The Experience of Psychosis: Fragmentation, Invalidation and Spirituality.
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http://hdl.handle.net/2292/705

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The Experience of Psychosis: Fragmentation, Invalidation and Spirituality.

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A thesis submitted in fulfilment
of the requirements for the degree of
Doctor of Philosophy in Psychology,
The University of Auckland

2007

Abstract

This study is a qualitative investigation into the subjective experience of psychosis as expressed by clients of a first episode psychosis service in psychotherapy sessions. Fifteen participants, already engaged with the author in his clinical role, were recruited for this study. Recordings were made of psychotherapy sessions where participants' subjective experience of psychosis was being discussed as part of the normal course of therapy. Sixty two recordings were made in total, with a mean of 4.1 recordings with each participant.

Transcriptions of recordings were made by the author and analysed using Grounded Theory. Commonalities in the data were identified and sorted into categories. Relationships between these categories were explored. Initial analyses yielded 103 distinct categories, which were subsumed under the general headings of Storytelling and Authoring, Causes of Psychosis, Descriptions of Psychotic Experience, Impact of Experience, Responses to and Coping with Experience, Spirituality, and Māori Issues. Subsequent analysis yielded three theoretical constructs which capture the essence of the subjective experience of psychosis: fragmentation – integration, invalidation – validation, and spirituality.

Fragmentation – integration relates a sense of a loosening (or, less often, tightening) of connections and associations between aspects of experience, and applies to the personal and interpersonal domains. Validation – invalidation refers to the sense of having (or not having) confidence in one's ability to accurately perceive or construe experience and to convey this to self and others. Spirituality refers to an inclination to view the experience of psychosis, or aspects of it, in terms of a broad framework of meaning pertaining to how the individual views his or her relationship with the universe.

Findings from this research indicate that those who experience psychosis are eager to explore the meanings of their experience and are competent at reflecting on this experience based on their own subjective experience. Important contributions to our understandings of psychosis can be made by those who have such first-hand acquaintance with psychosis. Theoretical, research, clinical and training implications of this research are discussed.

Acknowledgements

Firstly, I would like to express my sincere gratitude to those who agreed to participate in this research. In particular, I appreciate their generosity in being willing to share their stories with me. I hope my analysis of these stories remains true to their unique nature and reflects my respect both for the stories themselves and the generosity of the individuals who shared them.

I also want to express my deep thanks to my supervisor, Dr John Read, whose encouragement for this research has been invaluable. Your support and enthusiasm for this research helped me get through those times when I struggled to see the value in what I was up to. Thanks for that sustenance. Similar thanks go to Dr Nick Argyle, co-supervisor, whose thoughtful comments on this research project at various stages along the way helped me look at things a bit differently, and drew my attention to areas I might otherwise have overlooked. Thanks to both of you for the commitment you have shown to this research project.

I am also grateful to the support shown for this research by Auckland District Health Board, and for my colleagues in the community mental health centre where I work, in particular my immediate colleagues in the First Episode Psychosis team.

Thanks also to Jerome for being Jerome.

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Abbreviations used in this thesis

ADHB	Auckland District Health Board
APA	American Psychiatric Association
BPS	British Psychological Society
CMHC	Community Mental Health Centre
ECC	Essentially Contested Concept
EM	Explanatory Model
FEP	First Episode Psychosis
HBM	Health Belief Model

1 Introduction

> 'So, I don't know what to believe. I feel angry when I see people like Alex being validated for his experience and me just being written off as a psychotic nutcase. Some of my friends don't even bother with me anymore.'

> 'I feel almost like unheard and not accepted, not good enough to be able to have those experiences. It's all right for Andrew to have them, oh yes Andrew. Every time that he has an experience, it gets round the group "Oh Andrew had this wonderful experience he did". Everybody believes him, but nobody believes that I am good enough to have them: "Oh, it's a psychotic breakdown; you're hearing things". That makes me feel inferior, you know.'

This thesis is an investigation into how individuals make sense of personal, subjective experiences. In particular, it is an analysis of how clients in a mental health service speak about experiences which mental health professionals commonly refer to as 'psychotic' experiences. This study examines those clients' ways of talking about their experiences. The quotes above (comments made by one of the participants in the study) illustrate some of the themes which permeate this study. These include challenges encountered by clients in making sense of their experience, and in having the sense they make validated, or more usually invalidated, by those around them.

The particular context within which this sense-making is investigated in this study is that of the relationship between a clinical psychologist (the author/researcher) working in a mental health service and clients of this service. These clients are engaged in a clinical service set up to meet the needs of young adults who are experiencing, or have recently experienced, their first psychotic episode. This thesis is an attempt to explore the sense which these clients develop of their 'psychotic' experiences. It is experiences of this nature that are used as the basis of the diagnostic term 'schizophrenia' (American Psychiatric Association, 2000). This research then is an attempt to explore the ways in which clients who might receive this diagnosis will, if given the opportunity, talk about the sense that they themselves make of their experiences.

I will argue that the sense that clients make of their experiences is both intrinsically interesting and of clinical significance. Though I will begin this introduction by exploring some of the philosophical issues that relate to the research, it is important to stress that clients' understandings of their experiences are (as I will show in chapter 6) of great practical importance, having an impact on many clinically significant variables such as levels of distress, engagement with services, and if and how clients choose to respond to their experiences. This research is primarily clinical in its orientation with the ultimate aim being to make some contribution to how it is that clinical services are delivered to clients who experience psychoses. This research was conducted with a view to developing greater appreciation of the subjective experience of psychoses in the hope that this can contribute to our theoretical understandings of and clinical approaches to these experiences.

However, I would also like to make clear that I see this study as more than just an investigation into the psychological processes involved and the clinical implications of the sense the client makes of unusual experiences. It is this, but I hope to show that it is also more than this insofar as this sense-making is located within philosophical and social frameworks. I hope that this research can both be informed by, and inform, some of the more general issues which will now be discussed.

In this introduction, I will provide an overview of areas of relevance to this research. I will begin by outlining a framework relating to the position and importance of subjective knowledge and subjective experience. This will include consideration of the philosophical and epistemological contexts within which this research can be located. My emphasis here will be on the 'interpretative turn' within philosophy and the social sciences. This provides a useful position from which to consider the importance of subjective experience, such as that held by the participants in this research. I will review literature which emphasises the role of interpretation and meaning-making within the storytelling tradition. Issues of language, power, and personal knowledge will also be discussed.

After setting out this conceptual framework, I will then move on to discuss matters of relevance to the clinical context within which this research takes place. This will require consideration of scientific and lay understandings of the kinds of experiences investigated here, as these provide a backdrop illustrating the kinds of understandings of these experiences that exist in the clinical environment as well as in the lay world. When discussing scientific or professional models of psychosis, my focus will be on providing an overview of some of the many models of psychosis which one finds in the literature, rather than examining the evidence used by adherents to support these models. I will then move on to discuss research into lay understandings of psychosis. This will include understandings held by members of the general public, by those who experience psychosis, and by their family members. These chapters will illustrate the range and diversity of understandings of psychosis held by those groups. As part of discussing these perspectives, I will propose a 'meta-theory' for making sense of psychosis, namely, that we can view this as an 'essentially contested concept'.

