doctors?
Hiyam	Good.

*Jody	What about the doctors? Do you think the doctors were good?
Tibah	Yes, I like my doctor. So nicely doctor...

This was somewhat surprising to me given that in a piece of earlier research with a range of people from refugee groups, very few constructed doctors in a positive light (Lawrence and Kearns, 2005). One possible explanation is that those interviewed as part of this research were so sick at the time of diagnosis that their main focus was on survival and recovery rather than evaluating the level of care received. One individual I spoke with, who had worked at a refugee camp in Somalia, said that Somalis tended to accept medical advice and authority quite willingly compared with other refugee groups who tended to be very suspicious about doctor's ideas and advice.

In general, doctors were held in high esteem and universally constructed as the legitimate holders of medical authority. Some elaborated upon this idea by describing particular functions of doctors. For some, doctors were constructed as 'distributors of medicine':

Raha	They just gave me the medication.
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For others they were seen as 'distributors of information':

*Jody	How would you describe your experience with the doctors and why?
Raha	Doctors used to see me once a week. Would update and explain what's going on, what's the next thing. I was happy with treatment...

Doctors' hold on 'medical truth' was evident in that a number of individuals answered my questions by quoting their doctor's views. For example:

*Jody	What are/were your expectations around recovery?
Adil	Doctors explained it. Said it would take nine months to recover.

*Jody	And, do you think things would have been different if you had had TB in the lungs? Do you think things would have been different?
Adil	I think things would be different. I heard lungs are more serious than here (points to lymph nodes). Although my doctor tell me that if I not went for treatment, it could pass all the way to lungs. But I've just heard, especially from the doctor that lungs are more worse...

Adil continued by adding that if his doctor had advised him to notify other people of his illness he would act immediately.

At times doctors were also described as being quite authoritarian. For instance, two participants spoke about the ultimatums given to them by their doctors. One individual was asked to remain in hospital for one month. When she objected due to the difficulty of caring for her children, she was told that if she did not stay, she would not be helped in the future if she became unwell again. Another individual who was not convinced that her diagnosis was correct was reluctant to start TB medicine. After doing a second test to prove to Tibah that she did have TB her doctors said:

Tibah	...It's TB. They say "You have to take it [medication]. You have to. If you don't, I [doctor] use the force...I use the force because I'm looking for your health, I am a doctor".
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After the second test and due to the urging of her husband, Tibah began the course of TB treatment.

One intriguing point that emerged was the way in which hospital nurses were rarely mentioned in comparison with hospital doctors. While this may in part be due to the medical hierarchy, hospital nurses were largely faceless, anonymous providers of basic care functions, such as showering or dispensing medicine:

*Jody	How would you describe your experience with the nurses and why?
Raha	Nurses they were good. Helped me take showers, bed and bring food.

While participants developed strong relationships with their PHNs, nurses at the hospitals were not spoken about as warmly, with particular nurses being singled out for being unfriendly and unhelpful. The exception to this was the nurses encountered at Starship Children's Hospital. These nurses were portrayed as being warm and caring and left a positive impression upon the children who were treated there. In addition, Abir recalls how volunteers working for Radio Lollipop would visit her at hospital and play fun and enjoyable games. These efforts helped Abir during a very difficult time of her life:

*Jody	And what about the nurses, what were the nurses like?
Abir	Some of them they used to come and play with me
*Jody	Oh really
Abir	Yeah,
*Jody	What would they do?
Abir	They used to play, bring you know games and they like, we are from the lollipops [Radio Lollipop] or something, you know the games play.

While the stay in hospital was an important milestone in the TB journey it was really only the beginning of what would be a long and gruelling recovery process.

### *DOTS and home based care*

*Jody	What has been your experience with doctors?
Jalilah	They are my friend. I like them
*Jody	What about the [PHN] nurses?
Jalilah	They are my best friend.

While many people were happy to return home after spending time in hospital, it marked a new phase of the treatment process. At this stage Public Health Nurses (PHN) became responsible for the care of those with TB through the DOTS (Directly Observed Therapy Short-course) programme. DOTS is the WHO standard for TB treatment and is designed to ensure successful treatment outcomes through observing patients taking their TB medication. At the beginning of the treatment process, participants were put on DOTS however many transitioned to some degree of self-administration as treatment progressed.

While participant contact with doctors was relatively infrequent and of short duration, the long length of time of home-based TB treatment (6-12 months) meant that participants had a great deal of interaction with their PHNs. Visits from PHNs came to be a part of the rhythm and nature of daily life for many participants. Furthermore, the role of PHNs was not limited to administering DOTS but they also cared for their patients in the wider sense of the term. This form of care, also documented by Searle (2004), was unique for many individuals who had never established such a relationship with any other health care worker. The strength of this relationship helped participants get through the harrowing treatment process and face the challenges of daily life. Overwhelmingly, participants spoke highly of the PHNs and were grateful for their assistance during the treatment process:

*Jody	What has been your experience with nurses?
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Hiyam	Very good. Explain to me everything and I will say thank you for them because they come to my house and give me medicine. Three tablets every day and one vitamin...I am very happy with Public Health Nurse.
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PHNs also were sensitive to the needs of their patients and acutely aware of the stigma faced by people with TB. They had gone to great lengths to protect the privacy of their patients and to avoid any association with TB. PHNs described to me the way in which they wore casual clothes (rather than a uniform) and drove unmarked cars to avoid drawing attention to the family they were visiting. This however, did not deter speculation amongst community members about what medical conditions different households were facing. Contact with nurses was also one of the primary ways in which people gained information about TB. In addition they helped translate complex medical information into a form that was easily understandable for their patients:

*Jody	What has been your experience with health service providers?
Adil	Good. Doctors explain. Nurses visit, explain disease. Helpful. I visit per month...when the nurse come and visit me she encourage me, explain to me more how to take, when to take, what to do. It was helpful...

*Jody	The nurse would come once a month?
Adil	Yes. The nurse would take with her, if I need more tablets or she would come and explain to me the result of the lab result.

PHNs also played an important role in supporting patients during the treatment process. The treatment process was often a harrowing one with the requirement of taking numerous tablets with a range of side-effects including nausea, itching and joint pain. This required perseverance from PHNs and participants alike. One person describes her experience of the treatment process:

Abir	Oh really hard. I had to get ready every day because my PHN came to my home and I had to get ready for the tablets and then I started to get, you know, started to hate them, the tablets and then like, I wish that I was dead, you know, because of the tablets.
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The frequency of such a treatment relationship also restricted individuals' freedom and ability to travel. At times Abir tried to 'escape' her PHN but was eventually tracked down. For example:

Abir	I didn't mind them [the nurses] but I did mind the tablets yeah because you can't go anywhere holidays and even if I go somewhere they're like come here you've got to have the tablets
*Jody	Really

Abir	And I have to come at that time
Barika	Sometimes she used to go when she finished school, go to cousin's house to watch TV, Sky movies but nurse used to come. She called her my cousin and she said "Yeah I'm here". Sometimes she [PHN] go my cousin's house and said "You can't hide me, I'm coming"!
Abir	I used to try hiding!

As the above accounts depict, the treatment process was a strenuous one for many people I spoke with, with a great burden of responsibility placed on individuals for their own care in terms of managing the myriad clinic visits, home visits, hospitalisation, x-rays, blood tests and a seemingly never-ending stream of follow up visits. It is important to remember that some people were also dealing with a raft of other health concerns both for themselves personally and other family members. This meant that some individuals were constantly interacting with a range of medical services. During the course of fieldwork I attended five chest clinic visits and was astounded at the amount of time these visits took. All in all, the recovery process required an enormous investment of time. While there is little recognition of this within wider academic literature, PHNs attempted to do what they could to assist individuals through this time. Adil appreciated how his PHN brought the medication with her saving him from having to go to the pharmacy to collect the medicine:

*Jody	And what pharmacy did you go to to collect your medicine from? The same one?
Adil	For TB medicine, I think she used to give it for me so I don't have to go, she always give me...

At times PHNs transported patients to their hospital appointments or gave taxi chits to help those without transportation. These taxi chits were often supplied to PHNs by Lung Health (formerly known as the TB Association). This charitable organisation has a long history of providing both practical and financial support to people with TB and other respiratory illnesses.

When Adil suffered facial paralysis as a side-effect of the TB treatment, his PHN contacted his employer explaining the situation and arranged sick leave. Accounts from other participants highlight this idea:

*Jody	And what about the nurse, does she come to your house?
Yaminah	She comes once a month. It is good, someone to support me.

*Jody	And what about with nurses. What was your experience with nurses? How did you, what did you think of the nurses who helped you?
Hala	Very good people. They helping me a lot and I always give thanks for them.

*Jody	What about the nurses?
Jalilah	They are my best friend. My PHN is like someone in my family. She picks me up, drops me off, changes appointment, makes appointments for children...

At the end of the lengthy treatment process, PHNs would sometimes provide a small gift to their patients. For instance, Hala received a vase and some flowers from her PHN when her treatment finished.

PHNs also went beyond a purely nursing role to care for individuals in terms of their everyday life circumstances. Given the financial hardships faced by Somali families PHNs would often provide practical support and assistance. In the nurse's records I noted a number of occasions when nurses gave people supermarket vouchers and clothes. They also acted as advocate for their patients. One nurse helped refer one person for home-based English tuition while Ishraq's PHN assisted with her family reunification application.

At the time I conducted this research, the PHNs working for ARPHS were assigned to particular parts of the city. As most Somalis live in close proximity to one another, this meant that a small handful of PHNs dealt with the vast majority of Somalis. Over time this extended involvement with Somalis came to be a great asset as they built up a great deal of knowledge about Somalis, their culture, ways of communication and politics. In particular, PHNs involved with Somalis had gained an appreciation for how Somali society works. Such knowledge is profoundly important particularly when dealing with sensitive topics such as multiple wives. PHNs also gained an appreciation for Somali networks. If a PHN was trying to locate a missing patient, due to her in-depth community knowledge, she knew at which different addresses she could find people.

While nurses gave practical assistance, they also knew how to deal with their Somali clients in order to produce a successful outcome. Somalis are often described as being very assertive and forthright and at times PHNs themselves had to be very assertive, particularly when some people wanted to discontinue treatment. Yet what is interesting is how participants recognised this and appreciated that their PHNs had been direct with them but in a respectful and culturally appropriate way. One person who was very reluctant to take her medication recalled:

Barika	Sometimes she cry when she take the tablets and she just nurse said "Abir I'm waiting you. You can't throw away this time".
Abir	There was one in my mouth and she was like, "just eat it"!

Yet while PHNs were assertive this was tempered with accounts of kindness, fun and good humour:

Barika	...She was so funny lady, we used to love her
*Jody	So you had a good relationship with your public health nurse
Barika	Yes
Abir	She was funniest, yeah...

To spur their patients on, PHNs would often bargain with their patients. One nurse recounted that if a patient refused to take their medication she would say “Ok, once you've taken your medication I will take you to your next appointment at the TB clinic”. Things that were bargained for included petrol vouchers, food vouchers, toys and transportation to clinic appointments in order to ensure continued compliance.

The strength of PHNs culturally-specific knowledge was recognised by participants as being essential in ensuring lengthy treatment regimens were completed. Towards the end of 2004 however, the structure of the PHN area-allocation was changed and new nurses were assigned to the Roskill/Mt Albert area. The close ties between nurses and their Somali patients appeared to me to be instrumental in ensuring positive outcomes for participants and PHNs alike. By relocating PHNs with many years of experience in caring for Somalis, years of hard-work, trust-building and relationships were lost.

In speaking with Somali individuals with TB, those with negative views about their PHN tended to arise due to the lack of a strong interpersonal relationship and the belief that their PHN did not understand them. Khalisah was unhappy at her PHN because she believed that she approached the family with 'commands' and was authoritarian rather than participatory. The family was very ambivalent about taking the TB medicine due to this strained relationship. The PHN on the other hand believed that this reluctance was because she “had not done a very good job of persuading” the family to take the medicine. During one conversation I had with this PHN she expressed frustration at how the family had missed appointments. I reminded her that the family had not received their appointment letter (it was delivered to the wrong house) and that they were not responsible for the mix-up.

Some nurses were seen by participants as being too authoritarian. One participant who enjoyed the company of her regular nurse found it difficult when other nurses came instead:

Tibah	...My PHN she is not, she is not too strong. Some nurses are too strong saying “Take tablets, take tablets”. But my PHN is nice, conversation and “How were you yesterday” and “How are you today?” because it really helps and I'm happy to take it.
*Jody	Like a friend?
Tibah	Yeah that's right. But nurses are coming and two weeks strong ladies are fighting with that and say to me “No complaint, OK - You have to take it”. I say “No I don't

	want to take it” and they say “You have to” and then I say “No I don't want to take it”. Yeah, fighting me
*Jody	Not nice
Tibah	Yeah, and not come back my house. My PHN is good though, gentle lady.

Within the literature there is often a dichotomy between the DOTS provider (typically a PHN) and the recipient/patient. Yet within many of the families with whom I worked, this distinction was not always as relevant. Given that there were a number of instances when entire families were receiving TB treatment, the mother often became responsible for administering medication to other family members:

Abal	Two day me, two day me...she used to start trusting me because she can't come all the times and then we become different times me and Abir and her and she just say 'oh guys you old enough this time to taking tablets'.
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This is similar to Shetty et al. (2004) who found that women were often the main caregivers during the TB treatment process. This responsibility was often a difficult for one for mothers to deal with particularly given the side-effects and children's reluctance to take medicine. In many situations, nurses were perceived as being authority figures who needed to be respected and obeyed. When mothers were responsible for ensuring the medication was taken, children sometimes tried to get out of having their medicines. This required mothers to be forceful and determined in order to overcome their children's resistance to the medication. In some cases, mothers themselves were also on TB treatment meaning that they were responsible for their own medication also. PHNs did remain involved however and would frequently do a pill-count to check that all the doses were being taken.

The other point that is often not recognised is that although DOTS is a fairly prescriptive programme, individual treatment regimes change frequently throughout the treatment process. Once a good relationship was established, people were allowed to choose whether they wanted daily DOTS visits, or to be visited two or three times per week but have to swallow more tablets during those visits. This is summarised by one person:

*Jody	What has been your experience with nurses
Hiyam	Very good. Explain to me everything and I will say thank you for them because they come to my house and give me medicine. Three tablets every day and one vitamin. Visit one time per month. I no longer use tick-off calendar. I don't think I need it anymore. Public health nurse give me three option. One, every day. Two, two times per week. Three, if you are very good person, trust person and I will come and check medicines. I choose three. I decide to take that responsibility.

There was also variation in the drugs used and those who administered them. Sometimes PHNs would visit, other times it would be a Healthcare Assistant. Healthcare Assistants (or nurse aides) would often carry out home visits for PHNs and administer medication to patients. The PHN did however maintain overall responsible for the treatment process.

## *Medication*

As discussed in Chapter Seven, Somalis place great emphasis on medication. This idea was repeatedly emphasised by participants in terms of TB medicine. Upon discovering the true cause of their illness, some expressed relief because of the availability of TB medicine in NZ. A similar finding, was documented in Shetty et al's (2004) research with Somalis in the UK. They note, "the belief in TB treatment was overwhelmingly positive. Despite the uncertain knowledge about many aspects of the disease, the importance of TB medication and the need to be compliant with treatment protocols was not in doubt among all subjects in this study" (Shetty et al., 2004:81).

As discussed in the section that describes participant response to diagnosis, a number of individuals expressed relief at finding out they have TB due to their knowledge of the existence of effective medication. For example:

Jalilah	At Mangere I had big Mantoux. For next one year they did investigations. Blood test was negative, chest xray negative, bone test ok, sputum test ok. Public Health people chasing me for one year. Doctor at Greenlane said one gland was bigger than the other one
Jody	How did you feel at that time?
Jalilah	I was happy at all those things. I wanted them to find it. Happy because I knew there was medicine...

What was interesting to me was the way in which this belief in medicine gave participants a sense of security. Moerman and Jonas (2002) in their critique of the placebo effect, discuss the meaning responses people have towards medicine and medication. They argue that medicine is imbued with meaning and that elements such as doctor's attire (white coats), manner, style and language have been linked with patient wellbeing and treatment outcomes. In terms of pharmacological medication, Moerman and Jonas cite a number of studies in which people responded to the colour, branding and descriptions of particular medicines (Moerman and Jonas, 2002:472). In this study I found that those who received TBI treatment believed that the medicine would protect them from ever being faced with the TB threat again. This belief may be, in part, due to the efforts of PHNs to persuade their patients to take TBI medication. In many people's words, it was seen as eradicating the germ and offering a complete cure. One individual explained how she was protected from ever getting TB in the future because she had taken six months TBI preventative medicine:

Barika But for us no, I don't think so because they told us, if you take this six month, even if you breathe, you know, if you take some, someone who has a TB, the six month protect you, six month tablet, will make you protect[ed from] the germs.

Another repeatedly cited belief, in accordance with biomedical views, was that once people start taking TB medication, they become non-infectious quite quickly. Of those who felt that TB was less stigmatised in the past, many added the qualification that it relies on people taking their medication:

Ghaniyah TB is not a kind of disease which has no treatment, it does have treatment and it is not difficult if you get the medication immediately, you can be healthy the rest of your life...some people they believe that, you know, that TB is the worst disease but it's not, it's not something difficult, it has treatment and some diseases are much worse than TB. If you have hepatitis likely you can die before someone has TB die and also TB has medication. Immediately you can be healthy as anyone...and if someone has TB that person is not contagious when he is having medication, he is normal.

Ghaniyah You are normal as soon as you got the treatment, you are normal, you have no any problems and your lifetime everyone will die but you are hundred percent sure that you have, you got treatment and you are perfect and your healthy is quite hundred percent ok and you are the same as everyone.

Yet while a great deal of trust is placed in medication, there are some who are doubtful and suspicious of the particular medication they take. According to one individual who has acted as an interpreter within the community, this is because of the large number of tablets individuals are required to take at once. It also touches on ideas regarding the origin of medicine as touched upon in Chapter Seven. Some Somalis are dubious as to the quality of some medicines and these concerns led some individuals to throw their TB medicine away:

\*Jody So you said that people throw away medicines because they didn't know if they could trust them? Anything else?

Husniyah Because they were given too many to take and were worried that the quantity might cause some damage. Also worried that other people might see they were taking tablets and think they had TB. I used to do interpreting and I used to feel so sad because people would throw their medicines away. I told the nurses at Mangere not to believe the people when they said they had taken their tablets because they wouldn't have.

\*Jody Because you said that people used to throw away tablets in Somalia also. Why did they do that then?

Husniyah        Because there were too many of them for TB and people thought they were not helping. Might take them one day but stop when they were feeling ok. People might not be educated about why they have to keep taking them.

Yet while there was a strong belief in the power of medication, a number of individuals suffered with strong side-effects from their TB medicine. The most common side effects were nausea and joint pain with others experiencing vision problems and hair loss. For the most part, people believed these side-effects occurred as a product of the internal battle the medicines were waging against the TB germs.

\*Jody            And how do taking the tablets make your body feel?  
Masarraah      Nausea and sometimes my heart plays [races] a bit  
\*Jody            Why do you think the tablets make you feel like that?  
Masarraah      I think the tablets are fighting the germs and that's why I feel sick.

Several individuals had severe joint pain mainly in their knees, ankles, shoulder and neck that greatly restricted movement with some people being unable to venture out of bed for quite some time:

Tibah            My joints are too sore. My joints and my joints are not working. Last time I'm not get up without help, sitting like this. It's too sore, the pain.

Yaminah        I started the medicine but the medicine make me sort of joints pain, side effect so sometime I even couldn't go to the toilet while I was receiving...

\*Jody            So what did you do when you were in lots of joint pain?  
Hala             I was 'ahhhh' I yell a lot. Everything, people, please can you help me, help! Was not working, please! I couldn't help...  
\*Jody            And did you go back to the doctor about the joint pain?  
Hala             Yeah, they know. They said it was the medicine only, was ok.

Nausea was another common side-effect that affected a large proportion of participants and made it very difficult to take the tablets. In some cases, participants would vomit after taking their medicine. This meant that they had to be given another tablet. For one individual to whom this happened a lot, the PHN would stay for half an hour later to ensure that the dose was properly taken:

\*Jody            And what was that like?

Ishraq	A lot of medicine. To take one time.
*Jody	And how did it make your body feel taking the tablets?
Ishraq	Sometimes making you sick, sometimes making vomiting.

Another frequent side-effect was itching. This was often treated with an antihistamine. One individual recounted the following experience in hospital after taking her first dose of TB medicine when she became overwhelmed with violent itching and scratching. At first she thought she had been given the incorrect medicine but the strong side-effect was explained to her as a reflection of the amount of TB germs in her system that the medicine was trying to fight:

Ishraq	Midnight they start for me the medicine. Then medicine was like drugs, I was sick and I was like I don't, I don't want anything and I called for the nurse and I told her. They say 'No, it's ok' and then I was like something you know scratch me and after fifteen minutes...and I called three times and all nurses come to me and I said 'no you're going to kill me, you give me wrong medicine' and they told me 'No, it's the TB medicine' and they call you know the doctor and they told me doctor is going to come like half an hour and I wait, I wait doctor. The nurse was sitting with me and the doctor coming and they give me something you know to stop you know like itching and give me like something that the panadol until morning. And then it's too hard I didn't know TB is like this one...and I didn't know TB is like this one. But the doctor say it's because the germs there was in my body too much because they wait two month [until diagnosis made]...
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Other serious side-effects were also experienced. One individual developed facial paralysis as a side-effect of his TB treatment. This resulted in paralysis of the left side of his face, one eye that would not close, dribbling, pain in the neck and ear that affected his vision and an inability to make facial expressions. This also made eating and sleeping very difficult. The day it happened was very distressing as Adil believed he was having a stroke. He contacted his PHN who took him to the GP where he received medication. At the time Adil was feeling very anxious and alone and keenly felt the pain of trying to reunite with his family in Kenya. At the time of writing Adil believes the paralysis is 80% resolved, although his vision and flexibility of the left-side of his face is still limited.

**Compliance**

As discussed in Chapter Four within the literature on TB, there is an enormous emphasis on the issue of compliance and the factors that both foster and hinder compliance. This emphasis is similarly borne out at the practitioner level where considerable effort is devoted to ensuring individuals complete their treatment. Such a focus has been internalised by participants whom I interviewed with people going to great lengths to tell me about how they tried extremely hard to

take all of their medicines and to not forget. This may be due to the vigilance of nurses and pill counting to ensure that no doses have been missed. For instance:

*Jody	Do you find it hard to remember to take your tablets?
Hiyam	It's like I never forget my breakfast.

Adil	First four weeks I had six tablets every day. Last six months I had three. I had nine months of medication in total. The last three months I took tablets with food so I would have them at work after my break. I never missed one. I tried very hard. The nurse would visit every one to two months to see if I had enough tablets. I had tablets first thing in the morning
*Jody	What was the treatment process like
Adil	Ok. I never missed. I felt weak
*Jody	Did you have a problem taking them every day
Adil	Never. Never had a problem. It's just tablets
*Jody	Did you sometimes want to stop?
Adil	Actually no
*Jody	Never?
Adil	Never. I never forget or miss...No. I tried my best.

Most individuals were aware that nurses visit people with TB to ensure that they are taking their medication. This supervision was seen as being necessary for those who were not responsible enough to monitor and manage their own health:

*Jody	Why do you think they visit some people every day?
Hiyam	Maybe they are lazy people, not responsible, brain not working properly because they have to think. The people who is giving medicines is healthy - I'm the one who needs them I have to take responsibility. I feel it's ok because if I miss some dose, check tablets. Useful reminder. I know [my PHN] will know if I miss a dose.

*Jody	And why did the people come to help you take your medicine do you think?
Hala	It is the government policy
*Jody	Why do you think the government has done that?
Hala	Because I have to become a healthy person.

*Jody	Why do you think some people don't take their medicine?
Adil	I think that, it depends on some people, whether they see this as survival thing, whether it disappear and some people are very, like they don't consider

	themselves as TB patient, they say “No, it can't happen to me” and they don't believe it first time
*Jody	Really, so they don't want to take their tablets?
Adil	Yeah, they don't want to take their tablets
*Jody	Because they think they don't have the disease
Adil	They don't have the disease and they cannot have it because it's impossible you know. Different types of people and some people are very busy and or very lazy. Sometimes they forget, their tablets sometimes, you have to chase them around. It's hard.

One individual felt that for her, daily DOT visits were a waste of nurses' time:

*Jody	How did you find the treatment process?
Jalilah	Ok, the family feel it is waster of time. Nurse coming was a waste of her time.

Of the participants I spoke with there was only one individual who admitted throwing away her TBI preventative medication. She later developed TBD:

Abir	You know before they give me tablet, you know like hundred of them, they like you have to eat it every day three of them and then I straight away, I used to throw them on the window every time because I didn't like tablets and I never eat it before It was the first time, they say you got infection, taking tablet for one year, and then I used to throw out the window then I started to get sick, sick, sick and then we had to, had to put me in the hospital, yeah
*Jody	So you were given six months of tablets
Abir	Yeah
*Jody	And did they give them to you all at once in a big bottle?
Abir	Yeah the whole thing
Barika	And they tell her, my Mum to watch her. So my Mum she did it. Used to tell her to take her medicine but she never, she always, you know, throw it.
Abal	In the rubbish
Abir	You know like, the thing, one day, one tablet, I have to take out the paper, the daily one, so I used to keep the things and then take the tablets
Barika	Throw the tablet?
*Jody	And the nurses believed it?
Abir	Yeah
Abal	Naughty
Barika	After six months we had all the infection and she get the biggest one. And for us maybe we lucky.

Abir's mother who was responsible for administering the medicine had no idea this was occurring:

*Jody	Did you know she had thrown the tablets away?
Abal	Tablet, no. Every day, water and tablet...ok, ok, kitchen...
Abir	She told me to eat and then I just go out to the, I went to the bathroom and I just throw out the window.

When I asked Abir why she had thrown the tablets away it was largely due to their taste. According to Abir she hated taking them. In the past when she was treated for another illness she was able to receive injections rather than tablets which she much preferred. Interestingly enough, when I viewed this participant's file there was a letter from the hospital clinic at the end of the treatment process stating that "on assessment today it appears that she has taken this medicine well with good compliance". This confidence however proved to be short-lived when Abir later developed TBD.

The second time around Abir was very closely monitored. According to Barika, the hospital nurse would stand over her waiting until the tablets had been swallowed:

Barika	They used to watch while she was taking the medicine. She used to get a special nurse who used to come every time while she was taking the medicine and watch her.
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Later when Abir was discharged from hospital and put into the care of the PHN, this vigilance continued:

Barika	Sometimes she cries when she take the tablets and she just nurse said 'Abir I'm waiting you'. You can't throw away this time
Abir	There was one in my mouth and she was like, 'just eat it'
*Jody	Did you tell them you'd thrown out the other ones?
Abir	Yeah they knew
*Jody	They knew. Hmmm. How did they know?
Abir	Because like you know they told me that you didn't eat the tablets ...

Abir credits her daily DOT visits as the reason why she completed this course of treatment:

*Jody	Do you think it helped that she came every day?
Abir	Yeah. Because if she wasn't coming I would be like throwing them again...

Monitoring of compliance is not only a Westernised value but was practiced back in Somalia. One Somali-trained doctor recalled how they used to battle with the topic of compliance and back in Somalia patients were held accountable to their elders and threatened with imprisonment if they did not comply. Another doctor who worked in Somalia also echoed a similar sentiment and said that most individuals had to report daily to get their medication and always did so.

### *Clinic visits*

Once individuals had completed their course of treatment, they had several follow-up appointments at the Chest Clinic at Greenlane hospital. As discussed in Chapter Five, while most of my participants had already completed TB treatment, I was granted permission to attend five outpatient clinic appointments with three different participants. For each of the three individuals I was able to provide transportation to the clinic that they otherwise would have struggled to organise. It was also a good opportunity to better get to know each participant. As I was often asked to accompany participants at very short-notice, I was unable to notify the clinic that I would be coming. At the time of consultation I introduced myself, explained my research and made sure the doctors were comfortable with me sitting in on the consultation.

The first visit on which I accompanied a participant was an eye-opener. After arriving, the participant, interpreter and myself were required to wait for 45 minutes beyond the designated appointment time. The encounter soon became tense as my notes from the visit describe:

*The doctor started off first of all by asking how Ishraq was, and how she felt. Ishraq said good. Ishraq then mentioned to the doctor that she has a persistent cough and that she was bringing up blood and phlegm. The doctor replied 'First you said you were fine and now you're not. You're changing your story'*

The interpreter tried to intervene by explaining that it was customary for Somali people to say 'fine' when asked how they are. This too was dismissed by the doctor as being something 'common to many cultures'. The acrimonious air of the consultation continued. Ishraq then complained about her throat/thyroid gland throbbing at night. This was met with the terse reply "Well this is the first time I've heard of this". Ishraq added that she had been to see someone at the hospital about it before. Initially the doctor seemed annoyed she couldn't be more specific. He then found the notes of her visit to an endocrinologist and said "Oh well, I'd better have a look at it then". When attempting to examine the area of complaint, the doctor sighed exasperatedly and rolled his eyes as Ishraq moved her head scarf to allow him to palpate the area. He expressed the opinion that the glands were not too enlarged and asked about the results of the endocrinology appointment. Ishraq said she was never told. He asked, "Well why didn't you ask your GP?" She said she had, but her GP had not told her either. The doctor then spent some time trying to find notes but gave up in frustration saying "I can't see any record of any letters. This is useless, I give up. This record

system is hopeless". Similar to the findings of Searle (2004), problems with technology and medical records took centre stage as frustration levels increased when Ishraq's medical notes and referral letters were unable to be located on the computer system. Notes I made during the remainder of the clinic visit are below:

*Ishraq tried to explain that she thought her throat was causing her persistent cough rather than her lungs. This was met with the reply "I'm not that interested in your interpretation". By this stage I was struggling to contain myself and refrain from jumping to Ishraq's defence. I struggled as I was there to observe and did not want to further worsen the situation by objecting to the way in which the doctor was speaking to the participant. I looked to Ishraq, worried about how this might be affecting her. She kept her eyes fixed firmly on the interpreter the whole time. Due to the cough, Ishraq was sent for additional sputum and blood tests to see if TB had returned. Ishraq asked about the blood test, and wondered why she never found out the results. This was met with the reply "Well patients don't find out, only the doctors. You are obsessed with tests aren't you". I was beside myself with anger by this point and struggled to remain an 'observer'.*

What appeared to be happening was that the doctor's attention was fixed firmly on test results and x-ray images rather than listening to the voice of the individual in describing her state of health. During an interview with Ishraq she described to me her concern at her cough and vomiting. Having completed a course of TB treatment she was worried that TB had maybe come back. The doctor dismissed these concerns but scheduled her for repeat blood and sputum tests and another visit in six weeks.

The second clinic visit I attended was quite different. This time we endured a wait of nearly two-and-a-half hours past our scheduled appointment time. The consultation was vastly different in terms of the way in which the other doctor related to Ishraq. The doctor was very courteous to Khalisah and apologised for the delay. He also communicated in a respectful, easy-to-understand way, pausing often to check whether Khalisah had any questions. The doctor asked Khalisah how she was feeling and whether there was any change from last time. He then asked her if she had been coughing and whether she had fever at night. She said she wasn't coughing but did feel like she was burning up in afternoons and at night. She also said she had a very sore stomach. Khalisah had evidence of TB in the past (evident from a recent chest x-ray) and there was some questions over whether this was old TB or active TB. She was also complaining of symptoms (stomach pain) that were potentially indicative of extra-pulmonary TB. In this appointment the doctor said he wanted to investigate the stomach pain before further investigating her TB status. He referred her to a gastroenterology appointment before re-scheduling the participant to another chest clinic appointment in six weeks time. I was surprised at the almost leisurely way in which the doctor was determining whether an individual had TB. I later discovered that the gastroenterology waiting list was very long and that Khalisah faced a wait of up to six months before she would be

seen. It also seemed a very long time to leave an individual before confirming whether or not they have TB. Even in the case of extra-pulmonary TB which is not infectious, the individual faces a long wait which undoubtedly has a toll on their health.

The third visit similarly involved a two-hour wait past our scheduled appointment time. By this time the interpreter had left as they had another booking. This meant that Ulfah had significant difficulties communicating with the doctor. The doctor asked whether Ulfah had been coughing and bringing up mucus. She said 'no' then changed her response slightly. This same pattern continued with Ulfah changing her reply to each question. It appeared as though she was struggling to understand the questions without the assistance of an interpreter. Ulfah then said that she had been getting pain in her right side. An excerpt from my field notes follows:

*He said 'Ok let's look at it'. She took off her scarves etc and then said 'Wait, wait'. He was on his feet getting ready to look at her. She went to her handbag and pulled out her glasses and a picture of a skeleton overlaid with the various layers of bones, muscles and organs. She showed him where her pain was. He rolled his eyes, sighed, said that he didn't have time for this and that this was a matter for the GP and that he wasn't running a GP service. He said 'Ulfah I have spent hours and hours with you and I don't have time. You come back in three months for another xray to see if things change'. She seemed quite forlorn and frustrated. Tears filled her eyes.*

From my understanding of the situation, Ulfah and the doctor were focusing on two separate issues. Ulfah was concerned about neck pain while the doctor was focused on the mass on the lungs. Ulfah asked for medicine but the doctor refused until he could test some of the mass so they knew what they were dealing with. The doctor continued by saying:

*That he had been over this with Ulfah many times and that he had organised the operation with surgeons before but she had then changed her mind. Ulfah said she was scared of the operation. The doctor just stared at her. Ulfah stood still in the room and seemed quite agitated. Ulfah asked me to explain. I said that they wanted to do a small cut and test the lump in her lungs. She said they had never shown her the picture (chest xray) before but she could see something and now knew what they were talking about. She asked if it was big operation and wanted to know who would clean her house and cook if she was in hospital. The doctor walked out and brought in the nurse. We went with her into an interview room and she asked very gently what the issue was. Ulfah said she was frightened of the operation because of "bleeding and infection". The nurse very gently answered Ulfah's questions and said she would speak again with the doctor.*

*Ulfah and I went and sat down again in the waiting room. She said "When I talked to the PHN I said no, the doctor no but because of you I say yes. You explain to me quiet and*

*slow, I understand now". Ulfah said that she was going to have the operation because of me. This made me feel a bit nervous but all I had tried to do was explain to her what the doctor and nurse were saying.*

Once again it was a difficult task observing the interaction that took place. I was surprised that the doctor did not seem to explore why Ulfah was so afraid of the operation. Talking with her later I found out that her GP and other family members had told her not to have the procedure. That, along with the recent death of her husband in hospital all contributed to her reluctance to have the procedure.

The fourth and fifth clinic visit I attended were follow-up visits for Ishraq. This time it was with a trainee intern. I introduced myself and explained what I was doing. The intern then proceeded to speak to me for much of the consultation and completed a 45 minute examination before fetching his supervisor. While the intern was very consultative and described each part of the examination the supervisor was brisk and dismissive. Despite Ishraq's accounts of pain, his palpation of the neck concluded with the comment that he did not think there was a problem and that there was nothing there. The final clinic appointment I attended was very short, in part due to Ishraq's inability to have a chest x-ray because she was pregnant. She spoke with the doctor about her concerns of recurrent TB and was scheduled for further tests.

Overall, there were a number of issues I observed in terms of the clinic visits. It is important to note that I was positioned alongside patients in this context and not in a position to represent the doctor's point of view. A study of the lifeworld of the clinic would be needed to be able to contextualise the clinicians' views and behaviours. The first issue was how the doctors appeared to be in a great hurry, trying to rush through patients giving them little time to express themselves. Although I am unsure whether this was due to over-booking or under-staffing, it may be why many of my participants experienced long delays in the waiting room. Secondly, the doctors appeared to dismiss individuals' explanations of their symptoms as being irrelevant opinion, referring instead to 'reliable sources' such as blood tests and x-rays. Kleinman's notion of 'explanatory models' is a particularly relevant one in this case (Kleinman, 1980; Kleinman, 1995). Kleinman suggests that people understand and make sense of health and illness in different ways. At times, the explanatory models of health care practitioners can conflict with those of patients and their families yet the healing process requires that these differences are bridged. What can be observed from the interactions between Somalis and chest clinic staff is competing explanatory models. Unlike other health care workers such as PHNs who attempted to bridge the dissonance between their biomedical explanatory model of TB and those of their patients', the specialists described in this section made very little effort to acknowledge and address the views and understandings their Somali patients had concerning their own bodies and wellbeing. Furthermore, differences in power meant that Somali clients were unable to challenge the doctor's opinion.

Another important issue that contributes to this sense of powerlessness is that of language. Due to the lengthy time delays (sometimes over two hours), some interpreters had to leave to go to other appointments. This resulted in some patients struggling to communicate effectively and to understand the complex medical terminology used by clinical staff. Because of the complex nature of the topics at hand, even some Somali interpreters struggled to understand and interpret the words being used. This resulted in frustration on the part of both patients and health professionals.

*The long road to wellness*

Following the TB treatment programme, most individuals reported that their health had improved considerably and that they have begun to feel more like their former selves:

*Jody	And what has it been like for you since you have finished your tablets and have recovered?
Abir	I feel much better
*Jody	Yeah. How has Abir been since she has got better from TB?
Abal	Feel better
*Jody	Different person?
Abir	Different. I'm getting more fatter now.

*Jody	What has been your experience since recovery?
Adil	Good. Now much better. Energy OK. Healthy. I have put on weight. Was 67kg then 87 and now 91kg. Some blood tests a little bit below normal to do with the liver. I have a card that I was given to go to doctor or get blood tests. I finished in December.

Yet, due to the long period of illness prior to diagnosis, many individuals were completely incapacitated and unable to function by the time they were diagnosed. As a result, the recovery process was particularly long and many still live with the effects of their illness (despite complying and completing the requisite course of TB treatment). For example, Tibah who had extra-pulmonary TB was confined to a wheelchair for three months and required home help for two years. This is a significant issue as Public Health officials often construct TB medication as the means by which the illness is resolved. Furthermore, this issue is compounded by the fact that once individuals are no longer infectious and have been discharged from the auspices of Public Health Services they are effectively on their own in terms of managing the repercussions on their health from having TB. This can often be a confusing time as, for some, the after-effects of TB can appear to be very similar to the actual disease itself.

In many ways, the after-effects of this infectious disease (TB) are similar to the experience of chronic illness (Dyck, 1995). Chronic illness and infectious disease are usually thought of as being

mutually exclusive illness types however, the long-term effects of TB upon participants' bodies reveals the limitations of such binary constructs. HIV/AIDS is another example of an infectious disease that can be managed on a long-term basis with the assistance of powerful drugs, this is in many ways similar to the management of a chronic illness. One individual who experienced extra-pulmonary TB in the back still has limited mobility and is often in pain. At the time of writing, Khalisah still experiences strong pain and fevers. Ishraq's story in particular is a clear example of this. Despite completing TB treatment, Ishraq continued to experience coughing, throat pain, vomiting, dizziness and lack of appetite; the same symptoms she experienced prior to diagnosis. Due to these ongoing health concerns, Ishraq attended the Greenlane chest clinic for nearly three years before moving overseas in 2005. This is a frustrating situation and Ishraq expressed great fear that the TB may have returned. In her words:

Ishraq	Until now I coughing you know now. I see the doctor in Greenlane hospital every three month and I went to the doctor and I said "You should check me again because I cough too much, even now I cough and I vomit" and they say "No now it's ok"... I was taking the medicine one year and they told me "No". I said "You need to check me again because I still cough too much" and they told me "No, you are ok" and every three months I go to see doctor and they say "No you ok, you don't have anything, maybe it's, you know the ... damage in your body [due to TB] and that's why".
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Although Ishraq has no clear idea as to why she is still feeling unwell, her health is very marginal as the following account demonstrates:

*Jody	So even now, you can't eat much?
Ishraq	No. Even people they eat three times a day, I eat one time, only lunch
*Jody	And how much would you have?
Ishraq	Small. Little
*Jody	So do you feel strong, does your body feel strong?
Ishraq	No
*Jody	No?
Ishraq	And even sometimes when I, I stand you know, I feel....
*Jody	Dizzy?
Ishraq	Yeah.

As participants' accounts depict, active TB not only results in an array of health difficulties but also ongoing disabilities due to the severity of the illness. In addition, many face anxiety about whether their TB has really been cured and whether it might come back. Furthermore, the stigma associated with TB has also had a profound influence on the wellbeing of a number of participants as will be considered in the following section.

## Living with stigma

As has been discussed in Chapter Eight, TB is a highly stigmatised disease although one that has different meanings for different people. While some believe that traditional stigma associated with TB has been remedied through the availability of effective treatment, others acknowledge that medical progress has not led to improvements in terms of stigma.

Despite the availability of TB medication in NZ, this biomedical “cure” does not address the social damage caused by having TB. While researchers and health professionals devote considerable resources into ensuring individuals with TB become non-infectious as soon as possible, the social ramifications of TB are experienced well past the point of infectivity or even cure. Within TB literature, stigma is used as an explanation for particular behaviour such as delayed presentation at health facilities or non-adherence to treatment regimens. Yet surprisingly, there are few accounts that seek to understand the meaning and experience of stigma for individuals with TB as a topic of enquiry in its own right. While reducing the risk of transmitting the infection to others is of utmost concern, it is important not to minimise and overlook the experiences of individuals with the disease.

Stigma is a complex phenomenon, and as participant accounts above demonstrate, is not uniformly experienced. Interestingly, those who were the most marginalised (socially, physically and economically) before contracting TB tend to be those who experienced stigma the most. In many ways it is not surprising that Somalis associated stigma with their illness. Following Goffman’s three-pronged typology of stigma, many Somalis occupy all three categories – possessing (sometimes multiple) physical ‘deformities’ (including TB), multiple indicators of marginality (ethnicity, religion and nationality) and for some, inferences about character and moral standing (Goffman, 1963). Rumours and comments made to me about particular families and individuals during my fieldwork support Goffman’s assertion that stigma (in this case about TB) becomes the dominant identity by which people are known. Furthermore, participants also recounted various strategies they had employed to limit disclosure about their illness and conceal the true nature of their affliction.

When asked about the impact of TB on their own lives, participants frequently spoke about isolation and separation. This isolation occurred both physically and socially throughout the various stages in the TB journey (diagnosis, treatment and post-treatment). For those with pulmonary TB, isolation occurred in a physical sense after being diagnosed with TB and subsequently hospitalised. This isolation within the ‘Infectious Diseases’ ward at the hospital, is designed to confine the spread of the disease and is the first of many instances of isolation that follow. This enforced isolation was a particularly difficult time for many participants as they were very unwell and also still coming to terms with the social ramifications of their illness.

For some, the facemask was a tangible and visible manifestation of stigma. When hospitalised with pulmonary TB, a face mask usually had to be worn by patients and visitors. This requirement appeared to be strictly enforced by hospital staff. The facemask was despised by all concerned. One respondent who was required to wear a facemask stated:

Abal	The first two nights when I took Abir to the hospital they tell me to put a mask on and I can't handle it that thing. I said I'm going to vomit and cough and I just throw it away and said that if my daughter has TB, I'm happy to get TB too. Why do I need to protect myself?
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One participant recounted how she was forced to wear the facemask when venturing out of the hospital:

Abir	They used to take me to Auckland Hospital because of my eyes and I had to wear a mask. They took me in a wheelchair to carry me, oh they were very bad
Jody	Did you feel really embarrassed by that?
Abir	Yeah. All the people were looking a lot. Look at this girl, she's got a TB
Barika	They didn't know whether you are, but when they see the mask they knew, this is the horrible thing, TB is coming.

Another process of isolation occurs within the household when the person with TB returns to their home after diagnosis. Historically, this person is separated from the rest of the family, required to sleep outside and eat separately with their own utensils rather than sharing in the communal meal. In some cases, their material possessions are also isolated from the rest of the family and sterilised.

During a family interview where one individual had been diagnosed with TB and a number of family members subsequently were found to have TBI, Barika described the struggle that had occurred during the time of Abir's sickness. Barika and other family members were suspicious that Abir had TB (despite the view of Abir's doctor that TB was not the cause of illness) and wanted Abir to be moved out of the house to a room outside. Barika blames this lack of separation for the subsequent infection of other family members:

Barika	My mum just let Abir drink and touch everything. That is why we get it. If we put Abir somewhere outside...
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During this struggle between family members, Abir's parents instructed other family members not to even mention TB as even thinking about it and talking about it might cause it to happen.

Further isolation and separation also tended to occur once an individuals' TB status become known to the community. As the Somali community is small and extremely closely-knit, it was very difficult for participants to keep their illness secret. In nearly all cases, participants described how people would now 'run away from them', reinforcing the sense of isolation and exclusion from social networks.

Other participants spoke of how friends now actively avoided them and would rarely visit and if they did visit, would not eat with them. Another said that while she still received visitors, they said bad things about her behind her back.

Adil talked about how being diagnosed with TB had caused shame for his family members in Somalia with the taint of TB reflecting on the family unit as a whole:

Jody	Did you tell your family?
Adil	Yes. They were sad because I was the first in the family to get TB
Jody	And how did your family react?
Adil	They were sad because I'm the only person, the first person who have this kind of thing. They actually encouraged me to take my medicine.

Perhaps the best example to illuminate this tension surrounding the degree to which TB is still a stigmatised disease is the issue of disclosure. When asked about perceptions of TB, some participants stated that TB was 'just like the 'flu'. When I asked them who they had disclosed their TB status to, it emerged that many were still reluctant to reveal their condition to others. This reluctance is depicted well in an interview held with one participant when she said that having TB is not of great concern to her, yet did not feel comfortable disclosing her condition to others:

*Jody	Who have you told about your TB?
Jalilah	My family. In Somalia, that person we have to run away, isolate. That person is dangerous. It's a very bad disease. In New Zealand, it's [TB] OK, once start treatment you can't pass it so not to worry. Nothing to worry about here in New Zealand
*Jody	Why did you decide to not tell other people?
Jalilah	Although we know there is medicine, still, where we come from, TB not a good disease, I didn't tell anyone. I feel it is not their business. I am also only new...

These efforts to limit disclosure were common for most participants. While many had disclosed their condition to family members (which in part may be due to the contact-tracing efforts of public health professionals), considerable effort went into hiding their condition from others. Interestingly, one participant mentioned that her doctor had advised her not to tell anybody that she had TB. According to Khalisah:

Jody	And how do you feel with other people knowing that you have TB germs?
Khalisah	I don't want anyone to know. I wouldn't tell anyone
Jody	And why is that?
Khalisah	Because it's part of Somali custom. It's our way. They will treat you like someone with very bad infectious disease.

For those who had not disclosed their illness to others, I asked them what they thought would happen if they did so. In this case, all respondents said that other people would 'run away' if they knew. For example:

Jody	How do you think people would react if you did tell them?
Abir	They will run away from me
Jody	Really?
Abir	Yeah. They will be like, you know, think they get disease or something, it can infect them.

Another participant stated that while she had endeavoured to limit the extent to which others had found out about her condition, her diagnosis became well-known and had come to influence the way people acted towards her.

Jody	Who have you told about your TB?
Raha	I haven't told anyone – no-one asked. But people found out. It's a small community.
Jody	And did those people act differently towards you?
Raha	Yes of course. They don't want to be close.
Jody	And what about other friends?
Raha	I don't have contact with anyone. I don't have any friends.
Jody	Is this after you had TB?
Raha	Before and after.

One observation from this excerpt is the extent to which this participant was socially isolated both prior to, and after contracting TB. In other words, this participants' social marginalisation prior to becoming sick was further exacerbated by the disease.

It also appears that the type of TB tends to influence the degree to which individuals feel comfortable in disclosing their illness to others. Some participants with extra-pulmonary TB (i.e. not infectious to others) appeared to be more comfortable telling others about their condition. For example:

Jody	And what was their reaction when you told your friends that you had TB, how did they react when you told them?
Hala	Normal. Because TB, because for the doctors they tell me, my TB I can't pass to other people, it's glands one. The chest one, when I'm coughing I can pass to the other people. Even my family they had the Mantoux test. That was negative. So you know nothing to worry, it was ok.

Participant's efforts to manage disclosure and the resulting stigma associated with TB began very early on in the process when the individual was first hospitalised. When in hospital it is customary for friends and family to visit. In this case though, the participant's family tried to prevent visitors from coming and finding out the cause of Abir's illness. As they said:

Abir	And then you know it's a little bit shame for us because they put a room for protection. When you visit her you have to protect and we tried to keep our friends, our family far away.
Abal	No visit Abir in hospital
Barika	Only mum and me, my mum and myself was visit her. But I just worried maybe I visit I will get it, the disease
Abir	You have to close your nose if you get anything
Barika	And we also worried about family and relatives and
Jody	How did you stop people coming?
Barika	We just keep telling we had operation, just another operation. But when they came to visit, they knew and keep telling each other 'oh that family, the daughter get TB. We should protect our kids, never play with Abir, don't go with Abir
Jody	Really
Barika	Yeah and they won't eat. After a little while they knew and we make for other, other, after little while everyone got TB. That family, six of them after Barika, six family.

This excerpt highlights the way in which family members attempted to manage the stigma of TB by limiting the extent to which people knew of Abir's condition. Because the hospital ward was clearly identified and high levels of protection were required, it was not long before visitors discovered the true reason for Abir's hospitalisation. As family members recount, people soon started acting differently towards the family and limiting the extent of interaction between themselves and Abir. This stigma intensified when other family members were also diagnosed with TB and they felt as if they were known as the 'TB family'.

These efforts to hide the true nature of their illness also meant that some tried to claim they were ill with other sicknesses. One community representative recounted a story of a leading community

member who claimed they had a bone problem. When this representative visited this person in hospital, the true nature of their hospitalisation became apparent when they found the individual in the infectious diseases ward. As stated by Mahir:

Mahir	People try to keep TB a secret. People claim they have bad bronchitis
Jody	Why?
Mahir	Because of the stigma.

While stigma is a complex and contested phenomenon, the implications of having TB are far-reaching, as the above participant narratives depict.

## Summary

This chapter has traced the contours of the TB journeys of the twenty-seven Somalis who have experienced TBI or TBD. Throughout this chapter, and within this thesis as a whole, I have repeatedly used the idea of ‘journeys’ in terms of the research process, Somalis migration histories and TB experiences. The notion of a journey is valuable as it captures the many facets of human experience. It conveys the temporal dimension of people’s stories and experiences and a sense of progression from one stage to another. It also is imbued with geographical overtones in terms of the way in which Somalis have moved within and between different places. Lastly, in a metaphorical sense it has been used to describe the passage from illness to wellness. While it is a helpful tool to structure the way we think about people’s experiences it is somewhat limited by the way it, somewhat artificially, compartmentalises events into discrete categories. It is essential to remember that TB is not experienced in isolation from an individual’s wider life and it is important to remember this when speaking of ‘TB journeys’. Another limitation of the concept of journeys is that it implies a sense of linearity and logical progression when in fact quite the opposite may be true. Nevertheless, as an organising tool and an analytical device it offers considerable benefits when considering people’s life experiences.