As a study of the subjective experience of mental health difficulties, it is important for a case to be made that subjective experiences of psychosis are significant considerations in the clinical context. To demonstrate this, I will outline some of the scientific literature investigating the individual's understanding of and subjective experience of psychosis which illustrates quite clearly that these are essential considerations in terms of theory, research and clinical practice. I will close this literature review by looking at subjective accounts of psychosis found in the public domain (books, journal articles, web sites, etc.) before briefly discussing the recovery movement, which emerged, in part at least, from such first-person accounts, and which is an important aspect of the context within with this research took place.

Following this literature review, I will discuss matters relating to methodology in qualitative research, before moving on to describe the method used in the present research, grounded theory. The results of this research will be presented in two chapters. In chapter 9 I will outline the more descriptive level of analysis of participants' accounts of psychosis. In chapter 10 I will present the conceptual, theoretical level of analysis, which delineates three theoretical constructs aimed at conveying the essence of the subjective experience of psychosis. Implications of these results will be discussed in chapter 11.

1.1 The Philosophical context: the ‘interpretative’ turn

The issues of knowledge and of understanding have long been of central concern to philosophers and can be found in both classical and post-modern philosophical writings (for example, Hospers, 1990; Kenny 1998; Russell. 1945). Philosophical investigations into the nature of language, knowledge and of understanding underwent a marked shift around the 1920s. This shift is reflected in the work of Wittgenstein, who moved away from his earlier position of logical positivism, to the ‘interpretative’ position developed in his later works (Harre, 1994). The logical positivist manifesto posited that the only true knowledge is scientific knowledge and that the meaning of language could be gauged through the ‘verification principle’, which assumes a direct correspondence between utterances and reality. This is a claim that statements are meaningful only if empirically verifiable or logically true (Lyons, 1995). Statements which did not meet this criterion were deemed to be meaningless.

Wittgenstein’s (1953) later philosophy took a quite different view on the nature of meaning, arguing that meaning is derived from the uses to which language is put within a range of contexts. That is, talk itself is seen as producing meaning, rather than only being meaningful through reflecting reality. Wittgenstein (1953) argued that it is only when we have some grasp of the meanings that inform a person’s behaviour that we can be said to have an understanding of this behaviour. Wittgenstein (1953) was particularly interested in the way in which language conveys meaning, and his views on the relationship between language and meaning have had a significant impact on science in general, and the social sciences in particular.

Wittgenstein’s ideas on meaning and interpretation have had such an impact on the social sciences in recent years that some writers (Rabinow & Sullivan, 1987; Harre, 1998) have argued that we are now witnessing a major ‘paradigm shift’ in the social sciences. By this, the writers mean to suggest that the basic epistemological assumptive framework which drives social science theory and research is undergoing a change of such proportions that we are in the midst of a Kuhnian (Kuhn, 1970) shift in the basic paradigmatic features of the social sciences.

What these writers are arguing is that some of the fundamental assumptions upon which social science rests are being questioned and usurped by the development of a new ‘interpretative’ approach to social science investigations. This new approach rests upon assumptions quite different in nature from those upon which more traditional ‘positivistic’ social science rests. Proponents (e.g., Bruner 1986; Drewery Winslate & Monk 2002; Harre, 1998) of this approach have argued for a re-examination of some of our most fundamental epistemological notions. Questions have been raised regarding, among other things: what constitutes knowledge; the relationship between the knower and the known; and even how it is that the principle ‘subject’ of social science studies – the human being – is to be conceptualised. Another aspect of this approach is the central emphasis that is given to meaning. This focus on meaning and interpretation has led to the development of quite different notions about the aims, functions, and methods of scientific investigations in the social sciences.

This new, developing approach to the scientific investigation of human beings has been referred to as, among other things, ‘the interpretative turn’ (Rabinow & Sullivan, 1987), ‘discursive investigations’ (Harre, 1994), ‘social constructivism’ (Gergen, 1977), ‘deconstructionism’ (White, 1991), and ‘folk psychology’ (Bruner, 1990). While these different writers have adopted different terms, common to all writers within this framework is the emphasis on interpretation and meaning. For that reason, I will adopt the terminology of Rabinow and Sullivan (1987) who refer to this approach as ‘the interpretative turn’.

Whether we view this new approach as reflecting a paradigmatic shift in social science, or as simply another perspective within social science theory and research, it is clear that conventional, positivistic social science is still alive and well. Indeed, much of the research that will be referred to in this thesis was carried out within the traditional positivistic framework. Thus, though at a theoretical level there may be a tension between conventional approaches to social science research and ‘interpretative’ approaches, in practice research continues to be carried out from both perspectives. I will now consider some of the main themes of the ‘interpretative turn’, as these have particular relevance for the research presented here.

1.1.1 Focus on meaning

As already noted, a distinguishing characteristic of research adopting this new approach is the focus on meaning and interpretation, which is in contrast to earlier paradigms in the social sciences, such as behaviourism and structuralism for which the meanings that individuals gave to experiences were considered of little significance. Within the interpretative framework, the meanings which individuals ascribe to their experience are deemed of central importance to researchers, a point made succinctly by Mischel, (1977; p.15) who argues that:

> 'One cannot understand what people do when one attempts to bypass completely any phenomenological understanding of what the thing means to them.'

Given the interdependence of meaning and context, to study meaning it is necessary to attend not only to behaviour, but also to the context within which it occurs. In its broadest sense we might see that 'culture' provides the contextual backdrop which renders our actions meaningful. Discussing the main aims of social science studies Bruner (1990; p.137) argued that a crucial aspect of investigations into human nature is the study of 'The culturally shaped notions in terms of which people organise their views of themselves, of others, and of the world in which they live.'

Another implication of the focus on meaning is the recognition that in order to investigate the meanings that individuals give to events, it is necessary to give greater attention to the accounts that people themselves give of their behaviour, as Harre (1994; p.21) has argued:

> 'Once one sees the task of understanding human behaviour as involving interpretation and empathy rather than prediction or control, the self reports of the people one is studying become very important in any psychological research project.'

1.1.2 View of humans

Harre's quote illustrates a shift in the focus of social science investigations, where the primary aim is now developing an understanding of the meanings which guide our lives, rather than simply external behavioural observations. An approach of the sort, advocated by writers such Bruner, Mischel, and Harre, rests upon quite specific (though not necessarily explicit) assumptions about what it is to be human. Research within this framework is developed from a perspective which views humans as being first and foremost meaning-makers. Hence, the aim of such investigations is to shed light on the webs of meanings which participants in the research have spun for themselves (Geertz, 1983).

A central aspect of the 'interpretative approach', which is of particular relevance to this thesis, is this view of human beings (both researchers and non-researchers alike) as being essentially and inevitably engaged in making interpretations of the worlds we find ourselves in. Any attempts to understand human behaviour which neglects this aspect of what it is to be human, will be inadequate in its efforts to capture the nature of social and psychological life. Thus, the sense that people make of experiences is seen not only as an interesting area of study, but rather as one of the central concerns of the social sciences.

1.1.3 Qualitative methodologies

This shift in focus inevitably led to the development of new methods to investigate the ways and means by which people construct their own particular meanings. A wide variety of such methods have been developed in recent years, such as ethnomethodolgy (Garfinkel, 1967) discourse analysis (Potter & Wetherell, 1987), and grounded theory (Glaser & Stauss, 1967). These methods, often referred to as 'qualitative methodologies', have been applied extensively in anthropology and in sociology, and only relatively recently have they come to be regularly used in psychological investigations (Henwood & Pidgeon 1992). Advocates of these qualitative methodologies argue that the social sciences cannot, and should not, be restricted to methods and aims derived from the traditional positivist scientific paradigm. In particular, writers (e.g., Geertz, 1983; Heron, 1981; Shotter, 1993) in this area have argued that conventional positivistic scientific methods are ill-suited to the study of topics such as culture, meaning, and interpretation.

1.1.4 Relationship between researcher and participants

One epistemological consequence of the focus on meaning and interpretation has been to reconsider the relationship between the researcher/scientist and those being studied. No longer are researchers seen as objective, distant scientists who investigate their ‘subjects’. Rather, there is greater recognition that researchers, like the participants in their studies, are engaged in the process of interpretation and meaning-making, both of which are seen as necessarily determined by the historical, social, cultural context within which research takes place.

This emphasis on context points to a pluralistic view of the nature of knowledge, whereby the researcher is seen as having no privileged position from which to make definitive truth claims. The researcher’s interpretations, like those of the people being studied, are viewed as being rendered meaningful only through their contextual positioning. Thus, researchers’ interpretations are considered one among many possible ways of viewing a given situation, each of which may, in its own way, illuminate or shade the area being investigated, and so enhance (or inhibit) our understanding. Rabinow and Sullivan (1987; p.7) express this position thus:

> ‘When we try to understand the cultural world, we are dealing with interpretations and interpretations of interpretations.’

Another important consideration for us here is the notion that meanings are not discovered, but are constructed, and are context dependent. This suggests that it is impossible for the researcher to remove him or herself completely from the process of meaning-making. That is, the researcher may (as I do in this research) form part of the interpersonal context within which the meaning is constructed. So, we must view the researcher as more than just a passive investigator into meaning: he or she is part of the context within which the meaning is both constructed and investigated, and therefore plays an active role in the construction of meaning. (The relationship between the researcher and participants in the present study will be discussed below: 8.6).

In summary, the ‘interpretative turn’ presents us with a view of human beings as being not simply behaving organisms, but rather as being constructers of meaning. It is by investigating these constructed meanings that we will be more able to understand, among other things, the ways in which the individual might behave. To do so, we must look to methodologies which are appropriate to this task: qualitative methods have been developed for this very purpose. Whatever methods we use, we must recognise that the researcher cannot make the claims of distance and objectivity of traditional social science. Rather, the researcher must acknowledge a role in the meanings that are constructed through the research project.

1.2 Storytelling, power and personal knowledge

I will now look more closely at how the interpretative turn has been incorporated within psychology. In particular, I will discuss the notions of 'storytelling', meaning-making, power and different 'ways of knowing'.

1.2.1 Storytelling and meaning-making

Within psychology, and reflecting the changes already referred to in the social sciences, there has been a growing interest in the study of the meaning of events for individuals. This approach contrasts with the concerns which permeated the behavioural paradigm, where the focus was largely on understanding human behaviour through the study of the impact of changes in environmental contingencies, with little attention being paid to what these changes might mean to the individual. This recent focus on individual meaning-making can be traced to the work of George Kelly (1955), although the focus on meaning does, of course, have a longer tradition within psychology, being found in the works of some of the founding fathers of psychology such as Wundt (1897), James (1892) and Freud (1904).

However, it is in Kelly's (1955) work that we can trace the first comprehensive expression of the constructivist framework within psychology. Kelly argued that it is through the application of our own 'personal construct' system that we navigate reality. Kelly's position has been developed by Mair (1977; 1988) and Bruner (1990), who have proposed that a natural elaboration of Kelly's constructivist framework and a fruitful model for investigating how meaning is constructed is that of 'storytelling'. This approach has proven particularly fertile within the area of clinical psychology, where a therapeutic model, narrative therapy, based on this premise has been developed (Mair, 1988; White & Epston, 1990).

The basic premise of the storytelling (or 'narrative') approach is that the mechanism by which experience is rendered meaningful is through 'storying', or 'narrating' it within some form of narrative structure. Expressing the essence of the storytelling approach Taylor (1996) has stated that 'narrative is the primary form by which human experience is made meaningful'. Similarly, White and Epston, (1990; p.10) have argued that 'Experience must be "storied" and it is this storying that determines the meaning ascribed to experience.'

The storytelling metaphor provides us with a framework for considering how it is that experience is rendered meaningful by the individual. As such, this is an appropriate framework for the current research, where it is possible to view the clients' understandings of their experiences as attempts to 'story' those experiences. Research, such as the present study, can similarly be seen as an attempt to 'story' the material collected. Thus, in principle, both the researcher and the participant are in the same business: storying experience in order to render it meaningful.

It is important to note that this storytelling approach, and the constructivist framework from which it derives, is more than simply a way of looking at how experience is made meaningful. There is a well-established constructivist literature which discusses the ontological and epistemological implications of constructivism (Mancuso, 1996; Bakhtin, 1986; Rorty, 1980). One assumption of the storytelling approach is that stories are not merely *descriptive* of experiences, but are seen as *constitutive.* That is, stories do not merely describe an independent objective reality, rather it is through the process of storying that reality as we experience it is constituted. In this vein, White (1991; p.28) states:

> 'The narrative metaphor proposes that persons live their lives by stories, and that these stories are shaping of life, and that they have real, not imagined, effects.'

Stories are seen as constituting the very fabric which makes life meaningful; expressing this relationship Taylor (1996) has stated that 'we live in stories the way fish live in water'.

One of the interesting implications of the storytelling epistemology is that the boundary between 'fact' and 'fiction' is blurred, and the notion of there being a single 'truth' is called into question. Instead, we are faced with an epistemology which allows for multiple stories, and a multiplicity of 'truths', each reflecting one particular way of storying the experience being considered. Claims to have access to an undisputed or objective 'truth' are viewed with some suspicion. Thus, Roberts (1999;

p.5) has suggested, somewhat ironically, that 'it may be only the deluded and the fundamentalist who *know* the truth'.

So, claims to some form of objectivity in one's storytelling are viewed with some scepticism and seen primarily as a rhetorical device, aimed at persuading others of the superiority of one interpretation over all others. In section 1.2.2 below, I will consider how the concept of power is helpful in analysing how it is that certain 'truths' claim to be, and may come to be regarded as, 'objective' truths, rendering other 'truths' invalid.