While each journey is as unique as the individual who made it, there are a number of common threads that can be teased out over the course of this chapter. The first thread is the way in which participants actively sought medical assistance once they recognised they were unwell. This was a turbulent process and involved considerable frustration and disappointment after repeated visits to GPs. The place of the hospital was central in the TB journey and was constructed as the place where relief and enlightenment finally occurred. Yet due to concerns with transmission, the TB ward at the hospital was also a setting associated with separation and captivity, characteristics that are strongly reminiscent of refugee camps and/or imprisonment that occurred during the Civil War. Small things such as the inability to open a window can potentially trigger painful memories of the

past and need to be dealt with sensitively by all concerned. This is just one example of how different 'places' are imbued with meaning and significance beyond material bricks and mortar.

For many people, the transition from hospital to home was welcomed, but heralded a new phase in the treatment process with the commencement of DOTS therapy. PHNs had a considerable role during this time and become intimately acquainted with the challenges faced by their Somali clients. In many cases, the care provided by these PHNs had a profound influence on participants' lives, not only in terms of TB treatment but also in addressing the wide-ranging resettlement challenges as discussed in Chapter Six. While the treatment process was long and arduous, all individuals successfully completed their DOTS treatment due to the strength of this relationship with their PHN. One influential factor that contributed to this was the way in which PHNs were involved in the daily lives of participants within their homes. Unlike the Chest Clinic specialists who interacted with their clients within a rushed clinical setting, PHNs had the opportunity to establish rapport and mutual understanding that significantly contributed to a good working relationship. This highlights the importance of place and the way in which different settings can contribute to different outcomes. Being invited and interacting within the homespace facilitated a different kind of relationship than that possible within a highly medicalised and hectic hospital setting.

Yet for some the havoc wreaked by TB is not over with some people continuing to live with the after-effects of the disease. This is in part due to the fact that participants were so unwell by the time their illness was diagnosed. A number of individuals described how they feel like they are living in a state of limbo as the damage to their body resulting from TB mimics the symptoms of active disease. One participant with ongoing throat and breathing problems who has poor overall health often worries that TB has in fact returned. This is problematic as people are discharged from the care of public health services once their treatment has been completed and are declared as being TB-free. As a result, people are required to manage these ongoing health problems by themselves returning once again to their GP who, for the most part, has had limited involvement during the TB treatment process.

Another common characteristic of the TB experience is that of stigma. While opinion was divided on the extent to which TB is still stigmatised, participants' accounts reinforce the idea that it is still associated with shame. Many were able to provide first-hand accounts of the impact the disease has had upon their social standing. Most commonly, this involved the contraction of social networks and damage to their social identity. Participants have responded to this in different ways with some individuals retreating and becoming further isolated whilst others have endeavoured to maintain their social networks and to re-establish their identity. While this is a considerable challenge for a population who are highly marginalised, it is yet another testament to the capacity of this resilient and resourceful population.

## Chapter 10: Conclusion

*Tuberculosis is a social disease, and presents problems that transcend the conventional medical approach ... its understanding demands that the impact of social and economic factors on the individual be considered as much as the mechanisms by which tubercle bacilli cause damage to the human body"*  
(Dubos and Dubos, 1953:vii).

Writing in 1953, Dubos and Dubos highlight the extent to which TB is an intrinsically social disease. Despite phenomenal advances in medical technology and knowledge, TB continues to affect a significant proportion of the world's population. Yet this burden is not evenly distributed with nations in the developing world bearing the brunt of this age-old scourge. Although TB rates within developed nations such as New Zealand have decreased dramatically since peaking in the 1940s, pockets of high rates of TB remain. These pockets are not random but are concentrated amongst population groups who are marginalised across a number of different dimensions. This research has made an original contribution to the body of knowledge and research on the social, cultural, political and economic dimensions of TB amongst a refugee/migrant population in Auckland.

Since the 1980s, the global resurgence of TB has been mirrored in New Zealand with rates fluctuating between nine and ten cases per 100,000 population (Ministry of Health, 2003a). This rate masks the high degree of internal variation with the TB rates of 'others' (i.e. not Pakeha, Maori or Pacific people) being 81.7 per 100,000. Frequently, within public opinion and political discourses, migrants are constructed as the 'diseased other', importing infections as they arrive in New Zealand. Data from the Ministry of Health however suggests that only 20% of overseas born TB cases are notified within the first year with many developing the disease after living in New Zealand for a number of years (Ministry of Health, 2003a). While this association with migrants and TB is well-established internationally and in New Zealand, very little is known about what it is about being a migrant that leads to TB. This research has addressed this shortcoming through explicitly engaging in the life-worlds of Somali refugees.

This thesis embraces the Dubos' idea that TB is a social disease and has considered the influence of wider social, political, economic and cultural factors on the experience of TB amongst a refugee group demonstrated to have high TB rates both here in New Zealand and in Somalia (Das et al., 2006b; World Health Organisation, 2006d). While there is a plethora of research that analyses the contribution of different variables to the 'TB problem', one shortcoming of statistical modelling is that it can artificially divorce highly related and interdependent aspects of people's lives. Somalis

ethnicity and socio-economic status for instance are not experienced in isolation from each other. This research has endeavoured to overcome this shortcoming through presenting narratives of experiences of health and illness, in the context of wider migration and resettlement journeys.

The thesis has explored the experience of health and disease amongst a marginalised refugee population in Auckland. TB has served as a lens through which to consider the way in which social, economic, political and cultural processes intersect at a variety of scales to create emplaced health experience. One important conceptual contribution of this thesis to health geography is that it ventures into the 'grey area' within the health/disease duality by highlighting the importance of wellbeing and wider life histories in terms of health experiences and outcomes. While TB is an important infectious disease in its own right, this thesis has highlighted the importance of taking the experience of peoples' wellbeing seriously. Despite common rhetoric, health is often and inadvertently reduced to the absence of disease. Refugee and migrant groups such as Somalis living in Auckland are frequently tarnished by association with infectious diseases such as TB, yet little recognition is given to the importance of the wider social determinants of their well-being as situated within time and space. For the population in question, resettlement has clearly brought unsettling experiences. A key contribution of the thesis has therefore been to highlight the necessity for health geography to (paradoxically?) move beyond health-as-defined-by-health care and embrace a view of health-as-wellbeing that is grounded in the material and social dynamics of everyday life

The thesis has also contributed to wider conceptualisations of structure and agency. Drawing upon participant narratives, I have highlighted the ways in which Somalis health and wellbeing experiences are influenced by wider structural forces whilst acknowledging the agency exerted by this population within the context of these constraints. While the structure/agency dynamic is helpful in conceptualising the complexities of human experience, the two dimensions are not mutually exclusive. For instance, discussion of the Auckland Somali Community Association (ASCA) highlighted the way in which structures (in this case the ASCA) can become 'enabling' in themselves (see Chapter 6). In this way, the thesis contributed to exploring a 'middle ground' within the structure/agency divide as it is played out within the experience of wellbeing.

## **Research reflections**

With the disciplinary evolution of medical/health geography, researchers are interested in considering the lived experience of illness beyond mapping disease distribution and diffusion. This is particularly evident in the wealth of literature focusing on chronic illnesses which has as its focus chronic illnesses (Dyck, 1995) including cancer (Kravdal, 2006), diabetes (Rytkönen et al., 2003) and fibromyalgia syndrome (Crooks, 2005). By comparison, there are few researchers who have considered the lived experience of infectious disease. One exception to this is HIV/AIDS which has been extensively researched (Chiotti and Joseph, 1995; Kearns, 1996; Wilton, 1996; Oppong,

1998; Law, 2003). Wallace et al. (1995) have also considered the relationship between TB and HIV/AIDS in New York City. Research conducted by Ng Shiu (2006) on the TB experiences of Pacific people living in Auckland, New Zealand is one of the few pieces of contemporary health geography research that focuses on the illness.

One possible reason for the dearth of geographical research on infectious disease is that the burden of chronic illness in the countries in which health geographers are usually located (UK, Canada, Australia and the United States), far outweighs that of infectious disease. This imbalance highlights one of the unique features of this study which is its focus on the characteristics of an infectious disease within a developed nation in a highly urbanised setting. This is unusual in that the vast majority of studies on the experience of infectious diseases occur in developing nations that face a high burden of disease. While such research is valuable and necessary, it is essential not to overlook (and thus minimise) the groups of people living in highly developed countries who continue to face high rates of infectious disease compared with the general population.

Yet it is important to remember that although infectious and chronic diseases are usually constructed as mutually exclusive categories, such binary constructs can be limiting. This is particularly evident in the accounts provided by a number of my research participants who continue to live with the long-term after-effects of TB despite no longer being infectious (Chapter Nine). Infectious diseases are often thought of as being relatively short in comparison with that of chronic illness however this is not always the case as my findings suggest. Similar ideas can also be noted in relation to HIV/AIDS. While HIV/AIDS is often conceptualised as a fast-moving epidemic with catastrophic impact, the development of powerful pharmaceuticals has resulted in the disease becoming similar to a chronic illness which can be managed on a long-term basis with an appropriate drug regimen (although access to such drugs is highly unequal). This highlights why it is important to consider the temporal dimension of disease, as rampant infectious diseases can have long-term effects on the lives of those with the illness. Such long-term effects are not limited to physical or bodily matters but also social and cultural effects which have a profound influence on the lives of individuals.

Not only is there an overwhelming focus on chronic illness within health geography research, but also the studies that have been conducted on TB remain distant, or at arms-length, from the realities of those with the illness. This is evidenced in the strong emphasis on mapping and modelling of the disease (Oppong et al., 2004) which is understandable given medical geography's close affinity with the epidemiological tradition. In addition to research that has considered spatial diffusion and distribution, other commentators have sought to engage with the macro-level structural forces contributing to the burden of disease (Elender et al., 1998; Kalipeni and Oppong, 1998). While such research contributes to our understanding of TB there remains therefore much scope for consideration of the lived experience of the illness. This thesis has endeavoured to address this gap by considering the lived experience of TB within a refugee community residing in

Auckland, New Zealand. In accordance with one of the key tenets of health geography, I have focused upon the realms of both health and disease despite the fact that this thesis is exclusively focused upon one disease. I have attempted to do this through documenting the different meanings and values Somali people attach to both health and disease and the way in which they respond accordingly. Such concerns are firmly rooted within a broad appreciation of the importance of place, both materially at the neighbourhood and national level and also socially, culturally, politically, economically and within a wider 'place-in-the-world' sense (Eyles, 1985). This thesis has followed in the footsteps of earlier work conducted with marginalised groups (Winchester and White, 1988) including people with disabilities (Valentine, 2003), children (Kearns and Collins, 2000) and immigrants (Dyck, 1995; 2006). While the scope of this thesis is indeed broad, such depth and breadth is critical in order to understand the complexity of the TB experience.

Throughout this thesis I have reflected upon my experience of conducting research amongst the Somali community. Given the fact that many Somalis are still coming to terms with events that happened during the refugee journey, I am in no doubt that research based on extensive community participation is the most appropriate given the sensitive and personal nature of health and wellbeing. In saying this, I did encounter resistance at many stages throughout the research process largely due to stigma. As a result, I had to modify my approach and my objectives.

At the outset of this research I was surprised at the lack of demographic data about Somalis both internationally and in New Zealand. An example of this is the under-counting of the Somali population within national census figures. This further reinforces Somalis' marginality and has a number of implications in terms of service provision and funding of social and government services for instance, health and education. In retrospect, it would have been very helpful to have conducted a census of the Auckland Somali population myself. However due to concerns from the leadership of the ASCA, I was strongly advised to not pursue this line of enquiry.

One challenge that arose during the research process was that of language. Given people's sensitivity about TB, some people chose not to have an interpreter even though we struggled to communicate in English. In hindsight, I think my research also would have benefitted had I been more fluent in Somali. Although I was able to understand words and phrases, it would have been extremely helpful to have learnt the language prior to beginning fieldwork. Another shortcoming of my research was that I was largely limited to working with a group of people with good community networks and relationships. As my research progressed I became aware of some individuals who did not associate themselves with the wider community and who were highly isolated. These people were very difficult to access and I regret not having the opportunity to speak with them further.

Reflecting the nature of my community participation and the gender difference in TB notifications, most of my research participants were women. In order to address this I conducted a focus group

with Somali men and arranged meetings with a range of different Somali men. This gender balance does however potentially influence the way in which my results can be interpreted. An opportunity for further research would be to explore in more depth the gendered dimensions of the Auckland Somali community. While much has been written about the experiences of women, there remains considerable scope to consider how processes of migration and resettlement have influenced men and their identity.

## **Somali resettlement experiences**

Prior to this study, there had been no detailed research on the Auckland Somali community and few other studies nationwide. I have considered the challenges faced by Somalis in rebuilding their lives in New Zealand with a special focus on their everyday lives. In accordance with Brah's (1996) conceptualisation of diaspora as comprising both a journey and a home, Somalis experiences of their homeland and the refugee journey are something that is re-lived on daily basis. Although bounded in time and space, events and memories from the past are closely interwoven with the present (Dyck, 2006). While mobility is an important part of Somali culture and identity, many of the individuals whom I interviewed carry with them a keen sense of home with which their current experiences of resettling in New Zealand are frequently compared. This sense of home highlights the way in which transnational connections can be established and maintained through shared memories, histories and feelings. As Burrell wrote, 'Memories and emotions can be the most powerful links to the homeland; the strongest transnational connections are sometimes those that are rarely acted out, voiced or expressed, but simply felt' (Burrell, 2003:333).

Although migrants are frequently conceptualised as being static and stationary once they have 'arrived' in their country of resettlement, this is far from the case. The forcible dispersion of Somalis due to the eruption of Civil War saw the beginning of a journey that for many has not ended. A number of the individuals with whom I spoke with are still in search of a better life. This is highlighted in the high levels of mobility both *within* the Auckland Somali Community and *between* different Somali communities throughout New Zealand and further afield. During the research process I personally witnessed the departure and arrival of many families. It is important to take this high degree of mobility into account and acknowledge that the Somali community as a group is continually changing and developing. It also highlights the extent to which this research is bounded in time and that future research with Auckland Somalis may yield different findings.

In addition to physical mobility, Somalis also have dense transnational networks and international connections. Although the relationships *between* different ethnic groups receive a lot of attention in New Zealand, the formation and maintenance of relationships with the majority population are not as significant as those with fellow Somalis scattered throughout the world. This is in contrast with the experiences of other migrant groups who tended to become (and wanted to be) incorporated with the host society (Glick Schiller et al., 1992). Indeed Somalis that I interviewed expressed a

desire to remain distinct from wider New Zealand populations in an effort to maintain their identity. However there was widespread recognition of the need to navigate through wider economic, social and political structures in order to access opportunities and resources, for instance obtaining an education so as to ensure employment opportunities.

Transnational linkages are maintained in a number of ways including through telecommunications, financial remittances, frequent visits, sharing videos, involvement in community associations and marriage alliances. An important point of recognition is the creative ways in which such linkages are maintained despite economic and political constraints. Indeed, my fieldwork with Somali individuals suggests that they are very entrepreneurial in navigating their way through complex bureaucratic processes and overcoming otherwise challenging financial constraints. The high level of remittances by Somalis is one good example of this. Despite the material hardships faced by refugees, many Auckland Somalis (like other diasporic Somalis) continue to send money back to needy relatives in Somalia. Evidence from my participants suggests that they are remitting as least as much as their peers internationally (De Montclos, 2003) although obtaining definitive data on this matter was very difficult.

This thesis represents the first in-depth consideration of Somali resettlement experiences in Auckland adding to the relatively few accounts of the Somali refugee diaspora (Griffiths, 1997; Berns McGown, 1999; Gundel, 2002). Compared with other diasporic Somali populations, the Auckland community possesses a number of unique features. Firstly, as there was no pre-existing Somali population before the beginning of the Civil War, the New Zealand Somali community is very young and comprised solely of refugees. This is an important distinction when compared with the resettlement experiences of Somalis in Canada or the UK. When the civil war broke out, many of the elite in Somalia paid for flights to these established communities thus these diasporic communities reflect the full gradient of social classes. In New Zealand however, the majority of Somali refugees are those settled involuntarily through the UNHCR resettlement programme although there has been frequent family reunification since.

Another difference is that overseas there is evidence of strong clan segregation with particular clans settling in particular countries. For instance, in the 1990s, many Majeerten settled in the Netherlands while members of the Marehan clan settled in Sweden (Griffiths, 1997). On a smaller scale, particular clans have clustered in particular parts of cities such as in London (El-Solh, 1991). This has not occurred to the same degree in New Zealand for a number of reasons: because UNHCR-resettled refugees originate from all clan backgrounds; the small size of the Auckland community requiring a higher level of inter-clan contact; and lastly due to the efforts of the ASCA to establish relationships between different clans. This situation highlights another point of departure from international trends in that many Somali community organisations have been plagued by clan frictions with each clan having their own association. To a large degree this is not the case in New Zealand where the ASCA represents the full range of clan groups. This is in part due to the

personal commitment of the leadership to distribute positions of power and resources across the spectrum of clan groups and it would be interesting to chart the future development of the organisation over time. Yet it is important that the diversity of Somali transnational experiences is also acknowledged. Given the clan conflict that precipitated the Civil War, there remains a degree of tension between different clan groupings. While this was a sensitive topic to talk about during the research process, these clan rivalries were most evident when it came to disagreement over the distribution of resources such as jobs within the ASCA.

Accounts from participants identified how Somali social structures have come to be modified and re-interpreted within a new socio-political context. Issues between different generations and the sexes are two good examples of this. Frequently, young people are forced to operate in and straddle two distinct worlds which can be challenging at times. Many Somali parents expressed great concern at the way in which children were losing their Somali identity to that of the popular culture. Community members also raised the issue of gender roles and the way in which these have changed during the resettlement process. Similar to the findings of authors such as Al-Sharmani (2006), women take on a very important role within the household particularly in terms of their ability to generate income. Likewise, I found this to be the case although in my research it appeared to be *young* women who were the main ones able to generate an income.

In common with the findings of other researchers who have worked with Somalis, religion proved to be a key marker of culture and identity. In accordance with observations made by (Tilikainen, 2003) and (Fangen, 2006), Somalis have become more religiously devout since arriving in New Zealand. According to participants this is due to a sense of isolation and a desire to maintain their identity and difference. It is also seen as a means of coping with difficult times in establishing a new life in a foreign land.

Yet while Somalis can be thought of as a transnational population, the Auckland Somali population is rooted within a particular place although the nature and structure of the community is dynamic and forever shifting in response to flows of people, ideas and resources. The vast majority of the Somali Community is located in Mt Roskill, a suburb on the western fringe of Auckland City that has undergone a dramatic transformation in the last few decades with the arrival of large numbers of migrants from the Pacific and more recently, people from refugee-producing countries including Somalia, Afghanistan, Iran and Iraq. This has changed both the social and built environment. The establishment of several Halal butcheries, spice shops, remittance agencies, mosques and Islamic clothing stores is testament to the changing population composition of the area. The founding of such services has allowed many Somalis to live within the confines of Mt Roskill as their everyday, essential activities (such as grocery shopping, visits to friends, collecting children from school) can be undertaken with members from their own cultural or religious background. This is one example of how transnationalism is comprised of everyday tasks which are just as important as the activities of the elite and members of large financial institutions (Conradson and Latham, 2005).

For many individuals, events that took place in their lives in Somalia, though rooted in the past both in time and space, are being relived here in New Zealand. Participants spoke about the losses they had experienced both in terms of their wellbeing and also in terms of family, history, memories and material resources. Traditionally refugees are typically constructed as victims who have always been poor and dispossessed. Yet some individuals I spoke with were mourning the loss of material possessions such as houses, cars, prestigious jobs and respected reputations. The loss and separation from family members was particularly acute and many felt they were prevented from settling well due to this factor. Many have begun the process of family reunification although the difficulties of this process have contributed to a compounding sense of loss of hope. Interestingly, participants directly attributed this sense of loss to the subsequent development of TB.

In accord with international research, Auckland Somalis experience numerous challenges in resettling in New Zealand particularly in terms of education, employment and income, social integration and support. International figures on settlement outcomes are sobering with Somalis often occupying the worst position in terms of resettlement and wellbeing. Many Somalis live below the poverty line (Opoku-Dapaah, 1994), in sub-standard overcrowded housing with little hope for improvement (El-Solh, 1991) and have extremely high rates of unemployment (De Montclos, 2003).

While many Somali refugees come to New Zealand with high hopes, these were soon dashed when they discover they are not able to build for themselves the kind of lives they dreamed of. The main resettlement challenges faced by individuals I interviewed were that of income, education, employment, housing, discrimination and challenges with family reunification. Many individuals are struggling to provide for themselves and their families on minimal government income support whilst trying to meet their obligations toward family members back in Somalia. While some Somali refugees are highly qualified, many struggle to obtain work in New Zealand as their qualifications are not recognised and the costs of re-training are prohibitive. As a result unemployment rates are exceptionally high (some figures suggest around 85% of refugees are unemployed (Fisk, 2003). Somalis also face discrimination and isolation at both the neighbourhood level and also in terms of wider political discourses on immigration and belonging. Somalis are a highly visible group due not only to outward differences in terms of skin colour, appearance and behaviour but also in terms of values, belief and identity. Compared with other similar groups (e.g. Ethiopians or Kenyans) Somalis have featured frequently within the media and are perhaps symbolic of wider debates surrounding New Zealand's identity and the place of immigrants in this country.

With these resettlement challenges in mind, Somalis can be regarded as experiencing multiple and overlapping disadvantages that transcend both time and space. Not only are Somalis coming to terms with trauma from the past but also difficulty in the present. These factors have a profound

influence on health and wellbeing that is clearly acknowledged by those to whom I spoke. The resettlement challenges detailed above are, in essence, a perfect breeding ground and one that I suggest is facilitating the development and continuing burden of TB. Yet one of the shortcomings of the weighty body of research outlining the hardships faced by Somali refugees is that it fails to acknowledge the agency exerted by Somalis in overcoming such obstacles. This study has tried to address this weakness by highlighting the creative and innovative ways in which Somalis have made a 'place' for themselves in Auckland, New Zealand and have endeavoured to establish new networks and social structures. In one of the few accounts of African refugee resettlement in New Zealand, Chile (2002) argues that many black African refugees are excluded from participating in the social, economic and political life in New Zealand. He notes that many of these communities gravitate towards one another and argues that in this situation they are "deprived of basic community structures, cultural environment and the social infrastructure that foster independence and inter-dependence" (Chile 2002:365). While I agree that this clustering has occurred, I contest the idea that this has relegated the Somali community to being passive victims of wider structural forces. Although the Mt Roskill area has one of the highest deprivation scores in the country, it is not a barren suburban wasteland but rather is a thriving, diverse and multi-cultural suburb. In the eyes of many Somalis it has become a highly sought-after area, evidenced by the long waiting lists for state housing in the area, as many Somalis want to move there to be close to fellow community members. While there are undoubtedly many social issues that need to be addressed in Mt Roskill, the establishment of key social service agencies in the area is one step in the right direction.

Despite the profound challenges of resettlement, Somali refugees I interviewed displayed astounding resilience and creativity in re-establishing a new life for themselves, both individually and corporately. On the whole, while social networks have been disrupted, people have established new types of networks. In addition the establishment and success of the ASCA has served to benefit the wellbeing and situation of the community as a whole; it is often cited as a leading example of what the mobilisation of a refugee community can achieve.

## **Health, illness and TB**

Whilst considering issues of health and illness, it has become apparent that Somali health and illness ideas and experiences are firmly rooted in wider social, political, economic and social contexts. In addition, they are not static but constantly being modified in response to wider social change. According to research participants, the challenges of resettlement have had a profound influence on their health and wellbeing. International research suggests that refugees have high and complex health needs and this was borne out in the narratives of community members. Many Somalis experience a wide range of chronic and acute conditions including diabetes, cardiovascular disease, arthritis, vision impairment, vitamin deficiencies and asthma. One of the main health issues is that of mental health. Many individuals I encountered described how they

face high levels of stress, anxiety, depression, fear and sorrow. For many this stems from events in the past including exposure to torture, violence, rape and forced separation. Contemporary resettlement challenges as described above were also seen to contribute to this level of distress particularly with family separation, financial hardship and ongoing worries about family back home. One of the most challenging factors cited by participants was having to cope with constant change during the migration and resettlement process. New Zealand is a very foreign place to a Somali and coming to terms with such an enormous array of change is quite a stressful process.

Although mental distress is often conceptualised biomedically as something requiring medical intervention, few individuals had sought the assistance of mental health care services. Most endeavoured to manage their suffering themselves, typically through drawing upon religious practices such as recitation of the Koran or seeking assistance from family and friends. Many women found that participating in the Muslim Women's Swimming Programme benefitted their overall psychological wellbeing. Interestingly, I observed the tendency for such distress to be typically manifested in bodily complaints with an extremely high proportion of Somalis complaining of numerous bodily pains including rheumatism, arthritis, joint and muscle pain. This has also been observed by other health and refugee workers both in New Zealand and overseas (Warfa et al., 2006). Part of this phenomena is due to the differences between Somali and Western-based models of mental health (Warfa et al., 2006). In addition, mental health is highly stigmatised as is the case for many people living in New Zealand.

Ideas about health have been strongly shaped by people's experiences of health and disease in Somalia. Despite the establishment of a Western hospital system, only those in the city with sufficient wealth were able to see doctors. Most Somalis managed their illnesses at home by themselves using Koranic or traditional remedies. Such practices were strongly evident in the context of New Zealand with many individuals using remedies prepared at home. Somalis did express a high degree of trust in Western biomedicine but equally drew on Islamic teachings and medical practices. Western doctors were held in very high esteem and constructed as the rightful holders of medical expertise. The two models of health were seen by participants as complementary and drawn upon at different times for different purposes. Acute complaints such as a broken arm were seen as the domain of western medicine while psychological issues were seen as something that could only be treated using Koranic healing. This has a number of implications for health practitioners in New Zealand given the high burden of psychological distress amongst Somalis.

Koranic healing was particularly important and shaped the way in which Somalis understood and responded to health and illness. This highlights how health and disease are influenced by social and cultural factors. Many people said that sickness was part of Allah's will and that it was important to accept Allah's will gracefully and seek the necessary treatment as instructed in the

Koran. This helps explain why taking medication is such an important part of Somali health beliefs and practices.

Participants frequently constructed Somalia as being intrinsically healthier than New Zealand due to the health-promoting physical and social environment. The heat and dryness of the Somali climate was seen as beneficial as was the regular physical activity through everyday activities such as shopping. The social environment whereby neighbours were strongly connected and many generations of families lived together was also seen as beneficial to health. New Zealand on the other hand offers none of these benefits with individuals reporting that the damp and cool climate damaged their health, limiting their ability to exercise. Reduced social networks and relationships were also seen as being negative in terms of health.

Although many individuals reported frequent presentation at their GPs, frequency of presentation does not necessarily equate with successful outcomes. As is the case with many people's TB journeys, consultations were hampered by issues of language and lack of knowledge in terms of the process of the New Zealand medical system and chain of referral. There was a great gap between the language and explanatory frameworks (Kleinman, 1980; Kleinman, 1995) employed by medical personnel and the understandings of their Somali clients. Despite these challenges, many participants spoke highly of the medical care they received and were grateful to be able to access medical services for little cost.

While this research is focused on TB, it is important to remember that TB is not experienced in isolation from the multiple health issues faced by participants of which TB is just one area of concern. In addition, disease is not experienced in isolation from people's wider lives. This realisation occurred early on in the research process when I discovered that although TB is seen as a terrible disease, it is regarded of less importance than the more pressing concerns of income, employment and family reunification.

While many studies of particular cultural groups have been done in relation to TB with the explicit aim of 'understanding' in order for erroneous beliefs and knowledge to be corrected, this research has sought to understand Somalis' experiences in their own right. Rather than approaching Somalis beliefs and knowledge about TB as being correct or incorrect, I have highlighted the multiple influences upon their attitudes.

Although TB is a completely treatable disease, it remains highly stigmatised. Participant's accounts of separation, isolation and marginality have highlighted the extent to which having TB can profoundly influence the social standing and acceptability of people in the eyes of others. Processes of separation and isolation initiated in the hospital also occurred on the home front. Of greatest concern to participants were the views of others. Frequently throughout the three years of fieldwork, I encountered this stigma towards the illness. I had to tread very carefully during this

time to avoid inflaming this situation and had to be extremely discreet and watchful. Additionally, the stigma associated with the disease impacted on participant recruitment. Nearly half of all participants who were approached declined to be interviewed. Many were fearful of talking about TB with a strange researcher and thus being further tainted with the reputation of the disease.

When talking to community members about TB, two different narratives emerged. The first minimised the seriousness of the disease by comparing it with less stigmatised conditions such as influenza. This narrative was difficult to understand at first given the second discourse emphasising the degree to which TB continues to be a highly stigmatised condition. As fieldwork progressed, it became apparent that these discourses tended to be operationalised within a public/private setting similarly outlined in Cornwell's (1984) ideas about public and private accounts. Typically, in a public setting, people spoke about how the disease was not stigmatised now that it was treatable. Participants also tried to portray the idea that Somalis are progressive, knowledgeable and educated about the nature of the disease. As I developed trust with research participants, accounts of ongoing stigma, shame, fear and isolation emerged. The fear of TB is rooted to some degree in the experience of the disease in Somalia. Often it was not treated and led to an often painful death. Due to the limitations of drug supplies, many families were unable to afford the medication and thus isolation proved to be one of the only ways in which the disease could be contained. Physical separation also mirrored the social stigma experienced not only by individuals but their entire families.

Despite the availability of TB medication in New Zealand, successfully completing TB treatment does not address the social damage resulting from TB. Participants who were most marginalised prior to developing the disease appeared to be the most affected by TB related stigma. Individuals described being gossiped about and isolated from wider community members. A number mentioned that people no longer came to visit them, a social practice that is a key part of Somali social relations. For some, having TB had caused shame upon the whole family. In order to manage this stigma, most did not disclose their illness to others and went to great lengths to keep their diagnosis secret. PHNs also had to be very careful to avoid associating their patients with the disease in any way. Despite these efforts, the small size and close-knit nature of the community meant that in many cases, others did find out.

When asked specific questions about the epidemiology of the disease, a wide variety of issues were raised in terms of the causes, transmission, symptoms. Few people mentioned germs as the cause of TB but rather embraced a socio-ecological approach to health that emphasised the variety of influences upon wellbeing including poverty and malnutrition. While some thought TB was hereditary or caused through moral deficiencies, others cited environmental and occupational factors such as exposure to steam, paint fumes and dust. One interesting explanation was that TB arises from injury to the lungs or as a result of a cold that worsens into influenza and subsequently becomes TB.

Ideas about transmission centred on the fact that the disease is spread from one person to another. Typically, this act was linked with poor living conditions such as those experienced in refugee camps which were crowded, unhygienic and lacking in the basic necessities of life. There were some who believed the disease could be spread through brief encounters and via household objects including eating utensils. People had an extensive knowledge of the symptoms of the disease including coughing, weight loss, weakness, fever and night-sweating. These symptoms were very well-recognised and had implications for the large numbers of individuals with extra-pulmonary TB whose symptoms did not necessarily fit the mould.

Somali ideas about TB reflect the social construction of the disease in Somalia and the country's wider social, economic, political and cultural constraints. Although these beliefs are being re-worked within the New Zealand context, for instance, with the ready availability of TB medicine, ideas about TB as a highly dangerous and feared condition still remain. The diversity of people's ideas about TB was mirrored in the diversity of narratives of those with the disease. As TB has a range of symptoms, individuals described various illness recognition processes. There were however two common points in the development of the condition at which people realised they were unwell. The first was the occurrence of unusual pain and the second was the inability to function normally. Those with extra-pulmonary TB experienced localised body pain which they justified initially in terms of the context of their everyday lives. For many, during the ensuing weeks this worsened to the point where they were unable to function at all. Those who experienced pulmonary TB believed that their initial symptoms would just go away however, when they started coughing they began to take their other symptoms more seriously. As the idea of self-responsibility is strongly advocated in Somali health beliefs, many people tried to treat their illness with soup, herbs and other home remedies. Others visited their doctor straight away. Common to nearly every person was frequent presentation to their doctor. This proved to be a very frustrating time for many as they became increasingly ill and yet their doctor's prescriptions did not offer the relief they had hoped for. As they became more unwell, a number of individuals directly admitted themselves to the Emergency Department at hospital.

Throughout the diagnosis process there was evidence of a clash between the explanatory models of patients and their providers. Patients' accounts of their own illness tended to be minimised and dismissed leading to a sense of frustration. Given the difficulties of diagnosing extra-pulmonary TB, it was a last resort diagnosis after every other condition had been ruled out. Once the diagnosis had been made, participants began the long and lengthy treatment process. For many this spanned up to a year.

Once patients were discharged from hospital, PHNs oversaw the completion of the DOTS treatment programme. During the treatment process, PHNs and patients spent a lot of time together and the relationship that was formed assisted participants through the difficult times of the

treatment process particularly in terms of the strong side-effects. PHNs did not simply distribute medicine but also cared for participants in terms of the wider context of their lives assisting with transportation, food and wider needs in their lives. Many attributed this relationship with their PHN as the key reason why they successfully completed the difficult treatment regimen. One of the key factors behind this effective relationship was the nurses' knowledge of Somali culture and social practices. This enabled them to work effectively cross-culturally. Yet not all participants enjoyed a strong relationship with their PHN. Those who did not have a good relationship with their PHN tended to have greater difficulty with the TB treatment process as a whole. Compliance has been a major focus of attention in recent years, particularly in light of concerns over treatment failure and the increase in MDR-TB. Participants were very cognizant of this and were eager to reassure me they did everything in their power not to 'miss a dose'. In total, all participants successfully completed their treatment programmes

Yet not all encounters with medical professionals were as interactive and rewarding. During chest clinic visits I attended, doctors were generally perfunctory, dismissive, expressing high frustration levels at their Somali patients. Once again, participants' accounts of their health and wellbeing were dismissed in favour of indisputable medical facts such as x-rays and blood test results. Participants were sometimes required to wait two hours for their scheduled appointment time by which point in time interpreters had left. This was both financially inefficient and also led to communication problems during the consultation.

As some participants were extremely unwell by the time they were diagnosed, their body had been irreparably damaged by the disease and even though they are no longer infectious, they still continue to live with the scars of the illness. A number of individuals still experience TB-like symptoms many months on from the completion of their treatment. This raises questions about the way in which TB treatment is heavily promoted by medical professionals as a complete 'cure' for TB.

## **Summary**

Although TB has long been associated with poverty and suffering, this association has at times been subsumed in the quest for medical victory over the disease. The resurgence of TB in the 1980s in developed nations brought this issue to the fore as commentators such as Farmer (1996; 1997; 2000) and Gandy and Zumla (2002a; 2003) highlighted the role of poverty, globalisation and rampant economic and political restructuring. In New Zealand, there has been a far greater focus on the relationship between TB and ethnicity than that of TB and poverty (Martin, 2000).

Poverty, linked with a lifecourse that includes exposure to TB, remains one of the leading explanations behind the occurrence of TB. Not until that poverty is addressed will many of the world's most marginalised people find relief. The prospect of the enormous, sobering and

seemingly impossible task of the eradication of poverty is potentially one explanation for why there remains a fervent desire to develop a 'magic bullet' vaccine against the disease. While this connection between poverty and TB is overwhelming, there are many small steps that can be undertaken (e.g. the assisting of marginalised people to obtaining affordable and adequate housing, meaningful employment and the improvement of family reunification processes). While such steps are part of the government's mandate, efforts need to be more closely focused on the needs of the people who need them most. Unfortunately, Somali refugees are also politically discriminated against and are the frequent target of racist attacks from political figures and thus tapping into deep-seated xenophobic fears of the wider New Zealand population. Sensitivities regarding the priorities and competing claims of different ethnic groups have made it politically unpopular to address the needs of refugee groups such as the Somali in Auckland. Until we approach the needs of such groups out of a sense of social justice, they will remain politically, economically and socially marginalised and vulnerable to the vicissitudes of political popularity contests.

While the experiences of Somali refugees are both grave and sobering, it is important not to forget the way in which they have survived against the odds and have re-established themselves and their community within Auckland, New Zealand. Despite profound suffering and hardship due to forces beyond their control, they are an excellent example of the human capacity for survival.

## Appendix 1

### Interview Details

Name	Gender	Interview Type	Tape-recorded	Interpreter*
Abal	M	Community	Yes	No
Abir	F	TBD	Yes	No
Adil	M	TBD	Yes	No
Akif	M	TBD	No	Yes
Akram	M	Community	Yes	No
Almas	F	Focus Group	No	Yes
Barika	F	TBI	Yes	No
Barir	M	TBD	Yes	Yes
Bayan	F	Focus Group	No	Yes
Durar	F	Community	Yes	No
Fakhir	M	Community	Yes	No
Falak	F	Focus Group	No	Yes
Furat	F	TBI	Yes	No
Ghadah	F	TBD	No	Yes
Ghaniyah	F	Community	Yes	No
Habib	M	TBI	No	No
Hiyam	F	TBI	No	Yes
Hala	F	TBD	Yes	Yes
Huma	F	Focus Group	No	Yes
Husniyah	F	Community	No	No
Iqbal	M	TBI	No	No
Ishraq	F	TBD	Yes	No
Jalilah	F	TBD	No	Yes
Jabbar	M	TBI	No	Yes
Kadar	M	Community	Yes	No
Kalila	F	Community	No	No
Khalisah	F	TBD	No	Yes
Mahir	M	TBI	No	Yes
Masarraah	F	TBI	No	Yes
Minnah	F	TBI	No	Yes
Muhab	M	TBI	No	Yes

Namir	M	Community	Yes	No
Nawal	F	Focus Group	No	Yes
Nuwwarrah	F	Community	No	No
Raha	F	TBD	No	Yes
Rashidah	F	Focus Group	No	Yes
Shafiqah	F	TBD	No	No
Shakirah	F	Focus Group	No	Yes
Talib	M	TBI	No	Yes
Tamam	M	Community	Yes	No
Tibah	F	TBD	Yes	No
Ulfah	F	TBD	Yes	No
Wardah	F	Focus Group	No	Yes
Wasimah	F	Focus Group	No	Yes
Yaminah	F	TBI	No	Yes

\* N.B. All interviews where there was no interpreter were conducted in English with a little Somali

## Appendix 2

### Project Information Sheet

**What is the study?** It is a social science study, in several different communities in Auckland, with a specific focus on TB. We want to understand the health and social context in which people are living as we believe that this is important to understanding TB. The communities included in the research are Pakeha, Maori, Pacific, and, we hope, Somali, and Asian. The last two groups represent more recent migrants. The Asian study will focus on young people, especially students, and not be confined to a single cultural group. We also are supporting a historical study of TB in NZ since 1945.

**Why do the study?** New Zealand is experiencing relatively high rates of TB in some of its communities. We believe that if we can understand the general health and social context which is allowing the transmission of TB, or its reactivation, and the difficulties and pressures that come with its treatment, then we will be able to make a contribution to helping reduce the rate of this disease. Part of the social context is the way in which both health and TB are regarded in different communities, the social and economic characteristics of communities, as well as the practical aspects of access, transport, sufficient income, sources of information and so on. These are all part of our study.

**Why the Somali community?** African New Zealanders are very often left out of health and social research. We wanted to include a relatively recent group of New Zealanders with an African background. Through discussion with our advisors, we learned that the Somali community is large and well organised and has experience of health research and health promotion. We are aware that TB is a sensitive issue and are concerned with anonymity of research participants. Because Somalis form a large community we thought anonymity would be more secure and people are less likely to be able to be identified.

**Who are we?** We are a group of staff and students from the University of Auckland. The staff are Associate Professors Robin Kearns (Geography), Lynda Bryder (History), Julie Park (Anthropology), Dr Judith Littleton (Anthropology). Dr Heather Worth, although now in Australia, is also on the team. The PhD students are Jody Lawrence, who hopes to work with you, Anneka Anderson, who hopes to work with the Asian young people, and Debbie Dunsford, who is doing the historical work. Alison Searle (MA student) is working with the Pakeha community, and next year two more researchers will work with Maori and Pacific Islands communities. We also have an advisory group.

**Funding and Ethics approval** We are funded by the Health Research Council of New Zealand and by the University. The funding is for the scholarships for the students, and our working expenses,

including payment for interpreters, translators and community advisors. We have ethics approval from Auckland Ethics Committee.

**How do we plan to work?** In partnership with the various communities. We have advisors from the public health field and would also seek advisors from your community to work with us. The first part of our research would be seeking what the community might want from such a study and allowing time for Jody to become familiar community members. Jody will want to participate in community events, and get to know people. Towards the end of the year, Jody would prepare a full proposal, detailing how the study would proceed and giving the rationale for it. She would hope that her community advisors would have input into this. She would be wanting to work with community members in general, as well as with people and families who have had experience with TB.

In addition, if there are university students or other community members who have an interest in this kind of research, we would hope to provide them with training opportunities.

Jody will be supported by the staff who are her supervisors, and Jody and Anneka may also team up to work together, in some situations.

Some of the questions we would like to ask during interviews with the Somali community.

What does being healthy mean to you? What is health? How can you be healthy?

Where do you go when you are feeling unwell?

Who do you rely on for advice about health and illness?

Are there healers within your community? When would you go and see them?

What do you know about TB? Why do some people get it and not others?

How should people with TB be treated?

## **Contact Details**

Jody [jody.lawrence@xtra.co.nz](mailto:jody.lawrence@xtra.co.nz) ph 3737599 ext 88457

Julie [j.park@auckland.ac.nz](mailto:j.park@auckland.ac.nz) ph 3737599 ext 88589

Robin [r.kearns@auckland.ac.nz](mailto:r.kearns@auckland.ac.nz) ph 3737599 ext 88442

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## Appendix 3

### Project Information Sheet (Somali translation)

#### War galin

#### Waa maxay barashada baaritaanka?

Waxaa waaye baaritaan ama barasho bulsho, dad waynaha kaladuwan oo ku nool Auckland, si gaar ahaaneed cudurka (TB) khaaxada.

Waxaan rabnaa in aan ogaano ama fahano bulshada sida ay u nooshahay, caafimaadkooda.

Waxaan rumeyn sanahay ama aaminsanahay in ay muhiim tahay fahanka cudurka khaaxada.

Dadwaynaha ka qayb qaadanaya baaritaankaan waxaa ka mid ah:

European (cadaanka ku nool wadankan)

Maori ga

Pacific ga

iyo waxaan rajeynaynaa

Asianka

Somalida

Asianka iyo Somalida waxay ka mid yihiin dadka ugu dambeyey oo wadanka soogala.

Baaritaanka Asianka wuxuu gaar ahaan fiirinayaa dadka yar yar, siiba ardayda, anagoo hal jinsiyad kaliya aan fiirinayn. Waxaa kale oo aan caawinaynaa baaritaan taariiqeedka qaaxada ee wadanka New Zealand oo socday ilaa 1945.

#### Waa maxay sababta aan baaritaanka u sameyneyno ?

Wadanka New Zealand oo khibrad cusub u yeeshay koritaanka ama fiditaanka cudurka khaaxada qaar ka mid ah dadweynaha ku nool wadanka.

Waxaan aamin sanahay hadaan fahano caafimaadka guud ahaaneed ee bulshada oo keenaikara khaaxada ama soo noqoshada khaaxada iyo dhibaatooyinka ka imaan kara daawaynteeda. Waxaan rajeyneynaa in aan caawino sidii lagu yareynlahaa cudurka khaaxada.

Barashada bulshada waxaa ka mid ah waxa ay ka aaminsanyihiin cudurka iyo caafimaad kooda, jidadka ay u marilahayeen daaweynta, waxay u baahdaan sida gaadiid, la'cag ku filan iyo wararka kala duwan sida ay u heli lahayeen iwm. Waxaan oo dhan waxay ka mid yihiin baaritaanka.

## **Sababta dadwaynaha soomaliyeed loogu daray.**

Africaanka New Zealand ku nool inta badan ka qeyb qaadashada baaritaanada dadweynaha caafimaadkooda waa laga tagijiray.

Waxaan rabnaa in aan ku darno koox cusub oo wadanka ku soo biirtay oo Afrikaan ah.

Markaan la faalonay lataliyayaasheena waxaan ogaanay in bulshada soomaalida ay badan yihiin ayna waayo arignimo u lee yihiin caafimaad baaritaan iyo hirgalinta caafimaadka.

Waxaa kale oo jira dadwaynaha soomaaliyeed way badan yihiin waxaan is niri sirta qofka way nabad galeysaa waxayna u badan tahay in dadka ka qayb qaadanaya baaritaanka aan la ogaan.

## **Yaa nahay anaga?**

Waxaan nahay koox isugu jira macalimiin iyo arday ka socota jaamacada Auckland.

Macalimiinta waa: Kalkaaliyaasha hormuudka jaamacada:

Robin Kearns (Geography) juquraafi.

Lynda Bryder (History) tariiq.

Julie Park (Anthropology)

Dr Judith Littton (Anthropology)

Dr Heather Worth-kooxda ayuu ka mid yahay hadase wuxuu jiraa Australia.

Ardayda samaynaysa PHD waa:

Jody Lawrence (soomalida ayay la shaqeynaysaa)

Anneka Anderson (Asian)

Debbie Dunsford (historical work)

Alison Searle MA student (cadaanka ayay la shaqeynaysaa).

Sanadka dambe labo qof oo baaritaan sameynaya waxay la shaqey doonaan Maori ga iyo Pacifiiga waxaa kale oo ka mid ah koox la taliyeyaal ah.

## **Lacag iyo ogolaanshaha xeerka**

Waxaa lacagta bixinaya gudiga caafimaad baarida ee New Zealand iyo jaamacada.

Lacagta waxaa loogu talagalay deeq waxbarasho ardayda iyo kharashka ku baxaya shaqooyinka ka mid ah

Lacagta loogu talagalay turjubaanada

Lataliyayaasha bulsha ka socda iwm.

Waxaa xeer ogo'laan ka haysanaa golaha Auckland ee xeererka

Qaabka aan doonayno in aan u shaqeyno waa?

Waxaan rabnaa in aan wada shaqeyno dadweynaha kala duwan.

Waxaa nala shaqeynaya bulshada caafimaadkooda lataliyayaal ka socota.

Waxaan rabnaa in ay nala shaqeeyaan lataliyayaal ka socda bulshadiina.

Qaybta koowaad oo barnaamijkaan baaritaanka aan doonayno waa in aan ogaano waxa dadwaynihiina jecelyihiin in ay ka fa'iidaan baaritaankaan.

Jody waxay jeceshahay in ay ka qayb qaadata kulamada bulshada, waxay kaloo jeceshahay in ay barato dadka.

Sanadka dhamaadkiisa Jody waxay diyaarineysaa codsi dhan oo ka faaloonaya sida uu barnaamijka u soconayo iyada oo siinaysa sabab u yeeleysa barnaamijkaan.

Waxaa kale oo ay jeceshahay in ay la shaqeyso guud ahaan dadweynaha iyo dadka ama qoysaska qaaxada khibrada u leh.

Waxaa kale, hadii ay jiraan arday jaamacad ama dadka mid ah bulshada oo jecel barnaamijyadaan oo kale waxaan jecel nahay in aan siino toobarid iyo fursadooyin.

Jody waxaa caawinaya macalimiin u ah kormeerayaaal howsha dusha ka ilaalinaya.

Waxaa laga yaabaa Jody iyo Anneka in ay wada shaqeeyaan mararka qaarkood.

Su'aalaha aan dooneyno in aan waydiino bulshada Soomaaliyeed xiliga wareysiga waxaa ka mid ah:

Maxaad ka fahansan tahay micnaha caafimaad? Muxuu yahay caafimaad? Sidee baad caafimaad ku yeelan kartaa?

Markaad xanuun satid xagee baad aa daa?

Xagee baad ama qofkee baad wargalin ka heshaa ku saabsan caafimaadka ama jirada?

Bulshadiina dhaxdeeda daaweeyayaal miyaa jira? Goorma ayaadse aadilaheyd?

Maxaad ka taqaan cudurka khaaxada? Maxay dadka khaarkood ugu dhacdaa khaarkoodna ugu dhicin?

Sidee baa dadka khaaxada qaba loo daa weeyaa?

Contact details( dadka kala xiriir ciwaanadan hoos ku qoran)

Jody [jody.lawrence@xtra.co.nz](mailto:jody.lawrence@xtra.co.nz) ph3737599 ext 88457

Julie [j.park@auckland.ac.nz](mailto:j.park@auckland.ac.nz) ph3737599 ext 88589

Robin [r.kearns@auckland.ac.nz](mailto:r.kearns@auckland.ac.nz) ph3737599 ext 88442

Judith [j.littleton@auckland.ac.nz](mailto:j.littleton@auckland.ac.nz) ph3737599 ext 88574

# Appendix 4

## TB Participant Information Sheet

### Participant Information Sheet

Principal Investigator:

Associate Professor Julie Park  
Department of Anthropology  
University of Auckland,  
Private Bag 92019  
Auckland

Phone: 3737599 x88589

Name of Study: Tuberculosis in New Zealand

#### Introduction

You are invited to take part in a study of tuberculosis in New Zealand – past and present. Your participation is entirely voluntary. If you choose not to take part you will receive the usual medical treatment. We will contact you in approximately one week to see if you are willing to take part in this research.

#### ABOUT THE STUDY

The aim of the study is to find out about the successful treatment and prevention of TB.

We are interviewing people who have had TB in the past and at present, people who have had TB patients in their families or among their friends, health professionals who work in the area, and members of the community. TB patients and their families will be identified by the Auckland District Health Board Public Health Team. Recruitment of community members will be through community networks matching as far as possible characteristics of the TB group

Approximately 100 participants will take part

The study will take place in various venues in the Auckland area.

The time span for this study is four years.

The study will consist of interviews of approximately one hour. People with TB will be asked for up to three interviews; other participants for one. The interviews will be audio-taped. With the participant's permission the audio-tape will be deposited in an oral history archive where it can be accessed by *bona fide* researchers approved by the Archive management, who will agree to preserve interviewees' anonymity. Other tapes will be destroyed on the conclusion of the study. Where tapes are transcribed, transcripts will also be archived under the conditions described above, with the participants' permission. Otherwise the transcripts will be destroyed after ten years.

### **BENEFITS RISKS AND SAFETY**

The study aims to benefit people with TB and the community through a greater understanding of how TB persists.

The study proposes no risk and the only inconvenience is the time taken for interview.

Participants will be offered a small gift, eg, fruit.

### **PARTICIPATION**

If you do agree to take part in this research you are free to withdraw from the study at any time, without having to give a reason and this will in no way affect your health care.

### **GENERAL**

Your GP will be told you are in the study, only if you give us permission to access your medical records.

If you want more information about this study you can access the website at <http://www.arts.auckland.ac.nz/ant/TBProject/TBproject.htm> or contact one of the researchers.

If you need an interpreter, one can be provided.

You may have a friend, family or whanau support to help you understand the risks and/or benefits of this study and any other explanation you may require.

During the interview you do not have to answer all the questions, and you may stop the interview at any time.

If you are a health professional taking part in this study, if you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact your professional organisation.