In considering the mechanism by which stories are constructed, there is a general consensus that language is of central importance, though there is some debate regarding the extent to which *all* meaning-making is viewed as language based. A radical position is adopted by Froman (1992; p.8) who proposes that 'Everything that is known is known in language', However, there are others who argue for a broader notion of storytelling extending to non-linguistic ways of meaning-making, such as 'emotional knowing', and Polanyi's (1958; 1966) notion of 'tacit knowledge' (see 1.2.4). It is worth noting that Kelly (1955) himself was at great pains to stress that his 'constructs' were not restricted to, nor equivalent to, language, but that many of our most powerful constructs are 'pre-verbal'. Indeed, it seems difficult to maintain the position that all meaning is language based. However, for the purposes of the present research, which is an investigation of how client's convey the meaning of their experience in language, it is sufficient to accept that language is one of our important meaning-making tools.

In this attention to language, we again see the influence of Wittgenstein (1953) who put forward the argument that language practises (or 'language games') are constitutive of meaning, and that it is through language that meaning is constructed. This notion has been adopted my Mair (1988) who discusses how it is that meaningful worlds, or 'habitations', are constructed through 'conversational practises'. A similar point is made by Lowe (1991) when he notes that

> 'The post-modern repudiation of a representational view of language suggests that meanings are not given or 'found' through conversation, but are progressively made or fashioned through conversation itself.'

These references to ‘conversation’ draw our attention to the social nature of meaning-making. Given the we are each born into a particular linguistic and cultural community, it seems clear that certain ways of storying experience may be more available to the individual than others. That is, the individual, born into the ‘language games’ (or more broadly ‘conversational practises’) of his or her culture, may have ready access only to those stories (or ways of storying) recognised and valued within that particular culture. As White (1991; p.28) has stated ‘Stories are inevitably framed by our dominant cultural knowledges.’ White (1991) argues that within any culture there will be conventions developed for identifying *which* aspects of the totality of experience are to be selected out and ‘storied’ and *how* these experiences are to be storied. White’s argument is that these conventions will reflect dominant cultural knowledges.

In summary, the storytelling approach provides us with a notion of human beings as constructors of meaning, who render the environment meaningful through some form of inner narrative; this inner narrative, which may be a largely (though not necessarily solely), linguistic in its form, is the mechanism by which a sense of self is created and maintained (Freeman, 1993). In addition, it is this narrative which determines which parts of the individual’s universe will be attended to, and hence made meaningful through story, and which parts will be ignored. However, it is important to note that this storytelling or narrating of experience is not viewed as a purely individual experience. Though it may be located in one sense *within* the individual, there is another sense in which this process is social in nature. This locating of storytelling within the social fabric, combined with the notion of there being the possibility of multiple truths or multiple stories, leads us to ask how it is that particular stories come to dominate whereas others are considered subordinate, or may even be silenced. Within the social realm it seems necessary to invoke the concept of power in analysing how it comes to pass that certain stories seem to be more valued than others. It is to this concept that I will now turn my attention.

1.2.2 Power

Foucault (1967; 1975; 1977) used his historical analyses of social institutions (in particular prison services and mental health services) to add substance to his argument that knowledge should be seen as multiple. That is, he argued for the notion of ‘knowledges’ rather than the uncountable and seemingly unquestionable notion of a unitary, indivisible ‘knowledge’. Through his historical analyses Foucault was able to show the variability in the ‘knowledge’ that characterised different ages and how this ‘knowledge’ was used to justify the different practises (in penal institutions or in mental health care) of the particular age. Thus, Foucault linked forms of knowledge with social practises, and within the power relations which pertain at any given time. For Foucault there is no knowledge or truth outside of networks of power relations.

Foucault argued that current dominant knowledges endeavour to disqualify, or discredit, competing knowledges (or ‘discourses’). These competing knowledges may be those knowledges of different historical epochs, or the knowledge of social groups which have less power than the dominant group. Foucault referred to these knowledges as ‘subjugated knowledges’, which include knowledges from previous ages, which have now been written out by revision of history. In addition to knowledges which have been subjugated through historical revision, Foucault considered also that, at any given time, knowledges which deviate from, and thereby challenge, the dominant discourse will also be subjugated in the present. This would include what Foucault referred to as ‘local popular’ or ‘indigenous’ knowledges. Here, Foucault is referring to the knowledge of any particular experience or institution that is held by those who are subject to this institution (such as the knowledge that prisoners have of penal institutions, or that patients have of mental health institutions and practises). These knowledges, Foucault (1980) argued, are made marginal, lowly ranked, and exiled from the domain of ‘legitimate’ knowledge. Foucault’s argument is that those with power act in such a way as to legitimise their own knowledge while simultaneously discrediting other knowledges. This process, by which competing truth claims are suppressed, is referred to by Rouse (1994), who credits Foucault with the concept if not the actual term, as ‘epistemic sovereignty’.

Foucault argued that dominant knowledges may be challenged through these subjugated knowledges being ‘resurrected’. That is, he argued that the very process of giving voice to marginalised discourses is, in itself, one of the means by which these knowledges are empowered, and, as a consequence, they challenge the dominant discourse, which endeavours to maintain its hegemony through effectively silencing other knowledges.

> 'It is through the re-appearance of this knowledge, of these local popular knowledges, these disqualified knowledges, that criticism performs its work.' (Foucault, 1980; p.82)

The resurrecting of subjugated knowledges can have the twin impact of relativising knowledge claims, and so puncturing claims of the dominant knowledge to be the *only* knowledge, and of promoting, or giving voice to, a discourse that is otherwise silenced. The current research was undertaken in the spirit of resurrecting a voice which is often effectively silenced in the professional literature on mental health: the voice of the person who is most familiar with the experience, the patient. The knowledge that clients in a mental health service have of their experience would appear to be a perfect example of a 'subjugated knowledge'. As I will show below (4.1), clients' knowledge of their experience has been historically 'subjugated' in the Foucaultian sense. This thesis then can be viewed as an attempt to 'resurrect' this knowledge, albeit through the perspective of a mental health professional.

1.2.3 Language and Power

Foucault's ideas regarding the relationship between knowledge and power have been particularly influential within the constructivist framework, and a close relationship between Foucault's notion of multiple knowledges and the more recent storytelling approach in psychology as outlined above is apparent. I will now look at how the concept of power has been incorporated within the storytelling framework.

As mentioned earlier, language is seen as one of the primary mechanisms of narrating experience, and, perhaps as a consequence of language being readily amenable to empirical investigations, it is often in the domain of language that the concept of power is studied. Hence, the following discussion regarding power and storytelling will focus largely on language. This is not to imply that language is the only, or even the primary source of power within any given society. A broader discussion of the relationship between power and psychological well-being can be found in the works of British clinical psychologist David Smail (1993), who considers the role of other factors such as physical and economic might. However, as the focus of this thesis is how clients use language to convey the meaning of their experiences, it is the role of language that most concerns us here.

1.2.3.1 The power to define reality

As noted above, Froman proposed a radical language-based metaphysics when he claimed that ‘reality’ is constructed through language. Froman (1992; p.4) argues that because ‘it takes power to establish meaning in language’ those with power will, through the use of language, construct a reality that best meets their needs. Further, notions of knowledge and truth are, for Froman (1992; p.8), a reflection of the power relations in a given society:

> ‘Behind the establishment of reality in language is power, involving, among other things, our notions of knowledge and truth.’