If you have any queries or concerns regarding your rights as a participant in this study you may wish to contact a Health and Disability Advocate, telephone 0800 555 050.

For Auckland District Health Board Maori Health support, please contact Mata Forbes, RGON; Co-ordinator / Advisor, Maori Health Services, Auckland Hospital, Grafton Mobile 021 348432; Tel (09) 307 4949 Extn 7292.

### **CONFIDENTIALITY**

No material which could personally identify you will be used in any reports on this study. During the study the data will be kept in locked University of Auckland facilities.

### **RESULTS**

This study consists of several different components that will be completed successively from 2004-2006. Results of the study can be accessed on the website noted above. For those participants who wish it, copies of summary reports will be available. The study will also be published in academic and health journals.

### **STATEMENT OF APPROVAL**

This study has received ethical approval from the Auckland Ethics Committee.

Please feel free to contact the researcher if you have any questions about this study.

## Appendix 5

### Consent Form (TB participants)

Name of Study: Tuberculosis in New Zealand

### REQUEST FOR INTERPRETER

(to be included on all consent forms)

English	I wish to have an interpreter.	Yes	No
Maori	E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero.	Ae	Kao
Samoan	Ou te mana'o ia i ai se fa'amatala upu.	Io	Leai
Tongan	Oku ou fiema'u ha fakatonulea.	Io	Ikai
Cook Island	Ka inangaro au i tetai tangata uri reo.	Ae	Kare
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu.	E	Nakai
	Other languages to be added following consultation with relevant communities.		

NB: other languages will be added when these are established

I have read and I understand the information sheet dated \_\_\_\_\_ for volunteers taking part in the study designed to investigate health knowledges and practices as they relate to tuberculosis.

I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my health care.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

I have had time to consider whether to take part.

I know who to contact if I have any questions about the study.

I consent to my interview being audio-taped

YES/NO

I consent to a copy of the audiotape being lodged in an appropriate oral history archive under the conditions described in the Participant Information Sheet

YES/NO

I consent to my transcript being lodged in an appropriate oral history archive under the conditions described in the Participant Information Sheet

YES/NO

I wish to receive a copy of my transcript

YES/NO

I wish to receive a copy of the summary report

YES/NO

I consent to my medical records that relate to tuberculosis being sought

YES/NO

I \_\_\_\_\_ (full name) hereby consent to take part in this study.

Date

Signature

Full names of Researchers:

Associate-Professor Julie Park, phone 3737599 x88589

Dr Judith Littleton phone 3737599 x87319

Associate-Professor Linda Bryder phone 3737599 x8

Dr Heather Worth phone 3737599 x87042

Associate Professor Robin Kearns phone 3737599 x88442

Project explained by

Project role

Signature

Date

## Appendix 6

### Consent Form (community members and health professionals)

**Name of Study: Tuberculosis in New Zealand**

#### REQUEST FOR INTERPRETER

(to be included on all consent forms)

English	I wish to have an interpreter.	Yes	No
Maori	E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero.	Ae	Kao
Samoan	Ou te mana'o ia i ai se fa'amatala upu.	loe	Leai
Tongan	Oku ou fiema'u ha fakatonulea.	lo	Ikai
Cook Island	Ka inangaro au i tetai tangata uri reo.	Ae	Kare
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu.	E	Nakai
	Other languages to be added following consultation with relevant communities.		

NB: other languages will be added when these are established

I have read and I understand the information sheet dated \_\_\_\_\_ for volunteers taking part in the study designed to investigate health knowledges and practices as they relate to tuberculosis.

I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my health care.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

I have had time to consider whether to take part.

I know who to contact if I have any questions about the study.

I consent to my interview being audio-taped

YES/NO

I consent to a copy of the audiotape being lodged in an appropriate oral history archive under the conditions described in the Participant Information Sheet

YES/NO

I consent to my transcript being lodged in an appropriate oral history archive under the conditions described in the Participant Information Sheet

YES/NO

I wish to receive a copy of my transcript

YES/NO

I wish to receive a copy of the summary report

YES/NO

I \_\_\_\_\_ (full name) hereby consent to take part in this study.

Date

Signature

Full names of Researchers:

Associate-Professor Julie Park, phone 3737599 x88589

Dr Judith Littleton phone 3737599 x87319

Associate-Professor Linda Bryder phone 3737599 x8

Dr Heather Worth phone 3737599 x87042

Associate Professor Robin Kearns phone 3737599 x88442

Project explained by

Project role

Signature

Date

## Appendix 7

### TBD Interview Questionnaire

#### Tell me a bit about yourself and your family?

1. Tell me about the events that led to you coming to New Zealand?
2. What has life been like for you since you have been living in NZ?

#### Now moving onto questions about health

3. What does health mean to you?
4. How do you recognise health in yourself?
5. How do you recognise health in others?
6. What do you do to keep healthy?
7. From where did you learn about health?
8. How do you know when you're not well?
9. What action do you take when you're not well?
  - a. a minor illness
  - b. a serious illness

#### Now moving onto questions about TB

10. What do you think caused your TB?
11. Why do you think it started when it did?
12. What are the main problems TB has caused you?
13. What do your friends & family think about your illness?
14. What do Somali people think about tuberculosis?
15. What do you tell people about your illness?
16. What was/is the treatment process like?
17. What has been your experience with health service providers?
18. What were/are your expectations around recovery?
19. What has been your experience since recovery?
20. Do you think having had TB will affect your future? Why? Why not?

## Appendix 8

### TBI Interview Questionnaire

#### Tell me a bit about yourself and your family?

1. Tell me about the events that led to you coming to New Zealand?
2. What has life been like for you since you have been living in NZ?

#### Now moving onto questions about health

3. What does health mean to you?
4. How do you recognise health in yourself?
5. How do you recognise health in others?
6. What do you do to keep healthy?
7. From where did you learn about health?
8. How do you know when you're not well?
9. What action do you take when you're not well?
  - a. a minor illness
  - b. a serious illness

#### Now moving onto questions about TB

10. Where do you think you got TB infection from?
11. What are the main problems TB infection has caused you?
12. What do your friends & family think about having TB infection?
13. Has having TB infection been a problem for your family?
14. What do Somali people think about tuberculosis?
15. What do you tell people about having TB infection?
16. What is the treatment process like?
17. Did the treatment process cause any problems?
18. What has been your experience with health service providers?
19. What were/are your expectations around recovery?
20. What has been your experience since recovery?
21. Do you think having had TB infection will affect your future? Why? Why not?

## Appendix 9

### General Community Interview Questionnaire

#### Tell me a bit about yourself and your family?

1. Tell me about the events that led to you coming to New Zealand?
2. What has life been like for you since you have been living in NZ?

#### Now moving onto questions about health

3. What does health mean to you?
4. How do you recognise health in yourself?
5. How do you recognise health in others?
6. What do you do to keep healthy?
7. From where did you learn about health?
8. How do you know when you're not well?
9. What action do you take when you're not well?
  - a. a minor illness
  - b. a serious illness

#### Now moving onto questions about TB

10. What do you think causes TB?
11. How can you catch TB?
12. How do you know if you have TB?
13. What kind of people get TB?
14. What are the problems caused by having TB?
15. How does having TB affect a family?
16. What kind of words do you associate with TB as a disease?
17. How do you think TB affects the future of those who have recovered from the illness?

# Appendix 10

## Focus Group Discussion Questions

### Health Ideas

1. What are the main health issues faced by the Somali community?
2. What things can you do to keep healthy?
3. What things are bad for your health?
4. What does the Koran say about 'health'?
5. What does the Koran say about diseases?
6. How does the climate affect health?
7. Four different medical problems (causes, symptoms, treatment)
  - a. Flu
  - b. Headache
  - c. Vomiting
  - d. Back-ache

### TB

8. What do you think causes TB?
9. How can you catch TB?
10. What happens to someone if they get TB?
11. What kinds of people are more likely to get TB?
12. In Somali culture, what do people think about tuberculosis?
  - a. In the past in Somalia?
  - b. In Somalia now?
  - c. In New Zealand?

## References

- Abbot, M. (1997) Refugees and immigrants. In *Mental health in New Zealand from a public health perspective*, (Eds, Ellis, P. and Collings, S.) Public Health Report Number 3. Public Health Group, Ministry of Health, Wellington, 250-264.
- Abdullahi, M. (2001) *Culture and customs of Somalia*, Greenwood Press, Westport.
- Abdulle, M. H. (2000) Somali immigrants in Ottawa: the causes of their migration and the challenges of resettling in Canada. Unpublished MA thesis. Department of History, University of Ottawa, Ottawa.
- Abu-Lughod, L. (1986) *Veiled Sentiments: Honor and poetry in a Bedouin Society*, University of California Press, Berkeley.
- Adair, R., Nwaneri, O. and Barnes, N. (1999) Health care access for Somali refugees: views of patients, doctors, nurses. *American Journal of Health Behavior*, **23(4)**, 286-292.
- Adams, K. and Assefi, N. (2002) Primary care refugee medicine: general principles in the postimmigration care of Somali women. *Primary Care Update*, **9**, 210-217.
- Agutu, W. (1999) Short-course tuberculosis chemotherapy in rural Somalia. *East African Medical Journal*, **74(6)**, 348-352.
- Ahmed, C. (1995) Finely etched chattel. The invention of a Somali woman. In *The invention of Somalia*, (Ed, Ahmed, E.) Red Sea Press, New Jersey, 157-190.
- Ahmed, I. (2000) Remittances and their economic impact in postwar Somaliland. *Diasters*, **24(4)**, 380-389.
- Ahmed, I. and Green, R. (1999) The heritage of war and state collapse in Somalia and Somaliland: local-level effects, external interventions and reconstruction. *Third World Quarterly*, **20(1)**, 113-127.
- Ahmed, S. (1999) Islam and development: opportunities and constraints for Somali women. *Gender and Development*, **7(1)**, 69-72.
- Al-Ali, N., Black, R. and Koser, K. (2001) The limits to 'transnationalism': Bosnian and Eritrean refugees in Europe as emerging transnational communities. *Ethnic and Racial Studies*, **24(4)**, 578-600.
- Al-Sharmani, M. (2006) Living transnationally: Somali diasporic women in Cairo. *International Migration*, **44(1)**, 55-75.
- Alitolppa-Niitamo, A. (2002) The generation in-between: Somali youth and schooling in metropolitan Helsinki. *Intercultural Education*, **13(3)**, 275-290.
- Allotey, P., Manderson, L. and Grover, S. (2001) The politics of female genital surgery in displaced communities. *Critical Public Health*, **11(3)**, 189-201.
- AMNI (2002) *Somalia. A cultural profile*. Anti-Racism, Multiculturalism and Native Issues (AMNI) centre, University of Toronto, Toronto.

- Andrews, G. (2002) Private complementary medicine and older people: service use and user empowerment. *Ageing and Society*, **22**, 343-368.
- Andrews, G. and Phillips, D. (2002a) Changing local geographies of private residential care for older people 1983-1999: lessons for social policy in England and Wales. *Social Science and Medicine*, **55**, 63-78.
- Andrzejewski, B. and Lewis, I. (1964) *Somali Poetry: An Introduction*, Oxford University Press, Oxford.
- Anstiss, S. (2001) *Refugee community profiles for service providers*. Auckland Refugees as Survivors Centre, Auckland.
- Anthias, F. (1998) Evaluating 'diaspora': beyond ethnicity? *Sociology*, **32(3)**, 557-580.
- Antunes, J. and Waldman, E. (2001) The impact of Aids, immigration and overcrowding on tuberculosis deaths in Sao Paulo, Brazil, 1994-1998. *Social Science and Medicine*, **52**, 1071-1080.
- Asthana, S. (1998) The relevance of place in HIV transmission and prevention. The commercial sex industry in Madras. In *Putting health into place. Landscape, identity and well-being*, (Eds, Kearns, R. and Gesler, W.) Syracuse University Press, Syracuse, 168-190.
- Auckland District Health Board (2001) *Health Needs Assessment Report*. Auckland District Health Board, Auckland.
- Auckland Healthcare (2000) Tuberculosis increasing in young Aucklanders. *Public Health Advice*, **6(1)**, 1-4.
- Auckland Somali Community Association (2006) *Report on the Somali Women's Needs Analysis Project. October 2006*. Ministry of Social Development Community Initiatives Fund, Auckland.
- Bailey, A. (2001) Turning transnational: notes on the theorisation of international migration. *International Journal of Population Geography*, **7**, 413-428.
- Banerjee, A., Harries, A., Nyirenda, T. and Salaniponi, F. (2000) Local perceptions of tuberculosis in a rural district in Malawi. *International Journal of Tuberculosis and Lung Disease*, **4(11)**, 1047-1051.
- Bardsley, M. and Storkey, M. (2000) Estimating the numbers of refugees in London. *Journal of Public Health Medicine*, **22(3)**, 406-412.
- Barnett, R. (2001) Coping with the costs of primary care? Household and locational variations in the survival strategies of the urban poor *Health and Place*, **7(2)**, 141-157.
- Barnhoorn, F. and Adriaanse, H. (1992) In search of factors responsible for noncompliance among tuberculosis patients in Wardha District, India. *Social Science and Medicine*, **34(3)**, 291-306.
- Basch, L., Glick Schiller, N. and Szanton Blanc, C. (1994) *Nations Unbound: transnational projects, postcolonial predicaments and deterritorialized nation-states*, Gordon & Breach, Basle.
- Bayer, R. and Wilkinson, D. (1995) Directly observed therapy for tuberculosis: history of an idea. *The Lancet*, **345(8964)**, 1545-1549.
- Bedford, R. (2002) Contested ground: the politicisation of immigration and belonging. *New Zealand Journal of Geography*, **114**, 8-16.

- Bedford, R. (2004) Out of Africa... New Migrations to Aotearoa. In *Glimpses of a Gaian world: Essays in honour of Peter Holland*, (Eds, Kearsley, G. and Fitzharris, B.) School of Social Science, University of Otago, Dunedin, 345-381.
- Bedford, R., Bedford, C., Ho, E. and Lidgard, J. (2002) The globalisation of international migration in New Zealand: contribution to a debate. *New Zealand Population Review*, **28(1)**, 69-97.
- Bedford, R., Ho, E. and Lidgard, J. (2000) *International migration in New Zealand: context, components and policy issues*. Population Studies Centre, Hamilton.
- Bedford, R., Spragg, B. and Goodwin, J. (1998) *International Migration 1995-1998: A report on current research and a bibliography*. New Zealand Immigration Service, Wellington.
- Bedford, T. and Burgess, J. (2001) The focus-group experience. In *Qualitative methodologies for geographers: issues and debates*, (Eds, Limb, M. and Dwyer, C.) Arnold, London, 121-135.
- Belich, J. (1996) *Making peoples: a history of the New Zealanders*, The Penguin Press, Auckland.
- Bell, D. (2001) *New to New Zealand. A guide to ethnic groups in New Zealand*, Reed, Auckland.
- Berns McGown, R. (1999) *Muslims in the diaspora: the Somali communities of London and Toronto*, University of Toronto Press, Toronto.
- Besteman, C. (1996) Representing violence and "othering" Somalia. *Cultural Anthropology*, **11(1)**, 120-133.
- Bhatti, N., Law, M., Morris, J., Halliday, R. and Moore-Gillon, J. (1995) Increasing incidence of tuberculosis in England and Wales: a study of the likely causes. *British Medical Journal*, **310(967-969)**.
- Blok, B., Grant, C., McNeil, A. and Reid, I. (2000) Characteristics of children with florid vitamin D deficient rickets in the Auckland Region in 1998. *New Zealand Medical Journal*, **113**, 374-376.
- Blunt, A. (2003) Geographies of diaspora and mixed descent: Anglo-Indians in India and Britain. *International Journal of Population Geography*, **9**, 281-294.
- Bondi, L. (2003) The Place of Emotions in Research: Between passionate immersion and cool contemplation in the practice of research. Faculty of Arts and Faculty of Science Graduate Workshop, University of Auckland, Monday 7 April 2003.
- Bowden, M. (1999) *Black hawk down*, Bantam Press, London.
- Bowron, J. (1996) New race and relations. Sunday Star Times. 4 August 1996. Auckland.
- Boyle, M. (2001) Towards a (Re)theorisation of the historical geography of nationalism in diasporas: the Irish diaspora as an exemplar. *International Journal of Population Geography*, **7**, 429-446.
- Boyle, M. (2002) Sticky stories, fluid narratives, or vanishing tales: the fate of 'nations' in a globalised world. *Scottish Geographic Journal*, **118(3)**, 153-163.
- Brah, A. (1996) *Cartographies of diaspora: Contesting identities*, Routledge, London.
- Brandt, A. (1985) *No Magic Bullet: A social history of venereal disease in the US since 1880*, Oxford University Press, New York.
- Braun, M. and Wiesner, P. (1994) Tuberculosis prevention practices and perspectives of physicians in DeKalb County, GA. *Public Health Reports*, **109(2)**, 259-266.

- Brouwer, J., Boeree, M., Kager, P., Varkevisser, C. and Harries, A. (1998) Traditional healers and pulmonary tuberculosis in Malawi. *International Journal of Tuberculosis and Lung Disease*, **2(3)**, 231-234.
- Bryder, L. (1988) *Below the magic mountain: a social history of Tuberculosis in Twentieth-century Britain*, Oxford University Press, Oxford.
- Bryder, L. (1996) "A health resort for consumptives": Tuberculosis and immigration to New Zealand, 1880-1914. *Medical History*, **40**, 453-471.
- Buckland, R. (1997) The everyday experience of Somali women in Canada: implications for health. Unpublished MSc thesis. Department of Nursing, University of Ottawa, Ottawa.
- Budiani, D. (2005) Quests for refuge, quests for therapy: displacement, illness and the body in urban Egypt. Unpublished PhD Thesis. Department of Anthropology, Michigan State University, Michigan.
- Burnett, A. and Peel, M. (2001) What brings asylum seekers to the United Kingdom? *British Medical Journal*, **322**, 485-488.
- Burns, C. (2004) Effect of migration on food habits of Somali women living as refugees in Australia. *Ecology of Food and Nutrition*, **43**, 213-229.
- Burrell, K. (2003) Small-scale transnationalism: homeland connections and the Polish 'community' in Leicester. *International Journal of Population Geography*, **9**, 323-335.
- Butler, R. (2001) From where I write: the place of positionality in qualitative writing. In *Qualitative methodologies for geographers*, (Eds, Limb, M. and Dwyer, C.) Arnold, London, 264-278.
- Bwire, R., Nagelkerke, N., Keize, S., Annee-v. Bavel, J., Sijbrant, J., Burg, J. v. and Borgdorff, M. (2000) Tuberculosis screening among immigrants in the Netherlands: what is its contribution to public health? *The Netherlands Journal of Medicine*, **56**, 63-71.
- Calder, L., Marmont, S., Cheng, A., Gao, W. and Simmons, G. (2001) Adherence with self-administered treatment of latent tuberculosis infection in Auckland. *New Zealand Public Health Report*, **8(7)**, 49-52.
- Cameron, J. (2005) Focussing on the focus group. In *Qualitative Research Methods in Human Geography* (Ed, I Hay) Oxford University Press, Melbourne, 83-102.
- Camp, D., Finlay, W. and Lyons, E. (2002) Is low self-esteem an inevitable consequence of stigma? An example from women with chronic mental health problems. *Social Science and Medicine*, **55(2)**, 823-834.
- Campbell, C. (2004) Care of women with female circumcision. *Journal of Midwifery & Womens Health*, **49(4)**, 364-365.
- Carey, J., Oxtoby, M., Nguyen, L., Huynh, V., Morgan, M. and Jeffery, M. (1997) Tuberculosis beliefs among recent Vietnamese refugees in New York state. *Public Health Reports*, **112**, 66-71.
- Cassanelli, L. (1982) *The shaping of Somali society. Reconstructing the history of a pastoral people, 1600 - 1900*, University of Philadelphia Press, Philadelphia.
- Cassell, J. (2002) Perturbing the system: "Hard science," "soft science," and social science, the anxiety and madness of method. *Human Organization*, **61(2)**, 177-185.
- Chile, L. (2002) The imported underclass: poverty and social exclusion in black African refugees in Aotearoa New Zealand. *Asia Pacific Viewpoint*, **43(3)**, 355-366.

- Chin, D., DeRiemer, K., Small, P., de Leon, A., Steinhart, R., Schechter, G., Daley, C., Moss, A., Paz, E., Jasmer, R., Agasino, C. and Hopewell, P. (1998) Differences in contributing factors to tuberculosis incidence in U.S.-born and foreign-born persons. *American Journal of Respiratory Care Medicine*, **158**, 1797-1803.
- Chiotti, Q. and Joseph, A. (1995) Casey House: interpreting the location of a Toronto AIDS hospice. *Social Science and Medicine*, **41(1)**, 131-140.
- Chouinard, V. (1997) Making space for disabling differences: challenging ableist geographies. *Environment and Planning D: Society and Space*, **15**, 379-387.
- Chouinard, V. (2000) Getting ethical: for inclusive and engaged geographies of disability. *Ethics, Place and Environment*, **3**, 70-79.
- Citrin, D. (2006) Somali tuberculosis cultural profile. Ethnomed, University of Washington, Harborview Medical Center. [www.ethnomed.org/clin\\_topics/tb/cultural/soma\\_tb\\_profile.htm](http://www.ethnomed.org/clin_topics/tb/cultural/soma_tb_profile.htm). Accessed 31 January 2007.
- Cliff, A., Haggett, P., Ord, J. and Versey, G. (1981) *Spatial diffusion: an historical geography of epidemics in an island community*, Cambridge University Press, Cambridge.
- Clifford, J. (1994) Diasporas. *Cultural Anthropology*, **9(3)**, 302-338.
- Clinton-Davis, L. and Fassil, Y. (1992) Health and social problems of refugees. *Social Science and Medicine*, **35(4)**, 507-513.
- Cloke, P. (2002) Deliver us from evil? Prospects for living ethically and acting politically in human geography. *Progress in Human Geography*, **26(5)**, 587-604.
- Cloutier-Fisher, D. and Skinner, M. (2006) Levelling the playing field? Exploring the implications of managed competition for voluntary sector providers of long-term care in small town Ontario. *Health and Place*, **12(1)**, 97-109.
- Cohen, R. (1996) Diasporas and the nation-state: from victims to challengers. *International Affairs*, **72(3)**, 507-520.
- Cohen, R. (1997) *Global diasporas. An introduction.*, UCL Press, London.
- Colgrove, J. (2002) The McKeown thesis: A historical controversy and its enduring influence. *American Journal of Public Health*, **92(5)**, 725-729.
- Comerasamy, H., Read, B., Francis, C., Cullings, S. and Gordon, H. (2003) The acceptability and use of contraception: a prospective study of Somalian women's attitude. *Journal of Obstetrics and Gynaecology*, **23(4)**, 412-415.
- Conradson, D. and Latham, A. (2005) Transnational urbanism: attending to everyday practices and mobilities. *Journal of Ethnic and Migration Studies*, **31(2)**, 227-233.
- Cornwell, J. (1984) *Hard-Earned Lives: Accounts of Health and Illness from East London*, Tavistock Publications, London.
- Cowie, R. and Sharpe, J. (1998) Tuberculosis among immigrants: interval from arrival in Canada to diagnosis: a 5-year study in southern Alberta. *Canadian Medical Association Journal*, **158(5)**, 599-602.
- Craddock, S. (1994) Diseases on the margin: morphologies of tuberculosis and smallpox in San Francisco, 1860-1940. Unpublished PhD thesis. Department of Geography, University of California, Berkeley.

- Crampton, P., Salmond, C., Kirkpatrick, R., Scarborough, R. and Skelly, C. (2000) *Degrees of Deprivation in New Zealand. An atlas of socioeconomic difference*, David Batemen, Wellington.
- Crang, M. (1997) Analyzing qualitative materials. In *Methods in human geography. A guide for students doing a research project*, (Eds, Flowerdew, R. and Martin, D.) Prentice Hall, Harlow, 183-196.
- Crang, P., Dwyer, C. and Jackson, P. (2003) Transnationalism and the spaces of commodity culture. *Progress in Human Geography*, **27(4)**, 438-456.
- Crooks, V. (2005) Life with fibromyalgia syndrome: A socio-spatial examination of chronically ill women's experiences of everyday life, doctor-patient interactions, and health care services. Unpublished PhD thesis. Department of Geography, McMaster University, Hamilton.
- Cross Cultural Health Program (1996) *Voices of the Somali Community*. Cross Cultural Health Care Program, Seattle.
- Cummings, K., Mohle-Boetani, J., Royce, S. and Chin, D. (1998) Movement of tuberculosis patients and the failure to complete antituberculosis treatment. *American Journal of Respiratory Care and Critical Medicine*, **157**, 1249-1252.
- Cundall, D. and Pearson, S. (1988) Inner city tuberculosis and immunisation policy. *Archives of Disease in Childhood*, **63**, 964-966.
- Curtis, S. (2004) *Health and Inequality: geographical perspectives*, Sage, London.
- Curtis, S. and Jones, I. (1998) Is there a place for geography in the analysis of health inequality? *Sociology of Health and Illness*, **20(5)**, 645-672.
- D'Haem, J. (1997) *The last camel. True stories of Somalia*, Red Sea Press, Lawrenceville.
- Danso, R. (2001) From 'There' to 'Here': an investigation of the initial settlement experiences of Ethiopian and Somali refugees in Toronto. *GeoJournal*, **55**, 3-14.
- Das, D., Baker, M. and Calder, L. (2006a) Tuberculosis in New Zealand 1995-2004. *New Zealand Medical Journal*, **119(1243)**, 1-15.
- Das, P., Baker, M., Venugopal, K. and McAllister, S. (2006b) Why tuberculosis incidence rates are not falling in New Zealand? *New Zealand Medical Journal*, **119(1243)**, 1-11.
- Davidson, J., Bondi, L. and Smith, M. (2005) *Emotional geographies*, Ashgate, Aldershot.
- Dawson, A. (2000) The changing geography of morbidity and mortality in post-communist Poland. *GeoJournal*, **50**, 97-100.
- De Montclos, M. (2003) A refugee diaspora. When the Somali go west. In *New African diasporas*, (Ed, Koser, K.) Routledge, London, 37-55.
- de Villiers, S. (1991) Tuberculosis in anthropological perspective. *South African Journal of Ethnology*, **14(3)**, 69-72.
- De Zoysa, R., Shoemack, P., Vaughan, R. and Vaughan, A. (2001) A prolonged outbreak of tuberculosis in the North Island. *New Zealand Public Health Report*, **8(1)**, 1-3.
- Dear, M. and Wolch, J. (1989) *The power of geography. How territory shapes life*, Unwin Hyman, Boston.