Froman’s general argument regarding the relationship between language and power is based upon the notion that those with power will be in a position to decide which aspects of reality will be named, and how it is that they will be so named. Froman (1992; p.166) argues that ‘The ability to name is to have control over what things are singled out as particular objects and events.’ For the purposes of the present discussion, there is no need to accept Froman’s radical and questionable position that language is *constitutive* of reality. It is sufficient to accept only that language is one of the ways in which power is expressed and maintained. That is, while few writers endorse the notion that reality is best viewed as an entirely linguistic product, the notion that language use is reflective of (and perhaps helps to maintain) power relationship finds greater support. This argument is put simply and succinctly by psychologist Dorothy Rowe (1992; p.29) who states that ‘Power is the ability to get other people to accept your definition of reality.’

Perhaps as a result of an explicit interest in power dynamics, the issue of language and power has been well investigated in the area of Gender Studies. In her discussion of the relationship between language, gender, and power, Gal (1995; p.178) argues that

> ’The strongest form of power may well be the ability to define social reality, to impose a vision of the world. And such visions are inscribed in language.’

Lakoff (1995) refers to the process of maintaining power over the making of meaning as ‘interpretative control’, a notion which bears some similarity to Foucault’s concept of ‘epistemic sovereignty’. Lakoff (1995; p33) argues that the relationship between language and power can be noted in the Bible in the book Genesis, when

> ‘Adam’s distinction from all other creatures (including Eve) is exemplified by the fact that he gets to name them: that is, to bring them under his control.’

1.2.3.2 Relationships between groups

We can see then that, from this perspective, the notion that language is a neutral tool that we use to simply reflect the reality that objectively surrounds us is seriously questioned. Instead, we have a view where language is heavily implicated in the construction of what it is that we think of as ‘real’, as well as determining the notions of knowledge and truth that purportedly help us evaluate claims made regarding what is real. Furthermore, this process occurs, necessarily, in a social milieu and the power relationships in the milieu are manifest in the ways in which language is used to construct particular concepts of reality. This process, argues Lakoff (1995; p29), is so insidious as to require our special attention to even notice it:

> ‘Interpretation of the less powerful by the more powerful has been taken for granted in this and many cultures for so long that it requires special awareness to notice it and novel responses to deal with it.’

Though Lakoff develops this argument in the context of consideration of gender relationships, it is clear that this concept can be extended to consider relations between any two groups where there is a power imbalance. Riggins (1997) has generalised this argument to relationships between majority groups and minority groups. Riggins argues that majority groups use discourses of identity to marginalise minority groups through the selection of vocabularies that seek to construct hierarchies, subordinations, and dominance in such a way as to disguise and mitigate the speaker’s or writer’s intent.

In terms of social relationship between groups, of particular concern to this thesis is the relationship between mental health professionals and clients. It would seem difficult to deny that a power differential exists between these two groups, clearly in favour of the professionals. White (1991) argues that professional disciplines have been successful in the development of language practices and techniques that imply that it is only those disciplines that have access to the ‘truth’ of the world. One consequence of this is to make it difficult for others (in this case clients of a mental health service) to challenge these global and unitary knowledges.

Having considered this issue of language and power thus far largely in general philosophical and sociological terms, I would now like to look at this issue at the level of the individual, specifically in the area of mental health. Froman (1992; p.97), discussing how individuals may find it difficult not to adopt the language terms which serve the interests of more powerful groups in society, argues:

> 'Talking in ways that others talk is to allow others to exercise power over us – seeing our lives in their terms is to give them power to use their ways of seeing things to understand, give meaning to, and to make knowledge of our lives.'

However, Froman recognises that this tendency of adopting the terminology of the powerful groups is a consequence of the relative powerlessness of the minority group. Again, discussing this in linguistic terms, Froman (1992; p.97) notes

> 'Most people (are forced to) live in language-poor worlds, and when they attempt to make explicit their language "enrichments", their alternative realities and meanings, they encounter the resistance of power.'

Thus, Froman acknowledges that there are very real constraints in place which make it difficult for individuals to be the 'author' of their own experiences, and that the language of the dominant group may come to permeate the language worlds of the minority or oppressed groups, even when it does not reflect the interests of those groups. A more thorough discussion of the socio-political factors involved in limiting the power available to certain groups and individuals and some of the psychological sequelae of this is found in Smail (1993).

Shotter (1981) has argued that whether or not one is able to be the author of one's own experience is more than just a psychological or sociological issue. He argues that 'authoring' should be thought of as a moral right. Shotter (1981; p.278) proposes that:

> 'In a moral world, no one but the person in question has the status, the authority, under normal conditions, to decide what his experience means to him.'

Shotter (1981; p.279) further argues that this right is a central part of autonomy and that 'authoring' extends not only to establishing for oneself what one's experience means but also being able to share this understanding with others

> ‘To be autonomous...is to be accorded the right of expressing one’s self, of telling others one’s thoughts, feelings, and intentions, and the right to be accorded their author.’

This theme is echoed by Lakoff (1995; p.33) who states that ‘To be denied the ability to name oneself or one’s context is to be deprived of self-knowledge, and of full consciousness.’ These issues relating to ‘authoring’ are of considerable importance in the present study, and will be returned to later (in the Results section and the Discussion) as ‘authoring’ is one of the prominent themes to have emerged in the present research from analyses of how clients discussed their experiences.

One consequence of not being able to define and describe one’s own experience is what Roberts (1999) has referred to as the ‘silencing’ of the individual’s story, or aspects of this story. By this, Roberts means that there may be certain aspects of the individual’s experience which might be difficult, or even impossible to ‘story’. Roberts (1999; p17) discusses this issue with particular reference to traumatic experiences when he states that ‘For some, the issue is not that a story is fractured, mysterious or lost, but that it cannot be spoken’. Roberts (1999; p.17) goes on to argue that ‘Silencing seems part of all traumatising or abusing experience’.

Though there may be many social factors (such as power relationships) as well as psychological factors (defence mechanisms) which contribute to the ‘silencing’ of particular stories or aspects of stories, it may be, as anthropologist Edward Bruner (1986) suggests, that some experiences are of such a nature that rendering them meaningful is difficult. That is, the experiences may lie beyond the limits of language and may therefore be something about which it is difficult or impossible to talk. This notion harks back to Wittgenstein’s (1922) famous dictum ‘Whereof one cannot speak, thereof one must remain in silence’. Both E. Bruner (1986) and Wittgenstein (1922) seem to be suggesting that there are certain ‘natural’ limits to what can and cannot be said in language.

This Wittgensteinian notion of that which cannot be said has been explored more recently by E. Bruner (1986; p.6), who has pointed out that however we view our storytelling processes:

> ‘Some experiences are inchoate, in that we simply do not understand what we are experiencing, either because the experiences are not storyable, or because we lack the performative and narrative resources, or because vocabulary is lacking.’

Bruner seems to be making the point that it may be a function of the limits of a particular language, or conversational practice, that makes it difficult or impossible to story certain aspects of experience. That is, there is a suggestion that it is somehow within the ‘natural’ limitations of a language that certain things cannot be said. This position appears not to acknowledge other factors, such as power relationships, which may influence what can, and cannot, be said in a particular language. From a Foucaultian perspective we might argue that the limits of language are determined, at least partly, by political and social factors. That is, even if we agree that language determines the limits of what can and cannot be said (which appears tautological) we may also want to argue that what language leaves unsaid is that which is most challenging to the powerful groups in society. Thus, certain experiences, and certain ways of talking about experiences, may, in Foucault’s terminology be ‘subjugated’. One such area where we might expect this to occur is in the area of mental health.

1.2.3.3 Narrative competence

Another perspective on the ‘silencing’ of those stories which challenge the dominant discourse, which is of particular relevance to the present research, proposes that ‘narrative competence’ is a prerequisite for telling one’s story (Prince, 1983). Narrative competence refers to the capacity of the individual for giving a full and coherent account of his or her experience. Some researchers have suggested that this may be compromised in schizophrenia, particularly where there is evidence of thought disorder and negative symptoms and that, as a result, those with schizophrenia may struggle to generate a coherent narrative (Lysaker, Whitaker & Davis, 2005). While this may be true for a sub-group of those with a diagnosis of schizophrenia, it is not, as I believe the present, and other, research shows, true of all of those who have this diagnosis. Participants in the present research, as well as numerous other research studies, clearly demonstrate ‘narrative competence’ sufficient to express their experience. So, while this may contribute to some of the difficulties those with this diagnosis have in expressing their narratives, it is not, I believe, sufficient to explain the 'silencing' of these narratives.

1.3 Storytelling, power and mental health

The notion of storytelling and attention to the power dynamics involved in constructing stories, leads us to ask questions relating to how it is that experience is 'storied' in the mental health arena, and whose interests are best served by these stories. By far the most dominant approach to conceptualising mental distress, in the Western world at least, is the diagnostic, medical framework. In essence, this approach rests on the notion that mental distress is, in principle, no different from other illnesses, in that it consists of particular groups of symptoms, which have particular causes, courses, and underlying pathologies, such that distinct conditions can be identified and labelled by trained clinicians. Diagnosis is now ubiquitous, in the Western medical world, so much so that in certain countries mental health care will only be provided if the individual is deemed to warrant a recognised diagnosis based on standardised diagnostic criteria. The specific diagnostic categories of particular relevance to this thesis will be discussed in the chapter 2. Here, more general issues pertaining to categorisation within mental health will be considered.

1.3.1 Categorisation and mental distress

While there have been some criticisms directed at any attempts to impose any form of classificatory system in the area of mental health, it seems to me that these criticisms are somewhat misguided. Classification is a necessary and inevitable aspect of trying to make sense of the world. As Bowker and Starr (1999; p.131) point out in their excellent overview of classification 'To classify is human and all cultures at all times have produced classification systems.' However, arguing that the process of classifying is inevitable does not mean that any classification system is therefore somehow 'natural' or 'transparent'. On the contrary, as Bowker and Starr (ibid) argue 'There is no such thing as a natural or universal classification system.' Echoing the position of Foucault, Bowker and Starr (1999; p5) point out that classification systems reflect particular ways of organising reality, and may promote one particular perspective and set of interests at the same time as 'silencing' other possible perspectives:

> ‘Each standard and each category valorizes some point of view and silences another. This is not inherently a bad thing – indeed it is inescapable,’

Bowker and Starr argue that while classification *per se* is natural and inevitable (and, as a requirement for survival, is ‘hard-wired’ into the brain), the particular classification system that we create or adopt will organise reality in a way that serves some purposes better than others. Any classification system will have implications for what we can and cannot say, and will reflect and express the interests of some, while silencing those of others. Bowker and Starr (1999; p.47) note that larger scale, more established classification systems may become ‘invisible, erased by their naturalization into the routines of life’. That is, as a classification system becomes more established, it may be less obvious that is it just one way of classifying phenomena, its historical roots become obscured, and proponents claim that this system is a ‘natural’ reflection of how reality is. This serves to strengthen the classification system and to silence or exclude other possible ways of classifying the phenomena under investigation.

Such a process is apparent in the area of mental health care, where there are powerful interests at stake, a fairly well-established system of categorisation operates and, commonly, claims are made that diagnostic categories are reflections of ‘reality’, rather than being a constructed classification system created as one way of navigating one particular aspect of the world (mental distress). Such claims may serve to obscure the socio-historical contributions made to such classification systems, as well as hiding whatever vested interests of which the classification system may be an expression.

In the area of mental health, diagnosis has never been free of controversy. It may be, as I will argue in chapter 2, that mental health and mental illness are notions that are *intrinsically* subject to disagreement and debate. Whether or not one accepts this, it is clear that there is some controversy in this area and challenges to the medical classification of mental health problems permeate the literature (see Bentall, (2003), Boyle (1990) and Read (2004) for examples of challenges to the medical approach to mental distress).

In addition to disagreements relating to the particular diagnostic classification system adopted in the area of mental health care, there has also been debate around the value of classifying such distress as being part of 'health'. This argument was made most forcefully and famously by Thomas Szasz (1961) who questioned whether or not psychological distress should be viewed in medical terms (and hence challenged the basis upon which diagnoses rest). While a full coverage of this debate is beyond the scope of the present thesis, I tend to agree with aspects of the position of Mindham, Scadding and Cawley (1992; p.161), who, in response to Szasz (1961; 1991) suggest:

> 'For logical and scientific reasons a nosology of disease (or a taxonomy of behaviour) is essential. Without categories or dimensions, there could be no order and no progression in our field of study and practice; we would be doomed to slosh around in impressionistic garbage.'

However, accepting that we may need some nosology or taxonomy, does not compel us to accept that this must be medical in its orientation. In terms of our discussion above on language and power, we can view diagnosis as, among other things, an attempt to enforce one particular way of viewing and talking about experience. It is also worth noting that diagnosis is done by the clinician rather than the client, and so, from Foucault's perspective, is likely to reflect more the interests and perspective of the clinician than those of the client. We can see that issues such as those raised above by Shotter (1981), regarding the moral right to define one's own experience, are called into question through the practice of diagnosing. We can see also that power relations between clinicians and patients are highlighted by this process. As Froman (1992; p.44) has argued 'To see people as schizophrenics requires the continuous application of power over language use.'

O'Hagan (1986), an ex-service user now employed as Mental Health Commissioner in New Zealand, discusses client-clinician relationships and power dynamics in a more general sense. She relates her experience as a consumer of mental health services attending a mental health conference, where she found the voice of the patient effectively silenced through the dominance of the voice of the clinicians attending the conference. O'Hagan (1986; p.32) speaks about the personal experiences of psychiatric patients as having been 'seized by the reality regulators and put under lock and key in seclusion'.