- Demissie, M., Getahun, H. and Lindtjorn, B. (2003) Community tuberculosis care through "TB clubs" in rural North Ethiopia. *Social Science and Medicine*, **56**, 2009-2018.
- Denholm, N. and Jama, I. (1996) *Female Genital Mutilation. A women's health care perspective in New Zealand*. Western Community Maternity Services, National Women's Hospital, Auckland.
- Denholm, N. and Jama, I. (1997) *Female genital mutilation health care survey*. FGM Education Programme, Auckland.
- Denholm, N. and Jama, I. (1998) *Female Genital Mutilation in New Zealand. Understanding and responding*. FGM Education Programme, National Women's Hospital, Auckland.
- Denholm, N. and Jama, I. (1998) *Female Genital Mutilation in New Zealand. Understanding and responding*. FGM Education Programme, National Women's Hospital, Auckland.
- Department of Labour (1994) *Refugee Women. The New Zealand Refugee Quota Programme*. New Zealand Immigration Service, Wellington.
- DeRiemer, K., Chin, D., Schechter, G. and Reingold, A. (1998) Tuberculosis among immigrants and refugees. *Archives of Internal Medicine*, **158(7)**, 753-761.
- Dicken, P. (1992) *Global shift: the internationalisation of economic activity*, Paul Chapman, London.
- Diiriye, R., Guerin, P. and Guerin, B. (2004) What some Somali women say about Female Genital Cutting. The 18th World Conference on Health Promotion and Health Education: Valuing Diversity, Reshaping Power: Exploring pathways for health and well-being, Melbourne, Australia, April 26-30 2004.
- Donkor, K. (2001) Geography of tuberculosis in the Greater Accra Region of Ghana. Unpublished MSc thesis. Department of Geography, University of North Texas, Texas.
- Doob, L. and Hurreh, I. (1970-71) Somali proverbs and poems as acculturation indices. *Public Opinion Quarterly*, **34(4)**, 552-559.
- Dorn, M. (1994) Social theory, body politics, and medical geography: extending Kearns's invitation. *Professional Geographer*, **46(1)**, 106-110.
- Dowling, R. (2000) Power, subjectivity and ethics in qualitative research. In *Qualitative research methods in human geography*, (Ed, Hay, I.) Oxford University Press, Melbourne, 23-36.
- Drysdale, J. (1964) *The Somali dispute*, Pall Mall, London.
- Drysdale, J. (2000) *Stoics without pillows. A way forward for the Somalilands*, Haan, London.
- Dubos, R. and Dubos, J. (1953) *The white plague. Tuberculosis, man and society*, Victor Gollancz, London.
- Dubos, R. and Dubos, J. (1987) *The white plague. Tuberculosis, man and society*, Rutgers University Press, New Brunswick.
- Duncan, J. (1990) *The city as text: The politics of landscape interpretation in the Kandyan kingdom*, Cambridge University Press, Cambridge.
- Duncan, J. (2000) Place. In *The Dictionary of Human Geography*, (Eds, Johnston, R., Gregory, D., Pratt, G. and Watts, M.) Blackwell, Oxford, 442.

- Dunn, J. (2002) Housing and inequalities in health: a study of socioeconomic dimensions of housing and self reported health from a survey of Vancouver residents. *Journal of Epidemiology and Community Health*, **56**, 671-681.
- Dyck, I. (1995) Putting chronic illness 'in place'. Women immigrants' accounts of their health care. *Geoforum*, **26(3)**, 247-260.
- Dyck, I. (2000) Putting ethical research into practice: issues of context. *Ethics, Place and Environment*, **3**, 80-86.
- Dyck, I. (2006) Travelling tales and migratory meanings: South Asian migrant women talk of place, health and healing. *Social and Cultural Geography*, **7(1)**, 1-18.
- Dyck, I., Lynam, J. and Anderson, J. (1995) Women talking. Creating knowledge through difference in cross-cultural research. *Women's Studies International Forum*, **18(5/6)**, 611-626.
- Edginton, M., Sekatane, C. and Goldstein, S. (2002) Patients' beliefs: do they affect tuberculosis control? A study in a rural district of South Africa. *International Journal of Tuberculosis and Lung Disease*, **6(12)**, 1075-1082.
- Eisenbruch, M. (1991) From post-traumatic stress disorder to cultural bereavement: diagnosis of Southeast Asian refugees. *Social Science and Medicine*, **33(6)**, 673-680.
- El-Solh, C. (1991) Somalis in London's East End: a community striving for recognition. *New Community*, **17(4)**, 539-552.
- El-Solh, C. (1993) 'Be true to your culture': Gender tensions among Somali Muslims in Britain. *Immigrants & Minorities*, **12(1)**, 21-46.
- Elender, F., Bentham, G. and Langford, I. (1998) Tuberculosis mortality in England and Wales during 1982-1992: its association with poverty, ethnicity and Aids. *Social Science and Medicine*, **46(6)**, 673-681.
- Elmi, A. (1999) *A study on the mental health needs of the Somali community in Toronto*. York Community Services and Rexdale Community Health Centre, Ontario.
- Elmore, K. (2006) The migratory experiences of people with HIV/AIDS (PWHA) in Wilmington, North Carolina. *Health and Place*, **12(4)**, 570-579.
- Emerson, R., Fretz, R. and Shaw, L. (1995) *Writing Ethnographic Fieldnotes*, University of Chicago Press, London.
- Exeter, D., Collins, D. and Kearns, R. (1999) *Identifying potential clinic sites in Auckland for new HCA-affiliated clinics*. Department of Geography, University of Auckland, Auckland.
- Eyles, J. (1985) *Senses of Place*, Silverbrook Press, Warrington.
- Fangen, K. (2006) Humiliation experienced by Somali refugees in Norway. *Journal of Refugee Studies*, **19(1)**, 69-93.
- Farah, M., Meyer, H., Selmer, R., Heldal, E. and Bjune, G. (2005) Long-term risk of tuberculosis among immigrants in Norway. *International Journal of Epidemiology*, **27(4)**, 1005-1011.
- Farah, N. (1970) *From a crooked rib*, Heinemann, London.
- Farah, N. (1980) *Sweet and sour milk*, Heinemann, London.
- Farah, N. (1998) *Secrets*, Arcade, New York.

- Farah, N. (2000) *Yesterday, tomorrow. Voices from the Somali diaspora*, Cassell, London.
- Farmer, P. (1996) Social inequalities and emerging infectious diseases. *Emerging Infectious Diseases*, **2(4)**, 259-269.
- Farmer, P. (1997) Social scientists and the new tuberculosis. *Social Science & Medicine*, **44(3)**, 347-358.
- Farmer, P. (2000) The consumption of the poor. Tuberculosis in the 21st century. *Ethnography*, **1(2)**, 183-216.
- Farmer, P. (2001) DOTS and DOTS-Plus. *Annals of the New York Academy of Sciences*, **953**, 165-184.
- Fishpool, M. (2001) *Somalia Profile*. Walden Publishing, Cambridge, England.
- Fisk, B. (2003) *Employment and migrants:- An Auckland Focus*. New Zealand Immigration Service, Auckland.
- Forde, A. (2003) TB at the border. 'Spread the Word' Tuberculosis Conference, Auckland, New Zealand, 13-14 November 2003.
- Friesen, W., Murphy, L. and Kearns, R. (2005) Spiced-up Sandringham: Indian transnationalism and suburban change in Auckland, New Zealand. *Journal of Ethnic and Migration Studies*, **31**, 385-401.
- Friesen, W., Murphy, L., Kearns, R. and Haverkamp, E. (2000) *Mapping change and difference: a social atlas of Auckland*. Occasional Publication 42, Department of Geography, The University of Auckland, Auckland.
- Fuller-Thomson, E., Robertson, A., Chaudhuri, N., Purdon, L. and Thompson, M. (2000) Towards respiratory health among immigrants in South East Toronto: life histories of Chinese and Caribbean immigrants. *Metropolis*. [www.ceris.metropolis.net/virtual%20library/health](http://www.ceris.metropolis.net/virtual%20library/health). Accessed 8 July 2003.
- Gandy, M. (2001) Science, society and disease: emerging perspectives. *Current Opinion in Pulmonary Medicine*, **7**, 170-172.
- Gandy, M. (2003) Life without germs: contested episodes in the history of tuberculosis. In *The return of the white plague: global poverty and the 'new' tuberculosis*, (Eds, Gandy, M. and Zumla, A.) Verso, London, 15-38.
- Gandy, M. and Zumla, A. (2002a) The resurgence of disease: social and historical perspectives on the 'new' tuberculosis. *Social Science and Medicine*, **55**, 385-396.
- Gandy, M. and Zumla, A. (2002b) Theorizing tuberculosis: a reply to Porter and Ogden. *Social Science and Medicine*, **55**, 399-401.
- Gastaldo, D., Andrews, G. and Khanlou, N. (2004) Therapeutic landscapes of the mind: theorizing some intersections between health geography, health promotion and immigration studies. *Critical Public Health*, **14(2)**, 157-176.
- Gatrell, A. (2002) *Geographies of Health. An introduction*, Blackwell, Massachusetts.
- Gerritsen, A., Bramsen, I., Deville, W., van Willigen, L., Hovens, J. and van der Ploeg, H. (2006) Physical and mental health of Afghan, Iranian and Somali asylum seekers and refugees living in the Netherlands. *Social Psychiatry and Psychiatric Epidemiology*, **41**, 18-26.

- Gesler, W. (1992) Therapeutic Landscapes: Medical Issues in light of the new cultural geography. *Social Science and Medicine*, **34(7)**, 735-746.
- Gesler, W., Arcury, T., Skelly, A., Nash, S., Soward, A. and Dougherty, M. (2006) Identifying diabetes knowledge network nodes as sites for a diabetes prevention program. *Health and Place*, **12(4)**, 449-464.
- Gesler, W. and Kearns, R. (2002) *Culture/Place/Health*, Routledge, London.
- Getahun, H. (1998) Partners against tuberculosis: Ethiopia's 'TB clubs'. *Africa Health*, **20**, 20.
- Giddens, A. (1984) *The Constitution of Society*, Polity Press, Cambridge.
- Gilmore, N. and Somerville, M. (1994) Stigmatization, scapegoating and discrimination in sexually transmitted diseases: overcoming 'them' and 'us'. *Social Science and Medicine*, **39(9)**, 1339-1358.
- Gilroy, N. and National TB Advisory Group (1999) Tuberculosis notifications in Australia, 1997. *Communicable Disease Intelligence*, **23**, 337-347.
- Glick Schiller, N., Basch, L. and Szanton Blanc, C. (1992) *Towards a transnational perspective on migration: race, class, ethnicity and nationalism reconsidered*, New York Academy of Sciences, New York.
- Glick Schiller, N. and Fouron, G. (1999) Terrains of blood and nation: Haitian transnational social fields. *Ethnic and Racial Studies*, **22(2)**, 340-366.
- Goffman, E. (1963) *Stigma: Notes on the management of a spoiled identity*, Prentice Hall, New Jersey.
- Goldman, J. (1994) Childhood tuberculosis in Leeds, 1982-1990: social and ethnic factors and the role of the contact time in diagnosis. *Thorax*, **49**, 184-185.
- Goyal, S., Mathur, G. and Pamra, S. (1978) Tuberculosis trends in an urban community. *Indian Journal of Tuberculosis*, **25**, 77-82.
- Grange, J., Gandy, M., Farmer, P. and Zumla, A. (2001) Historical declines in tuberculosis: nature, nature and the biosocial model. *International Journal of Tuberculosis and Lung Disease*, **5(3)**, 208-212.
- Greene, J. (2004) An ethnography of nonadherence: culture, poverty and tuberculosis in urban Bolivia. *Culture, Medicine and Psychiatry*, **28**, 401-425.
- Griffiths, D. (1997) Somali refugees in Tower Hamlets: clanship and new identities. *New Community*, **23**, 5-24.
- Griffiths, D. (2002) *Somali and Kurdish refugees in London*, Ashgate, Aldershot.
- Grineski, S., Bolin, B. and Agadjanian, V. (2006) Tuberculosis and urban growth: class, race and disease in early Phoenix, Arizona, USA. *Health and Place*, **12**, 603-616.
- Gubrium, J. and Holstein, J. (1994) Analysing talk and interaction. In *Qualitative methods in aging research*, (Eds, Gubrium, J. and Sankar, A.) Sage, Thousand Oaks, 173-88.
- Guerin, B. (2003) Combating prejudice and racism: New interventions from a functional analysis of racist language. *Journal of Community and Applied Social Psychology*, **13**, 29-45.
- Guerin, B., Abdi, A. and Guerin, P. (2003a) Experiences with the medical and health systems for Somali refugees living in Hamilton. *New Zealand Journal of Psychology*, **32(1)**, 27-32.

- Guerin, B., Abdi, A. and Guerin, P. (2003b) Living in a close community: the everyday life of Somali refugee children. *Australian Journal of Psychology*, **54(2)**, 119-129.
- Guerin, B., Guerin, P., Diiriye, R. and Yates, S. (2004a) Somali conceptions and expectations concerning mental health: Some guidelines for mental health professionals. *New Zealand Journal of Psychology*, **33(2)**, 59-67.
- Guerin, P. and Diiriye, R. (2004) Conducting a census of Somali in a small New Zealand town: issues, families and mobility. Institute of Australian Geographers Conference, Glenelg, Adelaide, April 13-16 2004.
- Guerin, P., Diiriye, R., Corrigan, C. and Guerin, B. (2003c) Physical activity programs for refugee Somali women: working out in a new country. *Women and Health*, **38(1)**, 83-99.
- Guerin, P., Diiriye, R. and Guerin, B. (2004b) Obstacles to employment for Somali: Negotiating new directions. New Directions, New Settlers, New Challenges: Foundation for Research, Science and Technology end-users meeting, Wellington, New Zealand, April 19-21 2004.
- Guerin, P., Diiriye, R. and Guerin, B. (2004c) Why "Mental Health" is not working: A case study of Somali refugees in New Zealand. . 18th World Conference on Health Promotion and Health Education: Valuing Diversity, Reshaping Power: Exploring pathways for health and well-being, Melbourne, Australia, 26-30 April 2004.
- Guerin, P. and Guerin, B. (2002) Relocating refugees in developed countries: The poverty experiences of Somali resettling in New Zealand. 5th International APMRN Conference, Fiji, (Eds, Lyon, K. and Voight-Graf, C.). University of Wollongong, Wollongong.
- Gundel, J. (2002) The migration-development nexus: Somalia case study. *International Migration*, **40(5)**, 255-281.
- Gwynne-Vaughan, S. (1999) Resettlement of Somali refugees in Ottawa. Unpublished MA thesis. Department of Geography, Carleton University, Ottawa.
- Haggett, P. (1976) Hybridizing alternative models of an epidemic diffusion process. *Economic Geography*, **52**, 136-146.
- Halane, F. (2004) "Otherness" - a challenge or an obstacle for Somali-Swedish women in Sweden. 9th Somali Studies Conference, Aalborg University, Denmark, 3-5 September 2004.
- Hall, S. (1990) Cultural identity and diaspora. In *Identity: community, culture, difference*, (Ed, Rutherford, J.) Lawrence and Wishart, London, 222-237.
- Hall, S. (2003) Cultural identity and diaspora. In *Theorizing diaspora. A reader*, (Eds, Braziel, J. and Mannur, A.) Blackwell, Massachusetts, 233-246.
- Hammersley, M. and Atkinson, P. (1995) *Ethnography: principles in practice*, Routledge, London.
- Hansard (2003) *Hansard, Questions for Oral Answer 8237*. New Zealand Parliament, 2nd September 2003. Wellington.
- Harrison, A., Calder, L., Karalus, N., Martin, P., Kennedy, M. and Wong, C. (1999) Tuberculosis in immigrants and visitors. *New Zealand Medical Journal*, **112**, 363-365.
- Hay, I. (Ed.) (2005) *Qualitative Research Methods in Human Geography*, Oxford University Press, Melbourne.
- Hayes, M. (1999) 'Man, disease and environmental associations': from medical geography to health inequalities. *Progress in Human Geography*, **23(2)**, 289-296.

- Health Canada (2000) *Tuberculosis in Canada 1997. Tuberculosis prevention and control*. Centre for Infectious Disease Prevention and Control, Population and Public Health Branch, Ottawa, Canada.
- Heath, T., Roberts, C., Winks, M. and Capon, A. (1998) The epidemiology of tuberculosis in New South Wales 1975-1995: the effects of immigration in a low prevalence population. *International Journal of Tuberculosis and Lung Disease*, **2(8)**, 647-654.
- Helman, C. (1991) Medicine and culture: limits of biomedical explanation. *The Lancet*, **337(8749)**, 1080-1084.
- Herman, T. and Mattingley, D. (1999) Community, justice, and the ethics of research: negotiating reciprocal research relations. In *Geography and ethics: journeys in a moral terrain*, (Eds, Proctor, J. and Smith, D.) Routledge, London, 209-222.
- Hill, P. and Calder, L. (2000) An outbreak of tuberculosis in an Auckland church group. *New Zealand Public Health Report*, **7(9/10)**, 41-43.
- Hobbs, M., Moor, C., Wansborough, T. and Calder, L. (2002) The health status of asylum seekers screened by Auckland Public Health in 1999 and 2000. *The New Zealand Medical Journal*, **115(1160)**, 1-7.
- Homedes, N. and Ugalde, A. (1993) Patients' compliance with medical treatments in the third world. What do we know? *Health Policy and Planning*, **8(4)**, 291-314.
- Hopkins, G. (2006) Somali community organizations in London and Toronto. *Journal of Refugee Studies*, **19(3)**, 361-380.
- Horst, C. (2001) *Vital links in social security: Somali refugees in the Dadaab camps, Kenya*. UNHCR, Nijmegen.
- Horst, C. (2002) Vital links in social security: Somali refugees in the Dadaab camps, Kenya. *Refugee Survey Quarterly*, **21(1 & 2)**, 242-259.
- Horst, C. (2004) Connected Lives: Somalis in Minneapolis dealing with family responsibilities and the migration dreams of relatives. 9th Somali Studies Conference, Aalborg University, Denmark, 3-5 September 2004.
- Horst, C. (2005) In "Virtual dialogue" with the Somali community: the value of electronic media for research amongst refugee diasporas. *Refuge*, **23(1)**, 51-57.
- Horst, C. and Van Hear, N. (2002) Counting the cost: refugees, remittances and the 'war against terrorism'. *Forced Migration Review*, **14**, 32-34.
- Housing New Zealand (2004) Personal Communication. 31 March 2004.
- Humpage, L. and Fleras, A. (2000) Systemic bias and the marginalisation of Somali refugee adolescents within New Zealand education. *New Zealand Sociology*, **15(1)**, 46-74.
- Hurtig, A., Porter, J. and Ogden, J. (1999) Tuberculosis control and directly observed therapy from the public health/human rights perspective. *International Journal of Tuberculosis and Lung Disease*, **3(7)**, 553-560.
- Hyndman, J. (1997) Border Crossings. *Antipode*, **29(2)**, 149-176.
- Hyndman, S. (1998) Making connections between housing and health. In *Putting health into place - landscape, identity and well-being*, (Eds, Kearns, R. and Gesler, W.) Syracuse University Press, New York, 191-207.

- Ingleby, D. (2005) *Forced migration and mental health : rethinking the care of refugees and displaced persons*, Springer, New York.
- Institute of Environmental Science and Research Limited (2006) *Notifiable and other diseases in New Zealand. Annual Report 2005*. Institute of Environmental Science and Research Limited, Auckland.
- Institute of Medicine of the National Academies (2006) *Genes, Behavior and the Social Environment*, The National Academies Press, Washington DC.
- Ip, M. (1996) *Dragons on the long white cloud: The making of Chinese New Zealanders*, Tandem Press, Auckland.
- Ip, M. and Friesen, W. (2001) The New Chinese community in New Zealand: local outcomes of transnationalism. *Asian and Pacific Migration Journal*, **10(2)**, 213-240.
- Israelite, N. (1999) Waiting for "Sharciga": resettlement and the roles of Somali refugee women. *Canadian Woman Studies*, **19(3)**, 80-86.
- Israelite, N., Herman, A., Alim, F., Mohamed, H. and Khan, Y. (1999) Settlement Experiences of Somali Refugee Women in Toronto. Presentation for the 7th International Congress of Somali Studies, York University, Toronto.
- Itzigsohn, J., Cabral, C., Medina, F. and Vazquez, O. (1999) Mapping Dominican transnationalism: narrow and broad transnational practices. *Ethnic and Racial Studies*, **22(2)**, 316-339.
- J. R. McKenzie Trust (2004) *Supporting Refugee Resettlement: Refugee Employment Programme. What Have We Learned So Far? A Report on the First Two Years of a Three Year Programme*. J. R. McKenzie Trust, Auckland.
- Jackson, K. (2006) *Fate, spirits and curses: Mental health and traditional beliefs in some refugee communities*, Rampart, Auckland.
- Jacobsen, K. and Landau, L. (2003) *Researching refugees: some methodological and ethical considerations in social science and forced migration*. UNHCR, Geneva.
- Jama, A. (2004) Som-Scan and UK Cooperative Associations. Paper for 9th Somali Studies International Conference, Aalborg University, Denmark, 3-5 September 2004.
- Jaramillo, E. (1998) Tuberculosis control in less developed countries: can culture explain the whole picture? *Tropical Doctor*, **28**, 196-200.
- Jatrana, S., Toyota, M. and Yeoh, B. (Eds.) (2005) *Migration and health in Asia*, Routledge, London.
- Jenkinson, B. (1999) Somali women's voices: being a Somali woman in New Zealand. Unpublished MSocSci Thesis. Psychology Department, Waikato University, Hamilton.
- Jimenez, A. (2003) Playing the blame game: casting guilt and avoiding stigma during a tuberculosis health crisis. *The International Journal of Sociology and Social Policy*, **23(6/7)**, 80-114.
- Johansen, R. (2006) Care for infibulated women giving birth in Norway. *Medical Anthropology Quarterly*, **20(4)**, 516-544.
- Johansson, E., Long, N., Diwan, V. and Winkvist, A. (2000) Gender and tuberculosis control. Perspectives on health seeking behaviour among men and women in Vietnam. *Health Policy*, **52**, 33-51.
- Johnston, R., Poulsen, M. and Forrest, J. (2003) The ethnic geography of New Zealand: a decade of growth and change, 1991-2001. *Asia Pacific Viewpoint*, **44(2)**, 109-130.

- Jones, K. and Moon, G. (1987) *Health, disease and society. An introduction to medical geography*, Routledge, London.
- Joseph, A. and Kearns, R. (1996) Deinstitutionalization meets restructuring: the closure of a psychiatric hospital in New Zealand *Health and Place*, **2(3)**, 179-189.
- Joseph, A. and Phillips, D. (1984) *Accessibility and utilization: geographical perspectives on health care delivery*, Harper & Row, London.
- Juvekar, S., Morankar, S., Dalal, D., Rangan, S., Khanvilkar, S., Vadair, A., Uplekar, M. and Deshpande, A. (1995) Social and operational determinants of patient behaviour in lung tuberculosis. *Indian Journal of Tuberculosis*, **42**, 87-94.
- Kalipeni, E. and Oppong, J. (1998) The refugee crisis in Africa and implications for health and disease: a political ecology approach. *Social Science and Medicine*, **46(12)**, 1637-1653.
- Kaplan, I., Dobert, M., Marvin, B., Roth, H. and Whitaker, D. (1977) *Area handbook for Somalia*, The American University, Washington.
- Kapteijns, L. (1995) Gender relations and the transformation of the Northern Somali pastoral tradition. *The International Journal of African Historical Studies*, **28(2)**, 241-259.
- Kapteijns, L. (2001) The disintegration of Somalia: a historiographical essay. *Bildhaan. An International Journal of Somali Studies*, **1**, 11-52.
- Karasz, A. (2005) Cultural differences in conceptual models of depression. *Social Science and Medicine*, **60(7)**, 1625-1635.
- Kearns, A., Hiscock, R., Ellaway, A. and Macintyre, S. (2000) 'Beyond four walls'. The psycho-social benefits of home: evidence from West Central Scotland. *Housing Studies*, **15(3)**, 387-410.
- Kearns, R. (1991) The place of health in the health of place: the case of the Hokianga Special Medical Area. *Social Science and Medicine*, **33(4)**, 519-530.
- Kearns, R. (1993) Place and health: towards a reformed medical geography. *Professional Geographer*, **45(2)**, 139-147.
- Kearns, R. (1994) Putting health and health care into place: an invitation accepted and declined. *Professional Geographer*, **46(1)**, 111-115.
- Kearns, R. (1996) AIDS and medical geography: embracing the Other? *Progress in Human Geography*, **20**, 123-131.
- Kearns, R. (1997) Narrative and metaphor in health geographies. *Progress in Human Geography*, **21**, 269-277.
- Kearns, R. (2000) 'Being there: research through observing and participating'. In *Qualitative Methods in Geography*, (Ed, Hay, I.) Oxford, Melbourne, 103-121.
- Kearns, R. (2002) *New geographies of disease: HIV/AIDS*, Blackwell, Malden.
- Kearns, R. and Barnett, J. (1999) 'To boldly go? Place, metaphor and marketing of Auckland's Starship hospital'. *Environment and Planning D: Society and Space*, **17**, 201-226.
- Kearns, R. and Collins, D. (2000) New Zealand children's health camps: therapeutic landscapes meet the contract state. *Social Science and Medicine*, **51(7)**, 1047-1059.
- Kearns, R. and Dyck, I. (2004) Culturally safe research. In *Cultural safety in Aotearoa New Zealand*, (Ed, Wepa, D.) Pearson Education, Auckland, 79-89.