O'Hagan (1986) discusses this exclusion of the voice of those who have first-hand experience of mental health problems from a conference on mental health as being both somewhat ironic and reflecting the interests of those who controlled the conference, in this instance mental health professionals. She relates her discussion to different ways of knowing, arguing that clients, by virtue of their first-hand experience of mental health issues, come to know differently from how those who have no such experience. O'Hagan sees this 'silencing' as a form of oppression, which rather than being unique to such conferences, permeates much of society, where the 'way of knowing' that consumers of mental health services have is devalued. Though she regrets that this way of knowing was largely excluded from the conference (and from society in general), she nonetheless goes on to suggest that there may be advantages to belonging to an oppressed group, because, as she states, 'The oppressed are free to know differently.' (O'Hagan, 1986; p.40)

1.4 Personal Knowing

O'Hagan (1986) has drawn our attention to an important distinction that can be made in the realm of knowledge. This is the distinction between first-hand or personal knowledge and distant 'objective' knowledge. This distinction is of great importance to the current research, where clients' first-hand personal accounts of their experiences are investigated. As such, a brief discussion of this form of knowledge is warranted. Though Berlin (1969) coined the term 'indigenous knowledge' to refer to the first-hand knowledge that participants in an activity maybe claim to possess, I prefer the term used by Polanyi (1958), 'personal knowing', as this emphasises the personal nature of this knowledge.

Though within the scientific and philosophical literature, there is greater attention given to 'objective' knowledge, there is nonetheless a reasonably well-developed literature on this other form of knowing which emphasises the role of personal experience. An early advocate of the view that there may be more than one form of knowledge, or one way of knowing, was Giambattista Vico writing in the 18th century. In his *magnum opus* Scienza Nuova, Vico (1968) developed the notion that there are different ways to come to know something, and that full knowledge can only be achieved through acquaintance with what Vico refers to as 'causes' of experience. What Vico meant by this was that we can know a thing fully only if we know why it is as it is, or how it came to be, or was made to be as it is, and not merely *that* it is. Vico's main concern was to show that human phenomena are accessible to us in a way that natural phenomena are not, as a result of our personal experience with human phenomena. Thus, for Vico knowledge of the external world differs from knowledge of the world of our own experience in that we can know more about our own and other people's experiences than we could ever about non-human aspects of the world. Vico argues that this *personal* knowledge is in fact superior, by virtue of our being more acquainted with the 'causes'. The point that Vico is making is, as reframed by Berlin (1976), that those who make or create something can understand it in a way that mere observers cannot.

Vico's approach to knowledge has been resurrected in more recent times by writers such as Buber (1975) and Polanyi (1958; 1966). Buber (1975) drew a distinction between two different ways of approaching experience, which he referred to as immediate lived experience and mediated experience and he argues that real knowledge can be attained only through living experiences with things. Common to the writings of both Buber and Polanyi is the notion that personal knowledge is more fundamental than, or 'prior to', objective or distant knowledge. Polanyi (1966; p.20) argues that scientific or objective knowledge rests upon tacit knowledge and that any attempts to rid knowledge of its personal component are doomed:

> 'Suppose that tacit thought forms an indispensable part of knowledge, then the ideal of eliminating all personal elements of knowledge would, in effect, aim at the destruction of all knowledge.'

Polanyi goes on to argue, like both Buber and Vico, that to fully understand something we must have some appreciation of this personal side of knowledge 'It is not by looking at things but by dwelling in them, that we understand their joint meaning.' If we accept the views expressed above by Vico, Buber and Polanyi, then it follows that we must see those who have first-hand lived experience of any particular phenomena as having crucial knowledge about that phenomenon. Further, we would be obliged to accept that any attempts to develop an understanding of these phenomena that excludes, or largely ignores, this first-hand lived experience will be incomplete.

Translating these arguments into the area of health care, we would be in a position where we would see the lived experience of those who have had mental health difficulties, such as psychosis, as being a crucial component of our understandings of those phenomena. I want to argue that this is in fact the case: that a fuller understanding of any experience is possible only if the first-hand lived exposure to the experience is taken into account. In this research the particular experience investigated is that of ‘psychosis’, to which I will now turn my attention.

2. Professional understandings of 'madness'

In this chapter I will consider professional and clinical approaches to developing a nosology of 'madness'. In particular, I will focus on two of the main and closely related nosological terms used by mental health workers and researchers in this area: 'schizophrenia' and 'psychosis'. The notion of 'schizophrenia' is, arguably, one of the cornerstones upon which the current dominant nosological system rests (Kendall & Gourley, 1970). It is a central component of mental health care, and an important social issue. Estimates of the social costs of schizophrenia have suggested that the direct health care costs of schizophrenia in Western countries lie between 1.5% and 3% of total health care budgets, with indirect costs (such as loss of productivity, and other social costs) being three or more times greater than the direct costs (Knapp, Mangalore & Simon, 2004; Lindstrom, 1996). Gunderson and Mosher (1975) estimate that the total costs of schizophrenia in the USA may be as much as 2% of the gross national product.

As a thesis investigating how it is that clients come to understand their experiences, it may seem somewhat contradictory that professional understandings of mental distress should be given such prominence. This is a tension which is impossible to avoid completely. Systems of categorising clients' difficulties (according to criteria developed by professionals rather than by clients themselves) are ubiquitous in mental health care and research. Indeed, the participants in the present study have already been subjected to such a categorisation: they are clients of a 'first episode psychosis' service, and as such must have reported experiences that meet the definition of psychosis as used by mental health services. Given that clients' experiences have already been categorised in this way, it is essential that we have some knowledge of the system of categorisation that has been used and the meanings of the main diagnostic terms.

2.1 Schizophrenia and psychosis

The main diagnostic terms used to refer to the kinds of experiences that clients of the present study report are 'psychosis', and 'schizophrenia' (in more common parlance, a term such as 'madness' or 'insanity' may be used; these terms will be used largely interchangeably in this thesis). Although other diagnostic terms (such as 'bipolar disorder', 'manic depression', 'schizophreniform disorder', 'schizoaffective disorder' and 'psychotic depression') are used, less commonly, these will not be explored in any great depth here. 'Schizophrenia' and 'psychosis' are the most commonly used diagnostic terms in referring to the kinds of experiences reported by clients who participated in the current study. Also, schizophrenia can serve as exemplar of current diagnostic thinking and practice in the area of mental health.

2.1.1. Historical factors

It seems reasonable to assume that attempts to make sense of strange or unusual behaviour have long been a feature of human societies. Indeed, as Read (2004b) shows, there is evidence of such efforts in many ancient writings, including Mesopotamian text and religious tracts such as the Old Testament. Inevitably, such accounts of madness reflect the culture of the time, with magical and spiritual explanations being commonplace, although more biologically based explanations are apparent in the writings of the ancient Greeks (Read, 2004b). Read suggests that accounts of madness reflect not only the cultural perspectives of the times, but more particularly the interests of specific, powerful groups within the society.

Our current nosology of madness is a relatively recent innovation, having its origins in the 19th century, when a shift towards a more medical approach developed. This shift reflects general changes that were occurring at this time within medicine, with the development of specific disease concepts. In an overview of concepts of madness used in the Western world prior to the 19th century, Sedler (1991) notes that there are particular difficulties in comparing retrospective accounts of 'madness' with more recently developed concepts such as 'schizophrenia'. The difficulty lies in the uncertainty regarding the terminology used, which has only recently come to be operationalised. Sedler (1991; p.48) states that 'The prehistory of schizophrenia is nothing less than the history of insanity prior to the mid-19th century.' He goes on to argue that the first coherent description of what later came to be termed 'schizophrenia' can be found in Haslam's (1809) treatise on madness. Clearly, one of the advantages of having a more explicit and operationally defined nosology of madness is in making comparisons across different times and places possible. We can trace the beginnings of our current nosology of madness to the work of Emil Kraepelin (1919).