- Kearns, R. and Joseph, A. (1993) Space in its place: Developing the link in medical geography. *Social Science and Medicine*, **37(6)**, 711-717.
- Kearns, R. and Moon, G. (2002) From medical to health geography: novelty, place and theory after a decade of change. *Progress in Human Geography*, **26(5)**, 587-607.
- Kelly, L. (2003) Bosnian refugees in Britain: questioning community. *Sociology*, **37(1)**, 35-49.
- Kelly, P. (1999) Isolation and stigma: the experience of patients with active tuberculosis. *Journal of Community Health Nursing*, **16(4)**, 233-241.
- Kelly, P., Scott, L. and Krause, V. (2002) Tuberculosis in East Timorese refugees: implications for health care needs in East Timor. *International Journal of Tuberculosis and Lung Disease*, **6(11)**, 980-987.
- Kempainen, R., Nelson, K., Williams, D. N. and Hedemark, L. (2001) Mycobacterium tuberculosis disease in Somali immigrants in Minnesota. *Chest*, **119(1)**, 176-180.
- Keyes, E. (2000) Mental health status in refugees: an integrative review of current research. *Issues in Mental Health Nursing*, **21**, 397-410.
- Kistemann, T., Munzinger, A. and Dangendorf, F. (2002) Spatial patterns of tuberculosis incidence in Cologne (Germany). *Social Science and Medicine*, **55**, 7-19.
- Kivisto, P. (2001) Theorizing transnational immigration: a critical review of current efforts. *Ethnic and Racial Studies*, **24(4)**, 549-577.
- Kleinman, A. (1980) *Patients and Healers in the Context of Culture*, University of California Press, Berkeley.
- Kleinman, A. (1987) Explanatory models in health-care relationships: A conceptual frame for research on family-based health-care activities in relation to folk and professional forms of clinical care. In *Encounters between patients and doctors: An anthology*, (Ed, Stoeckle, J.) MIT Press, Cambridge, 273-283.
- Kleinman, A. (1995) *Writing at the Margin: Discourse Between Anthropology and Medicine*, University of California Press, Berkeley.
- Klov Dahl, A., Graviss, E., Yananehdoost, A., Ross, M., Wanger, A., Adams, G. and Musser, J. (2001) Networks and tuberculosis: an undetected community outbreak involving public places. *Social Science & Medicine*, **52(5)**, 681-694.
- Knight, R., Hotchin, A., Bayly, C. and Grover, S. (1999) Female genital mutilation - experience of The Royal Women's Hospital, Melbourne. *Australia and New Zealand Journal of Obstetrics and Gynaecology*, **39(1)**, 50-54.
- Knox, P. and Taylor, P. (1995) *World cities in a world system*, Cambridge University Press, Cambridge.
- Kochi, A. (1991) The global tuberculosis situation and the new control strategy of the World Health Organisation. *Tubercle*, **72**, 1-6.
- Kocs, D., Raviglione, M., Nunn, P., Kochi, A. and Snider, D. (1995) Tuberculosis treatment in developing nations. *Journal of the American Medical Association*, **274(2)**, 125-127.
- Kopinak, J. (1999) The health of Bosnian refugees in Canada. *Ethnicity and Health*, **4(1/2)**, 65-82.
- Koser, K. (2003) *New African diasporas*, Routledge, London.

- Kravdal, O. (2006) Does place matter for cancer survival in Norway? A multilevel analysis of the importance of hospital affiliation and municipality socio-economic resources *Health and Place*, **12(4)**, 527-237.
- Kümpers, S., Mur, I., Hardy, B., Van Raak, A. and Maarse, H. (2006) Integrating dementia care in England and The Netherlands: Four comparative local case studies. *Health and Place*, **12(4)**, 404-420.
- Kuper, A. and Kuper, J. (1985) *The Social Science Encyclopedia*, Routledge, London.
- Kusow, A. (1998) Migration and identity processes among Somali immigrants in Canada. Unpublished PhD thesis. Department of Sociology, Wayne State University, Detroit.
- Kusow, A. (2006) Migration and social formations among Somali immigrants in North America. *Journal of Ethnic and Migration Studies*, **32(3)**, 533-551.
- Kwan-Gett, T. (1998) Somali tuberculosis cultural profile. Ethnomed, University of Washington, Harborview Medical Center. [http://ethnomed.org/ethnomed/clin\\_topics/tb/somali\\_tb.html](http://ethnomed.org/ethnomed/clin_topics/tb/somali_tb.html).
- Landolt, P., Autler, L. and Baires, S. (1999) From Hermano Lejano to Hermano Mayor: the dialectics of Salvadoran transnationalism. *Ethnic and Racial Studies*, **22(2)**, 290-315.
- Law, R. (2003) Communities, citizens, and the perceived importance of AIDS-related services in West Hollywood, California *Health and Place*, **9(1)**, 7-22.
- Lawrence, J. (2003) *New settler health needs and health care service responses: a case study in Mount Roskill. Report on a Health Research Council Summer Studentship*. The University of Auckland, Auckland, (Available from author).
- Lawrence, J. (2005a) Muslim Women's Swimming programme: Initial evaluation. Unpublished report, Auckland. (Available from author).
- Lawrence, J. (2005b) Muslim Women's Swimming Programme: Second Evaluation, November 2004. Unpublished report, Auckland. (Available from author).
- Lawrence, J. (2005c) Refugee Health Issues: Working Paper. The Auckland Regional Settlement Strategy, Unpublished report, Auckland. (Available from author).
- Lawrence, J. (2005d) Refugee Nutrition Promotion Programme: An evaluation of a pilot programme conducted in the Auckland Somali Community. Unpublished report, Auckland. (Available from author).
- Lawrence, J. (2005e) Refugee Youth Physical Activity Programme: An evaluation. Unpublished report, Auckland. (Available from author).
- Lawrence, J. (2005f) Somali Women's Nutrition Programme July - September 2004: Evaluation. Unpublished report, Auckland. (Available from author).
- Lawrence, J. and Kearns, R. (2005) Exploring the 'fit' between people and providers: Refugee health needs and health care services in Mt Roskill, New Zealand. *Health and Social Care in the Community*, **13(5)**, 451-461.
- Lawrence, J., Kearns, R., Park, J. and Bryder, L. (2007) Discourses of disease: Representation of tuberculosis within New Zealand newspapers 2002 - 2004. *Forthcoming*.
- Le Heron, R. and Pawson, E. (1996) *Changing places: New Zealand in the nineties*, Longman Paul, Auckland.

- Lee, K. (2003) Introduction. In *Health impacts of globalization. Towards global governance*, (Ed, Lee, K.) Palgrave, Basingstoke, 1-7.
- Lerner, B. (1997) From careless consumptives to recalcitrant patients: the historical construction of noncompliance. *Social Science and Medicine*, **45(9)**, 1423-1431.
- Levitt, P. (1996) Keeping feet in both worlds: transnational practices and immigrant incorporation in the United States. In *Toward assimilation and citizenship. Immigrants in liberal nation-states*, (Eds, Joppke, C. and Morawska, E.) Palgrave, Basingstoke, 177-194.
- Lewis, I. (1961) *A pastoral democracy*, Oxford University Press, Oxford.
- Lewis, I. (1965) *The modern history of Somaliland. From nation to state.*, Weidenfeld and Nicolson, London.
- Lewis, I. (1994) *Blood and bone: the call of kinship in Somali society*, Red Sea Press, Lawrenceville.
- Lewis, I. (1998) Doing violence to ethnography: a response to Catherine Besteman's "Representing violence and 'othering' Somalia". *Cultural Anthropology*, **13(1)**, 100-108.
- Lewis, I. (2001) *Understanding Somalia. Guide to culture, history and social institutions*, Haan Associates, London.
- Lewis, T. (1996) *Somali Cultural Profile*. Ethnomed, Washington.
- Lewis, T., Ahmed, B. and Hussein, K. (1996) Voices of the Somali community. Ethnomed, University of Washington, Harborview Medical Center.  
<http://www.ethnomed.org/ethnomed/voices/somali.html>. Accessed 5 May 2003.
- Liam, C., Lim, K., Wong, C. and Tang, B. (1999) Attitudes and knowledge of newly diagnosed tuberculosis patients regarding the disease, and factors affecting treatment compliance. *International Journal of Tuberculosis and Lung Disease*, **3(4)**, 300-309.
- Lieban, R. (1976) Traditional medical beliefs and the choice of practitioners in a Phillipine city. *Social Science and Medicine*, **10**, 289-296.
- Liefooghe, R., Baliddawa, J., Kipruto, E., Vermeire, C. and Munynck, A. (1997) From their own perspective. A Kenyan community's perception of tuberculosis. *Tropical Medicine and International Health*, **2**, 809-821.
- Liefooghe, R., Michiels, N., Habib, S., Moran, M. and De Muynck, A. (1995) Perception and social consequences of tuberculosis: a focus group study of tuberculosis patients in Sialkot, Pakistan. *Social Science and Medicine*, **41(12)**, 1685-1692.
- Lillebaek, T., Andersen, A., Bauer, J., Dirksen, A., Glismann, S., de Haas, P. and Kok-Jensen, A. (2001) Risk of Mycobacterium tuberculosis transmission in a low-incidence country due to immigration from high-incidence areas. *Journal of Clinical Microbiology*, **39(3)**, 855-861.
- Lillebaek, T., Andersen, A., Dirksen, A., Smith, E., Skovgaard, L. and Kok-Jensen, A. (2002) Persistent high incidence of tuberculosis in immigrants in a low-incidence country. *Emerging Infectious Diseases*, **8(7)**, 679-684.
- Lilley, S. (2004) Vulnerable migrant groups: a housing perspective. Unpublished BA Honours dissertation. Department of Geography, University of Canterbury, Christchurch.
- Limb, M. and Dwyer, C. (2001) Introduction: doing qualitative research in geography. In *Qualitative methodologies for geographers: issues and debates*, (Eds, Limb, M. and Dwyer, C.) Arnold, London, 1-22.

- Link, B. and Phelan, J. (2001) Conceptualizing Stigma. *Annual Review of Sociology*, **27**, 363-385.
- Link, B. and Phelan, J. (2002) McKeown and the idea that social conditions are fundamental causes of disease. *American Journal of Public Health*, **92(5)**, 730-732.
- Littleton, J., Park, J., Thornley, C., Anderson, A. and Lawrence, J. (2007) Do immigrants or immigration give you TB? *Forthcoming*.
- LoBue, P., Moser, K. and Catanzaro, A. (2001) Management of tuberculosis in San Diego county: a survey of physicians' knowledge, attitudes and practices. *International Journal of Tuberculosis and Lung Disease*, **5(10)**, 933-938.
- Long, N., Johansson, E., Diwan, V. and Winkvist, A. (1999a) Different tuberculosis in men and women: beliefs from focus groups in Vietnam. *Social Science and Medicine*, **49(6)**, 815-822.
- Long, N., Johansson, E., Diwan, V. and Winkvist, A. (1999b) Longer delays in tuberculosis among women in Vietnam. *International Journal of Tuberculosis and Lung Disease*, **3**, 1-6.
- Long, N., Johansson, E., Diwan, V. and Winkvist, A. (2001) Fear and social isolation as consequences of tuberculosis in Vietnam: a gender analysis. *Health Policy*, **58**, 69-81.
- Lopez-Zetina, J., Lee, H. and Friis, R. (2006) The link between obesity and the built environment. Evidence from an ecological analysis of obesity and vehicle miles of travel in California. *Health and Place*, **12(4)**, 656-664.
- Luling, V. (1997) Come back Somalia? Questioning a collapsed state. *Third World Quarterly*, **18(2)**, 287-302.
- Lum, D. and Koelmeyer, T. (2005) Tuberculosis in Auckland autopsies, revisited. *New Zealand Medical Journal*, **118(1211)**.
- MacIntyre, C., Goebel, K. and Brown, G. (2005) Patient knows best: blinded assessment of nonadherence with antituberculous therapy by physicians, nurses, and patients compared with urine drug levels. *Preventive Medicine*, **40**, 41-45.
- Macintyre, S. and Ellaway, A. (1998) Social and local variations in the use of urban neighbourhoods: a case study in Glasgow. *Housing Studies*, **4(1)**, 91-94.
- Macintyre, S., Ellaway, A. and Cummins, S. (2002) Place effects on health: how can we conceptualise, operationalise and measure them? *Social Science and Medicine*, **55(1)**, 125-139.
- Macintyre, S., Ellaway, A., Der, G., Ford, G. and Hunt, K. (1998) Do housing tenure and car access predict health because they are simply markers of income or self esteem? A Scottish study. *Journal of Epidemiology and Community Health*, **52(10)**, 657-664.
- Macintyre, S., Hiscock, R., Kearns, A. and Ellaway, A. (2000) Housing tenure and health inequalities: a three dimensional perspective on people, homes and neighbourhoods. In *Understanding Health Inequalities*, (Ed, Graham, H.) Open University Press, Buckingham, 129-142.
- Macintyre, S., Maciver, S. and Sooman, A. (1993) Area, Class and Health: should we be focusing on places or people? *Journal of Social Policy*, **22(2)**, 213-234.
- MacPherson, C. (2001) One trunk sends out many branches: Pacific cultures and cultural identities. In *Tangata o te Moana Nui*, (Eds, MacPherson, C., Spoonley, P. and Anae, M.) Dunmore, Palmerston North, 66-81.

- Macq, J., Solis, A., Martinez, G., Martiny, P. and Dujardin, B. (2005) An exploration of the social stigma of tuberculosis in five "municipios" of Nicaragua to reflect on local interventions. *Health Policy*, **74**, 205-217.
- Madjar, V. and Humpage, L. (2000) *Refugees in New Zealand : the experiences of Bosnian and Somali refugees*. School of Sociology and Women's Studies, Massey University (Albany), Auckland.
- Malinowski, B. (1922) *Argonauts of the Western Pacific*, Dutton, New York.
- Malkki, L. (1992) National geographic: the rooting of peoples and the territorialization of national identity among scholars and refugees. *Cultural Anthropology*, **7(1)**, 24-44.
- Malkki, L. (1995) Refugees and exile: from "refugee studies" to the national order of things. *Annual Review of Anthropology*, **24**, 495-523.
- Manderson, L. and Allotey, P. (2003) Story-telling, marginality, and community in Australia: how immigrants position their difference in health care settings. *Medical Anthropology*, **22**, 1-21.
- Manukau City Council (2006) *Auckland Regional Settlement Strategy*. Auckland Sustainable Cities Programme. A regional partnership with the Sustainable Development Programme of Action, Auckland.
- Martin, P. (2000) Tuberculosis in New Zealand: why do we have twice as much as Australia? *New Zealand Medical Journal*, **(113)**, 68-69.
- Massey, D. (1994) A global sense of place. In *Space, Place and Gender*, (Ed, Massey, D.) Polity, Cambridge, 146-156.
- Mayer, J. (2000) Geography, ecology and emerging infectious diseases. *Social Science and Medicine*, **50**, 937-952.
- Mayer, J. and Meade, M. (1994) A reformed medical geography reconsidered. *Professional Geographer*, **46(1)**, 103-106.
- McCrone, P., Bhui, K., Craig, T., Mohamud, S., Warfa, N., Stansfeld, S., Thornicroft, G. and Curtis, S. (2005) Mental health needs, service use and costs among Somali refugees in the UK. *Acta Psychiatrica Scandinavica*, **111**, 351-357.
- McDermott, K. (2004) *Review of adult refugee education programmes*. Ministry of Education, Auckland.
- McDowell, L. (1992) Doing gender: feminism, feminists and research methods in human geography. *Transactions of the Institute of British Geographers*, **17**, 399-416.
- McElnay, C., Thornley, C. and Armstrong, R. (2004) A community and workplace outbreak of tuberculosis in Hawke's Bay in 2002. *New Zealand Medical Journal*, **117(1200)**, 1-7.
- McKeown, T. (1976) *The modern rise of population*, Edward Arnold, London.
- McLeod, A. and Reeve, M. (2005) The health status of quota refugees screened by New Zealand's Auckland Public Health Service between 1995 and 2000. *New Zealand Medical Journal*, **118(1224)**, 1-17.
- McMichael, C. (2002) 'Everywhere is Allah's place': Islam and the everyday life of Somali women in Melbourne, Australia. *Journal of Refugee Studies*, **15(2)**, 171-188.
- McMichael, C. and Manderson, L. (2004) Somali women and well-being: social networks and social capital among immigrant women in Australia. *Human Organization*, **63(1)**, 88-99.

- McMurray, C. and Smith, R. (2001) *Diseases of globalization. Socio-economic transitions and health*, Earthscan, London.
- Meade, M. and Earickson, R. (2000) *Medical Geography*, The Guilford Press, New York.
- Meade, M., Florin, J. and Gesler, W. (1988) *Medical Geography*, The Guilford Press, New York.
- Metz, H. (1993) *Somalia. A country study*, Federal Research Division, Library of Congress, Washington.
- Migration Research Group (2006) *Strangers in Town: Enhancing Family and Community in a More Diverse New Zealand Society (2002 - 2008)*. Migration Research Group, University of Waikato, Hamilton.
- Minister of Health (2003) *Direction of the Minister of Health relating to eligibility for publicly funded personal health and disability services in New Zealand*. Ministry of Health, Wellington.
- Ministry of Education (2001) *More than words: The New Zealand adult literacy strategy*. Tertiary Education Policy, The Ministry of Education, Wellington.
- Ministry of Education (2003a) *The adult ESOL strategy*. Tertiary Education Learning Outcomes Policy, Ministry of Education, Wellington.
- Ministry of Education (2003b) *English for speakers of other languages (ESOL): Refugee handbook for schools*. Auckland: ESOL Team, National Operations, Ministry of Education, Wellington.
- Ministry of Education (2004) Personal Communication. 16 April 2004.
- Ministry of Health (2001) *Refugee Health Care: A Handbook for Health Professionals*. Ministry of Health, Wellington.
- Ministry of Health (2003a) *Guidelines for Tuberculosis control in New Zealand*. Ministry of Health, Wellington.
- Ministry of Health (2003b) *Infectious diseases in New Zealand: 2002 Annual Surveillance Summary*. Ministry of Health, Wellington.
- Mitchell, D. (1995) There's no such thing as culture: towards a reconceptualization of the idea of culture in geography. *Transactions of the Institute of British Geographers*, **20(1)**, 102-116.
- Mitchell, D. (2000) *Cultural Geography. A critical introduction*, Blackwell, London.
- Moerman, D. and Jonas, W. (2002) Deconstructing the placebo effect and finding the meaning response. *Annals of Internal Medicine*, **136(6)**, 471-476.
- Mohamed, H. (1999) Resistance strategies: Somali women's struggles to reconstruct their lives in Canada. *Canadian Woman Studies*, **19(3)**, 52-57.
- Mohamed, H. (2004) Somali immigrants in Finland. Somali women between two cultures. 9th Somali Studies Conference, Aalborg University, Denmark, 3-5 September 2004.
- Mollica, R., McInnes, K., Sarajli, N., Lavelle, J., Sarajli, I. and Massagli, M. (1999) Disability associated with psychiatric comorbidity and health status in Bosnian refugees living in Croatia. *Journal of the American Medical Association*, **282(5)**, 433-439.
- Moonan, P., Opong, J., Sahbazian, B., Singh, K., Sandhu, R., Drewyer, G., T LaFon, Marruffo, M., Quitugua, T., Wallace, C. and Weis, S. (2006) What is the outcome of targeted tuberculosis screening based on universal genotyping and location? *American Journal of Respiratory and Critical Care Medicine*, **174(5)**, 599-604.

- Moorhead, L. (2000) White plague in Black Los Angeles: Tuberculosis among African Americans in Los Angeles 1930-1950. Unpublished PhD thesis. Department of Geography, The University of Carolina at Chapel Hill, Chapel Hill.
- Morison, L., Dirir, A., Elmi, S., Warsame, J. and Dirir, S. (2004) How experiences and attitudes relating to female circumcision vary according to age on arrival in Britain: a study among young Somalis in London. *Ethnicity and Health*, **9(1)**, 75-100.
- Morris, C. (2002) Station wives in New Zealand: Narrating continuity in the High Country. Unpublished PhD thesis. Department of Anthropology, University of Auckland, Auckland.
- Mortensen, A. (2006) Personal Communication. 30 November 2006.
- Mortensen, A. (2007) Refugees as 'Others'. Social and Cultural Citizenship Rights for Refugees in New Zealand Health Services? Unpublished PhD Thesis. Department of Sociology, Massey University, Auckland.
- Muecke, M. (1992) New paradigms for refugee health problems. *Social Science and Medicine*, **35(4)**, 515-523.
- Mukhtar, M. (1996) The plight of the agro-pastoral society of Somalia. *Review of African Political Economy*, **23(70)**, 1-11.
- Murdie, R. (2002) The housing careers of Polish and Somali newcomers in Toronto's rental market. *Housing Studies*, **17(3)**, 423-443.
- Murphy, L. (2004) To the market and back: Housing policy and state housing in New Zealand. *GeoJournal*, **59(2)**, 119-126.
- Murphy, L., Friesen, W. and Kearns, R. (1999) Transforming the city: people, property and identity in millennial Auckland. *New Zealand Geographer*, **55(2)**, 60-65.
- Murphy, L. and Kearns, R. (1994) Housing New Zealand Limited: privatisation by stealth. *Environment and Planning A*, **26**, 623-637.
- Nair, D., George, A. and Chacko, K. (1997) Tuberculosis in Bombay: new insights from poor urban patients. *Health Policy and Planning*, **12(1)**, 77-85.
- Nanda, S. and Warm, R. (2007) *Cultural Anthropology*, Wadsworth/Thompson Learning, Belmont.
- National Health Committee (1998) *The social, cultural and economic determinants of health in New Zealand: Action to improve health*. National Advisory Committee on Health and Disability, Wellington.
- Navio, J., Yuste, M. and Pasicatan, M. (2002) Socio-economic determinants of knowledge and attitudes about tuberculosis among the general population of Metro Manila, Philippines. *International Journal of Tuberculosis and Lung Disease*, **6(4)**, 301-306.
- Needham, D., Bowman, D., Foster, S. and Godfrey-Faussett, P. (2004) Patient care seeking barriers and tuberculosis programme reform: a qualitative study. *Health Policy*, **67(1)**, 93-106.
- Nelson, H. (1982) *Somalia. A country study*, The American University, Washington.
- New Zealand Herald (2002) Two men charged with murder of Elikena Inia. New Zealand Herald. 10 September 2002. Auckland.
- New Zealand Immigration Service (2004a) *A future together: The New Zealand Settlement Strategy in Outline*. New Zealand Immigration Service, Wellington.

- New Zealand Immigration Service (2004b) *Refugee Voices*. New Zealand Immigration Service, Wellington.
- New Zealand Immigration Service (2005) Health Policy changes effective 28 November 2005. New Zealand Immigration Service, Wellington.  
<http://www.immigration.govt.nz/migrant/general/generalinformation/news/changestohealthpolicyeffective28November2005.htm>. Accessed 29 November 2006.
- Ng Shiu, R. (2006) The place of tuberculosis. The lived experience of Pacific peoples in Auckland and Samoa. Unpublished MA thesis. School of Geography & Environmental Science, University of Auckland, Auckland.
- Ni Laoire, C. (2003) Editorial introduction: locating geographies of diaspora. *International Journal of Population Geography*, **9**, 275-280.
- Nichter, M. (1994) Illness semantics and international health: the weak lungs/TB complex in the Philippines. *Social Science and Medicine*, **38(5)**, 649-663.
- Nielsen, K. (2004) *Next stop Britain: the influence of transnational networks on the secondary movement of Danish Somalis*. Sussex Centre for Migration Research, Denmark.
- Office of Ethnic Affairs (2005) *Profile of African people in New Zealand*. Office of Ethnic Affairs, Wellington.
- Ogden, J., Walt, G. and Lush, L. (2003) The politics of 'branding' in policy transfer: the case of DOTS for tuberculosis control. *Social Science and Medicine*, **57(1)**, 179-188.
- Olds, K. and Yeung, H. (1999) (Re)shaping 'Chinese' business networks in a globalizing era. *Environment and Planning D*, **17**, 535-555.
- Ongley, P. and Pearson, D. (1995) Post-1945 international migration: New Zealand, Australia and Canada compared. *International Migration Review*, **29(3)**, 765-793.
- Opoku-Dapaah, E. (1994) *Somali refugees in Toronto: a profile*, York University Centre for Refugee Studies, Toronto.
- Oppong, J. (1998) A vulnerability interpretation of the geography of HIV/AIDS in Ghana 1986-95. *Professional Geographer*, **50(4)**, 437-448.
- Oppong, J., Mikler, A., Moonan, P. and Weis, S. (2004) From medical geography to computational epidemiology - dynamics of Tuberculosis transmission in enclosed spaces. *Lecture Notes in Computer Science*, **3473**, 189-197.
- Palinkas, L., Pickwell, S., Brandstein, K., Clark, T., Hill, L., Moser, R. and Osman, A. (2003) The journey to wellness: stages of refugee health promotion and disease prevention. *Journal of Immigrant Health*, **5(1)**, 19-28.
- Parr, H. (2002) Medical geography: diagnosing the body in medical and health geography, 1999-2000. *Progress in Human Geography*, **26(2)**, 240-251.
- Parr, H. (2003) Medical geography: care and caring. *Progress in Human Geography*, **27(2)**, 212-221.
- Pearce, J. and Boyle, P. (2005) Examining the relationship between lung cancer and radon in small areas across Scotland. *Health and Place*, **11(3)**, 275-282.
- Peltola, H., Mohamed, O., Kataja, M., Salminen, S., Tuittula, T., Peltola, T. and Brander, E. (1994) Risk of infection with Mycobacterium tuberculosis among children and mothers in Somalia. *Clinical Infectious Diseases*, **18**, 106-111.

- Perkins, J., R Sanson-Fisher, Byles, J. and Tiller, K. (1999) Factors relating to cervical screening in New South Wales, Australia. *Health and Place*, **5(3)**, 223-233.
- Pernice, R. (1994) Methodological issues in research with refugees and immigrants. *Professional Psychology: Research and Practice*, **25(3)**, 207-213.
- Pernice, R. and Brook, J. (1996) Refugees' and immigrants' mental health: association of demographic and post-immigration factors. *The Journal of Social Psychology*, **136(4)**, 511-519.
- Peterson, S. (2000) *Me against my brother. At war in Somalia, Sudan, and Rwanda*, Routledge, New York.
- Phillips, D. and Rosenberg, M. (2000) Researching the geography of health and health care: Connecting with the Third World. *GeoJournal*, **50**, 369-378.
- Portes, A., Guarnizo, L. and Landolt, P. (1999) The study of transnationalism: pitfalls and promise of an emergent research field. *Ethnic and Racial Studies*, **22(2)**, 217-237.
- Poss, J. (1998) The meanings of tuberculosis for Mexican migrant farmworkers in the United States. *Social Science and Medicine*, **47(2)**, 195-202.
- Pratt, G. and Yeoh, B. (2003) Transnational (counter) topographies. *Gender, Place and Culture*, **10(2)**, 159-166.
- Purohit, S., Gupta, M., Madan, A., Gupta, P., Mathur, B. and Sharma, T. (1988) Awareness about tuberculosis among general population: a pilot study. *Indian Journal of Tuberculosis*, **35**, 183-187.
- Ramachandran, R., Diwakara, A., Ganapathy, S., Sudarsanam, N., Rajaram, K. and Prabhakar, R. (1995) Tuberculosis awareness among educated public in two cities in Tamilnadu. *Lung India*, **13(3-4)**, 108-113.
- Rapson, B. (2003) Out of Africa. Metro Magazine. April 2003, Issue 262, 66-74.
- Raviglione, M., Narain, J. and Kochi, A. (1992) HIV-associated tuberculosis in developing countries: clinical features, diagnosis and treatment. *Bulletin of the World Health Organisation*, **70(4)**, 515-527.
- Raviglione, M. and Pio, A. (2002) Evolution of WHO policies for tuberculosis control, 1948-2001. *The Lancet*, **359(9308)**, 775-785.
- Raviglione, M., Sudre, P., Rieder, H., Spinaci, S. and Kochi, A. (1993) Secular trends of tuberculosis in Western Europe. *Bulletin of the World Health Organisation*, **71(3-4)**, 297-307.
- Reeve, M. (1997) Refugee health: an assessment. Medical screening program at the Mangere Refugee Resettlement Centre. Unpublished MPH dissertation, University of Auckland, Auckland.
- Reeve, M. (2004) *Quota refugee and asylum seeker health screening at Mangere Refugee Reception Centre*. Auckland District Health Board, Auckland.
- Reidpath, D., Burns, C., Garrard, J., Mahoney, M. and Townsend, M. (2002) An ecological study of the relationship between social and environmental determinants of obesity. *Health and Place*, **8(2)**, 141-145.
- Riessman, C. (2000) Stigma and everyday resistance practices: childless women in South India. *Gender and Society*, **14(1)**, 111-135.

- Riessman, S. (1993) *Narrative Analysis*, Sage, Newbury Park.
- Rose, G. (1997) Situated knowledges: positionality, reflexivities and other tactics. *Progress in Human Geography*, **21(3)**, 305-320.
- Rosenfield, S. (1997) Labeling mental illness: The effects of received services and perceived stigma on life satisfaction. *American Sociological Review*, **62**, 660-672.
- Rosenkrantz, B. (1994) *From consumption to tuberculosis : a documentary history* Garland, New York.
- Rothman, S. (1994) *Living in the shadow of death: tuberculosis and the social experience of illness in American history* Basic Books, New York.
- Rousseau, C., Said, T., Gagne, M. and Bibeau, G. (1998) Between myth and madness: the premigration dream of leaving among young Somali refugees. *Culture, Medicine and Psychiatry*, **22**, 385-411.
- Rubel, A. and Garro, L. (1992) Social and cultural factors in the successful control of tuberculosis. *Public Health Reports*, **107(6)**, 626-637.
- Rytkönen, M., Moltchanova, E., Ranta, J., Taskinen, O., Tuomilehto, J. and Karvonen, M. (2003) The incidence of type 1 diabetes among children in Finland—rural—urban difference. *Health and Place*, **9(4)**, 315-325
- Safran, W. (1991) Diasporas in modern societies: myths of homeland and return. *Diaspora*, **1**, 83-99.
- Salmela, A. (2004) "Did you see her standing at the marketplace?" Moral purity and socio-spatial behaviour of Somali girls in the city of Turku, Finland. 9th Somali Studies Conference, Aalborg University, Denmark, 3-5 September 2004.
- Samaan, G., Roche, P., Spencer, J., Antic, R., Bastian, I., Christensen, A., Hurwitz, M., Konstantinos, A., Krause, V., Misrachi, A., Tallis, G., Waring, J. and McKinnon, M. (2003) Tuberculosis notifications in Australia, 2002. *Communicable Diseases Intelligence*, **27(4)**, 449-458.
- Samatar, S. (1991) *Somalia: a nation in turmoil*. Minority Rights Group, London.
- Samers, M. (2003) Disapora unbound: Muslim identity and the erratic regulation of Islam in France. *International Journal of Population Geography*, **9**, 351-364.
- Sarsby, J. (1984) The fieldwork experience. In *Ethnographic research: a guide to General conduct*, (Ed, Ellen, R.) Academic Press, London, 87-132.
- Schaer, C. (2002) Where the races meet. Weekend Herald. 23-24 November. Auckland.
- Schneider, A., Snyder-Joy, Z. and Hopper, M. (1993) Rational and symbolic models of attitudes towards AIDS policy. *Social Science Quarterly*, **74(2)**, 349-366.
- Schulte, A. (2002) Consensus versus disagreement in disease-related stigma: a comparison of reactions to Aids and cancer patients. *Sociological Perspectives*, **45(1)**, 81-104.
- Schwoebel, V., Antoine, D., Veen, J. and Jean, F. (1999) *Surveillance of tuberculosis in Europe: report on tuberculosis cases reported in 1997*. Euro TB, Saint-Maurice.
- Scott, J. (2001) *A study of the settlement experiences of Eritrean and Somali parents in Toronto*. Community Information Centre for the City of York, Eritrean Canadian Community Centre of Metropolitan Toronto, SIWA -Somali Immigrant Women Association, Toronto.

- Searle, A. (2004) Having TB: The experience of Pakeha in Auckland. Unpublished MA thesis. Department of Anthropology, University of Auckland, Auckland.
- Shandy, D. (2001) Routes and Destinations: Secondary Migration of Nuer Refugees in the United States. *Negotiating Transnationalism*. Committee on Refugees and Immigrants Selected Papers, Volume IX, Arlington, (Eds, Hopkins, M. and Wellmeier, N.). American Anthropological Association.
- Shandy, D. (2003) Transnational linkages between refugees in Africa and the diaspora. *Forced Migration Review*, **16**, 7-8.
- Sheikh, F. (2000) Somalia: background history. [http://www.fazalsheikh.org/01\\_a\\_camel](http://www.fazalsheikh.org/01_a_camel). Accessed 20 May 2003.
- Shetty, N., Shemko, M. and Abbas, A. (2004) Knowledge, attitudes and practices regarding tuberculosis among immigrants of Somalian ethnic origin in London: a cross-sectional study. *Communicable Disease and Public Health*, **7(1)**, 77-82.
- Shorten, A. (1995) Female circumcision: understanding special needs. *Holistic Nursing Practice*, **9(2)**, 66-73.
- Shurmer-Smith, P. (2003) Doing ethnography. In *The student's companion to geography*, (Eds, Rogers, A. and Viles, H.) Malden, Blackwell, 249-252.
- Simich, L., Mawani, F., Wu, F. and Noor, A. (2003) *Meanings of social support, coping, and help-seeking strategies among immigrants and refugees in Toronto*. University of Toronto, Toronto.
- Sinnerbrink, I., Silove, D., Field, A., Steel, Z. and Manicavasagar, V. (1997) Compounding of premigration trauma and postmigration stress in asylum seekers. *The Journal of Psychology*, **131(5)**, 463-470.
- Sinnerbrink, I., Silove, D. and Manicavasagar, V. (1996) Asylum seekers: general health status and problems with access to health care. *Medical Journal of Australia*, **165**, 634-637.
- Smallman-Raynor, M. and Phillips, D. (1999) Late stages of epidemiological transition: health status in the developed world. *Health and Place*, **5**, 209-222.
- Smith, M. (2000-2001) Desperately seeking asylum: the plight of asylum seekers in Australia. *New Doctor*, **74**, 21-23.
- Smyth, F. (2005) Medical geography: therapeutic places, spaces and networks. *Progress in Human Geography*, **29(4)**, 488-495.
- Soja, E. (1985) The spatiality of social life: Towards a transformative retheorisation. In *Social relations and spatial structures*, (Eds, Gregory, D. and Urry, J.) MacMillan, London, 90-127.
- Solomon, N. (1999) *Refugees and Asylum Seekers in New Zealand: Directions for Public Health*. Public Health Operating Group of the Northern Regional Health Authority, Auckland.
- Sooman, A. and Macintyre, S. (1995) Health and perceptions of the local environment in socially contrasting neighbourhoods in Glasgow. *Health and Place*, **1(1)**, 15-26.
- Spears, I. (2003) Reflections on Somaliland and Africa's territorial order. *Review of African Political Economy*, **95**, 89-98.
- Spoonley, P. (2001) Transnational Pacific communities: transforming the politics of place and identity. In *Tangata o te Moana Nui*, (Eds, MacPherson, C., Spoonley, P. and Anae, M.) Dunmore, Palmerston North, 81-96.

- Statistics New Zealand (2001) 2001 Census. <http://xtabs.stats.govt.nz/eng/TableFinder/index.asp>. Accessed 25 February 2004.
- Statistics New Zealand (2003) *Customised data report*. Statistics New Zealand, Wellington.
- Statistics New Zealand (2006) *New Zealand in profile. An overview of New Zealand's government, economy and people*. Statistics New Zealand, Wellington.
- Stephenson, P. (1995) Vietnamese refugees in Victoria, B.C.: an overview of immigrant and refugee health care in a medium-sized Canadian urban centre. *Social Science and Medicine*, **40(12)**, 1631-1642.
- Suleiman, B. (2000) Tuberculosis quality of care. World Health Organisation. [www.emro.who.int/tdr/frs/proj00-01.pdf](http://www.emro.who.int/tdr/frs/proj00-01.pdf). Accessed 28 September 2004.
- Sumartojo, E. (1993) When tuberculosis treatment fails. A social behavioural account of patient adherence. *American Review of Respiratory Disease*, **147**, 1311-1320.
- Summerfield, D. (1999) A critique of seven assumptions behind psychological trauma programmes in war-affected areas. *Social Science and Medicine*, **48(1)**, 1449-1462.
- Talbot, E., Kenyon, T., Halabi, S., Moeti, T., More, K. and Binkin, N. (2000a) Knowledge, attitudes and beliefs regarding tuberculosis preventative therapy for HIV-infected persons, Botswana, 1999. *International Journal of Tuberculosis and Lung Disease*, **4(12)**, 1156-1163.
- Talbot, E., Moore, M., McCray, E. and Binkin, N. (2000b) Tuberculosis among foreign-born persons in the United States, 1993-1998. *Journal of the American Medical Association*, **284(22)**, 2894-2900.
- Temple, A. (2003) Security fears rise in Somalia after teachers killed. Reuters Foundation. [www.alertnet.org](http://www.alertnet.org). Accessed 18 November 2003.
- Thomas, C. (2002) A literature review of the problems of delayed presentation for treatment and non-completion of treatment for tuberculosis in less developed countries and ways of addressing these problems using particular implementations of DOTS strategy. *Journal of Management of Medicine*, **16(4/5)**, 371-400.
- Thomas, M. and Ellis-Pegler, R. (2006) Tuberculosis in New Zealand: poverty casts a long shadow. *New Zealand Medical Journal*, **119(1243)**, 1-3.
- Thornley, C. (2006) Tuberculosis in Auckland, New Zealand: epidemiology and overview. Tuberculosis workshop, McMaster University, Canada, June 2006.
- Thornley, C. and Pikhholz, C. (2007) Patterns of tuberculosis epidemiology in Auckland by birthplace and ethnicity RAL-e, **Forthcoming**.
- Tilikainen, M. (2003) Somali women and daily Islam in the diaspora. *Social Compass*, **50(1)**, 59-69.
- Tocque, K., Doherty, M., Bellis, M., Spence, D., Williams, C. and Davies, P. (1998) Tuberculosis notifications in England: the relative effects of deprivation and immigration. *International Journal of Tuberculosis and Lung Disease*, **2(3)**, 213-218.
- Trlin, A. (1998) The New Settlers Programme: a progress report. *Population Association of New Zealand Newsletter*, **November 1998**, 8-9.
- Tulsky, J. P., White, M., Young, J., Meakin, R. and Moss, A. (1999) Street talk: knowledge and attitudes about tuberculosis and tuberculosis control among homeless adults. *International Journal of Tuberculosis and Lung Disease*, **3(6)**, 528-533.

- Uba, L. (1992) Cultural barriers to health care for Southeast Asian refugees. *Public Health Reports*, **107(5)**, 544-549.
- UNDP (2001) *Somalia. Human Development Report 2001*. UNDP, New York.
- UNDP (2002) *Somalia. Socio-economic Survey 2002*. UNDP, New York.
- UNDP (2005) *Human Development Report*. UNDP, New York.
- UNFPA (2006) *State of World Population 2006*. UNFPA, New York.
- UNHCR (2000) U.S. Committee for refugees world refugee survey 2000 - Somalia. [www.unhcr.ch](http://www.unhcr.ch). Accessed 17 November 2003.
- UNHCR (2002) *Refugee resettlement: An international handbook to guide reception and integration*. United Nations High Commissioner for Refugees regional office for Australia, New Zealand, Papua New Guinea and the South Pacific,
- UNHCR (2003a) Italian woman wins Nansen Refugee Award for work in Somalia. [www.unhcr.ch](http://www.unhcr.ch). Accessed 15 April 2003.
- UNHCR (2003b) *The State of the World's refugees*. UNHCR, Geneva.
- UNHCR Somalia (2003) *UNHCR Somalia - 2003 Country Operations plan - towards sustainable reintegration, recovery and enhanced protection for returnees and refugees*. UNHCR, Geneva.
- United Nations (1951) *Article 1. United Nations Convention relating to the status of refugees*. United Nations conference on the status of refugees and stateless persons, Geneva.
- United Nations Security Council (2003) *Report of the Secretary-General on the situation in Somalia*. United Nations Security Council, New York.
- United States Committee for Refugees (2002) *World Refugee Survey 2002*. United States Committee for Refugees, New York.
- Utteh, H. (1997) The plight of Somali refugees in Europe, with particular reference to Germany (1993). In *Mending rips in the sky. Options for Somali communities in the 21st century*, (Eds, Adam, H. and Ford, R.) Red Sea Press, Lawrenceville, 449-460.
- Valentine, G. (1997) Tell me about...: using interviews as a research methodology. In *Methods in Human Geography. A guide for students doing a research project*, (Eds, Flowerdew, R. and Martin, D.) Addison Wesley Longman, Harlow, 110-126.
- Valentine, G. (2003) Geography and ethics: in pursuit of social justice - ethics and emotions in geographies of health and disability research. *Progress in Human Geography*, **27(3)**, 375-380.
- Valtonen, K. (2002) Social work with immigrants and refugees: developing a participation-based framework for anti-oppressive practice Part 2. *British Journal of Social Work*, **32**, 113-120.
- van der Oest, A., Chenhall, R., Hood, D. and Kelly, P. (2005) Talking about TB: multicultural diversity and tuberculosis services in Waikato, New Zealand. *New Zealand Medical Journal*, **118(1216)**, 1-12.
- van der Werf, T., Dade, G. and van der Mark, T. (1990) Patient compliance with tuberculosis treatment in Ghana: factors influencing adherence to therapy in a rural service programme. *Tubercle*, **71**, 247-252.

- van Ewijk, M. and Grifhorst, P. (1997) Controlling and disciplining the foreign body: a case study of TB treatment among asylum seekers in the Netherlands. In *The new migration in Europe: social constructions and social realities*, (Eds, Koser, K. and Lutz, H.) MacMillan, London, 242-259.
- Van Hear, N. (1998) *New diasporas. The mass exodus, dispersal and regrouping of migrant communities*, UCL Press, London.
- Van Hear, N. (2003) *From durable solutions to transnational relations: home and exile among refugee diasporas*. UNHCR, Copenhagen.
- Vertovec, S. (1999) Conceiving and researching transnationalism. *Ethnic and Racial Studies*, **22(2)**, 447-462.
- Vertovec, S. (2003) Migration and other modes of transnationalism: towards conceptual cross-fertilization. *The International Migration Review*, **37(3)**, 641-665.
- Vissandjee, B., Kantiebo, M., Levine, A. and N'Dejuru, R. (2003) The cultural context of gender identity: female genital excision and infibulation. *Health Care for Women International*, **24**, 115-124.
- Volinn, I. (1983) Health professionals as stigmatizers and destigmatizers of diseases: alcoholism and leprosy as examples. *Social Science and Medicine*, **17(7)**, 385-393.
- Volmink, J., Matchaba, P. and Garner, P. (2000) Directly observed therapy and treatment adherence. *The Lancet*, **355(9212)**, 1345-1350.
- Wahlbeck, O. (2002) The concept of diaspora as an analytical tool in the study of refugee communities. *Journal of Ethnic and Migration Studies*, **28(2)**, 221-238.
- Wallace, D. (1994) The resurgence of TB in New York city: a mixed hierarchically and spatially diffused epidemics. *American Journal of Public Health*, **84**, 1000-1002.
- Wallace, R. and Wallace, D. (1993) Inner-city disease and the public health of the suburbs: the sociogeographic dispersion of point-source infection. *Environment and Planning A*, **25**, 1707-1723.
- Wallace, R. and Wallace, D. (1997) The destruction of US minority urban communities and the resurgence of tuberculosis: ecosystem dynamics of the white plague in the dedeveloping world. *Environment and Planning A*, **29**, 269-291.
- Wallace, R. and Wallace, D. (1999) Emerging infections and nested martingales: the entrainment of affluent populations into the disease ecology of marginalization. *Environment and Planning A*, **31**, 1787-1803.
- Wallace, R., Wallace, D., Andrews, H., Fullilove, R. and Fullilove, M. (1995) The spatiotemporal dynamics of AIDS and TB in the New York metropolitan region from a sociogeographic perspective: understanding the linkages of central city and suburbs. *Environment and Planning A*, **27**, 1085-1108.
- Wallace, R., Wallace, D., Ullmann, J. and Andrews, H. (1999) Deindustrialization, inner-city decay, and the hierarchical diffusion of AIDS in the USA: how neoliberal and cold war policies magnified the ecological niche for emerging infections and created a national security crisis. *Environment and Planning A*, **31**, 113-139.
- Wanyeki, I. (2003) Use of a dwelling-referenced geographic information system to characterize urban tuberculosis. Unpublished MSc thesis. Department of Epidemiology and Biostatistics, McGill University, Montreal.

- Warfa, N., Bhui, K., Craig, T., Curtis, S., Mohamud, S., Stansfield, S., McCrone, P. and Thornicroft, G. (2006) Post-migration geographical mobility, mental health and health service utilisation among Somali refugees in the UK: a qualitative study. *Health and Place*, **12**, 503-515.
- Warin, M., Baum, F., Kalucy, E., Murray, C. and Veale, B. (2000) The power of place: space and time in women's and community health centres in South Australia. *Social Science and Medicine*, **50(12)**, 1863-1875.
- Warsame, M. (2006) Personal Communication. 12 December 2006.
- Watkins, R., Plant, A. and Gushulak, B. (2002) Tuberculosis rates among migrants in Australia and Canada. *International Journal of Tuberculosis and Lung Disease*, **6(7)**, 641-644.
- Watson, B. (2005) From Somalia to a life in New Zealand. North Shore Times. June 2 2005. Auckland.
- Watters, C. (2001) Emerging paradigms in the mental health care of refugees. *Social Science & Medicine*, **52(11)**, 1709-1718.
- Webersik, C. (2004) Differences that matter: the struggle of the marginalised in Somalia. *Africa*, **74(4)**, 516-533.
- Westaway, M. (1989) Knowledge, beliefs and feelings about tuberculosis. *Health Education Research. Theory & Practice*, **4(2)**, 205-211.
- White, A. (2002) Organic functionalism, 'community' and place: refugee studies and the geographical constitution of refugee identities. *Geoforum*, **33**, 73-83.
- Whitlock, G., Calder, L. and Perry, H. (2001) A case of infectious tuberculosis on two long-haul aircraft flights: contact investigation. *New Zealand Medical Journal*, **114**, 353-355.
- Wiles, J., Rosenberg, M. and Kearns, R. (2005) Narrative analysis as a strategy for understanding interview talk in geographic research. *Area*, **37(1)**, 89-99.
- Williams, A. (2002) Changing geographies of care: employing the concept of therapeutic landscapes as a framework in examining home space. *Social Science and Medicine*, **55(1)**, 141-154.
- Wilton, R. (1996) Diminished worlds? The geography of everyday life with HIV/AIDS. *Health and Place*, **2(2)**, 69-83.
- Wilton, R. (2000) Sometimes it's ok to be a spy: ethics and politics in geographies of disability. *Ethics, Place and Environment*, **3**, 91-97.
- Winchester, H. and White, P. (1988) The location of marginalised groups in the inner city. *Environment and Planning D: Society and Space*, **6**, 37-54.
- World Bank (2003) *World Development Report 2003*. World Bank, Washington DC.
- World Bank (2006) *World Development Report*. World Bank, Washington DC.
- World Health Organisation (1994) *TB - a global emergency*. WHO, Geneva.
- World Health Organisation (2005) *Global tuberculosis control: surveillance, planning, financing. WHO Report 2005*. WHO, Geneva.
- World Health Organisation (2006a) Country Profile: Ethiopia.  
[www.afro.who.int/tb/country\\_profiles/eth.pdf](http://www.afro.who.int/tb/country_profiles/eth.pdf). Accessed 5 December 2006.

- World Health Organisation (2006b) Country Profile: Kenya.  
[www.afro.who.int/tb/country\\_profiles/eth.pdf](http://www.afro.who.int/tb/country_profiles/eth.pdf). Accessed 5 December 2006.
- World Health Organisation (2006c) *Global tuberculosis control. Surveillance, planning, financing*. WHO, Geneva.
- World Health Organisation (2006d) TB country profile - Somalia.  
[www.emro.who.int/stb/countryProfile\\_som\\_05.pdf](http://www.emro.who.int/stb/countryProfile_som_05.pdf). Accessed 4 December 2006.
- World Health Organisation (2006e) TB country profile: Djibouti.  
[www.emro.who.int/stb/Countryprofile\\_som\\_us.pdf](http://www.emro.who.int/stb/Countryprofile_som_us.pdf). Accessed 5 December 2006.
- World Health Organisation (2006f) Tuberculosis Fact Sheet No. 104.  
<http://www.who.int/mediacentre/factsheets/fs104/en/#global>. Accessed 1 November 2006.
- World Health Organisation (2006g) Tuberculosis facts.  
[http://www.who.int/tb/publications/2006/tb\\_factsheet\\_2006\\_1\\_en.pdf](http://www.who.int/tb/publications/2006/tb_factsheet_2006_1_en.pdf). Accessed 14 November 2006.
- Yang, Z., Kong, Y. and Wilson, F. (2004) Identification of Risk Factors for Extrapulmonary Tuberculosis. *Clinical Infectious Diseases*, **38(2)**, 199-205.
- Yeung, H. (1998) *Transnational corporations & business networks : Hong Kong firms in the ASEAN Region*, Routledge, London.
- Yeung, H. (2003) Globalization. In *The Student's companion to geography*, (Eds, Rogers, A. and Viles, H.) Blackwell, Malden, 103-107.
- Zarowsky, C. (2004) Writing trauma: emotion, ethnography, and the politics of suffering among Somali returnees in Ethiopia. *Culture, Medicine and Psychiatry*, **28**, 189-209.
- Zwarenstein, M., Schoeman, J., Vundule, C. and Lombard, C. (1998) Randomised controlled trial of self-supervised and directly observed treatment of tuberculosis. *Lancet*, **352**, 1340-1343.