Kraepelin, writing in Germany in the late 19th Century, broke down the unitary notion of 'insanity' into two distinct disorders: manic-depression and dementia praecox ('senility of the young', Bentall, 2003; p.15). Kraepelin made this distinction based on different symptom clusters which he considered characteristic of each condition. Manic-depression was characterised primarily by gross disturbances of mood (euphoria, grandiosity, and pressure of speech), whereas dementia praecox was characterised by a wide range of symptoms, such as catatonia, stereotyped behaviours, problems of attention, and unusual perceptions. The common thread to these symptoms, in Kraepelin's mind, was the deterioration of intellection functions. Though he considered these to be distinct and unitary disorders, he later proposed subtypes of dementia praecox including the catatonic type (characterised by motor retardation), and the hebephrenic type (characterised by incongruity). In Kraepelin's view manic-depression was associated with a more optimistic prognosis, whereas dementia praecox was considered to lead to inevitable and irreversible deterioration.

Eugene Bleuler (1857 – 1939) took up and developed Kraepelin's concept of dementia praecox, within a paradigm influenced, initially at least, by Freudian theory. Bleuler suggested that the common denominator of the various subtypes of dementia praecox was the 'breaking of associative threads' which were deemed to hold thoughts, emotions and behaviour together (Birchwood, Hallett & Preston1988; p.16). Bleuler attributed this breaking of associations to intra-psychic conflicts. Somewhat at odds with the pessimistic Kraepelinian view, Bleuler rejected the term dementia praecox in favour of his own neologism 'schizophrenia' (derived from Greek 'skhizo', split, and 'phren', mind), a term first used by Bleuler in 1908 (Barham, 1995). Ultimately, Bleuler's term and concept came to usurp Kraepelin's notion of dementia praecox. Unlike Kraepelin's pessimistic position, Bleuler's view created a basis for a psychotherapeutic approach, and recognised considerable variability in outcome, with many patients recovering from the condition. According to Barham (1995), Bleuler's position came under overwhelming criticism which led to Bleuler moving away from Freudian theory and closer to organic psychiatry.

Despite the fact that there have been continual modifications to the definition of schizophrenia, with an even wider variety of developments in attempts to explain and treat schizophrenia, the basic notion of schizophrenia has remained largely intact, though certainly not unchallenged, since the time of Kraepelin and Bleuler.

2.1.2. Current definitions: schizophrenia and psychosis

The current operational definition of schizophrenia which is most commonly used in clinical settings and in research is to be found in the American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders, DSM IV-R, (APA, 2000). This manual uses what has been referred to as a 'Chinese menu' approach to diagnosis (Bentall, 2003; p.60), where a specified number of symptoms from a set list are required for a diagnosis to be made.

In the DSM IV-R, Schizophrenia is defined as the presence of any two from a list of five 'characteristic symptoms': delusions, hallucinations, disorganised speech, grossly disorganised or catatonic behaviour, and negative symptoms (such as affective flattening, or avolition). The two symptom requirement is dropped under certain conditions, namely if the delusions are considered 'bizarre' or if the hallucinations are of a particular type (that is voices providing a running commentary on the person's behaviour or voices conversing with one another). In addition, importance is given to the duration of the symptoms and any loss of function; some disturbance must be apparent for 6 months (including at least one month duration of the symptoms listed above) before a diagnosis can be made. The manual also lists a range of sub-types of schizophrenia (e.g. paranoid, disorganised, simple).

Investigations into the prevalence of schizophrenia have yielded inconsistent results. Though some have argued that the prevalence of schizophrenia is consistently and cross-culturally found to be around 1% (British Psychological Society [BPS], 2000; Carpenter & Buchanan, 1995; Sartorius, Jablensky & Korten, 1986), other studies (as reviewed by Read, 2004a) have found quite different prevalence rates, thus casting doubt on the claims to uniform frequency. Among the very few findings in the literature on schizophrenia about which there is any genuine consensus, is the repeated finding that it is in late teens and early 20s that a diagnosis of schizophrenia is most likely to be made, with onset commonly being a little earlier for men than for women (Hafner, Maurer, Loffler & Riecher-Rossler, 1993; Harrop & Trower, 2003).

The term ‘psychosis’ has generally been less clearly defined than schizophrenia. Like schizophrenia, how the term has been used has varied over time. In the 1970s, ‘psychosis’ (meaning ‘out of touch with reality’, or ‘un-understandable’) was contrasted with ‘neurosis’ (which implied understandable, and recognised by the individual as a problem). This psychosis-neurosis distinction formed the bedrock of the diagnostic framework of the time (Bentall, 2003; p.38). The DSM IV-R uses the term ‘psychoses’ to refer to a range of symptoms which vary across diagnostic categories. Somewhat oddly, and rather confusingly, the term has slightly different meanings depending on which particular diagnosis it is being used with. For example, in schizophrenia (and other closely related diagnoses), ‘psychosis’ refers to hallucinations, disorganised speech or behaviour, whereas in delusional disorder, ‘psychosis’ is (tautologically) equivalent to ‘delusional’. Not surprisingly, given its lack of a clear operational definition, the term psychosis is much less commonly used in research than are diagnostic terms such as ‘schizophrenia’.

Despite (or perhaps because) of the relative looseness with which the term psychosis has been used, it does seem to have found favour among certain clinicians and researchers, who may, for quite different reasons, be critical of the diagnostic approach favoured by the APA. For example, the recent influential report by the BPS (2000) recommends the use of the term psychosis, rather than schizophrenia, arguing that psychosis is a less pejorative term, which can be used to cover a whole range of unusual perceptions and beliefs. Figures relating to the incidence of psychosis suggest that around 3% of the population will have psychotic experiences of one sort or another which leads to involvement with mental health services, although as recent studies have shown, many people who have psychotic experiences never come to the attention of mental health services (Bak et al., 2003).

Whatever terms we may use, and whatever reservations and criticisms may be levied at those terms it is important that we do not lose sight of the fact that ‘madness’ is a significant and often highly distressing condition for the individual and for his or her family. Also, as noted above the social and health implications of schizophrenia are considerable. This is reflected in a Science editorial stating quite bluntly that ‘schizophrenia is the worst disease known to man’ (from Carpenter & Buchanan, 1995).

2.2. Conceptual difficulties with ‘schizophrenia’

In addition to the lack of a consensus regarding some of the basic statistical, demographic and epidemiological data relating to schizophrenia, the concept itself has been subject to strong criticism from a range a quarters and for a variety of reasons: ethical, scientific and clinical. These will now be considered.

2.2.1. Ethical challenges to schizophrenia

An ethical challenge to the very concept of ‘mental illness’ as well as to more specific notions such as ‘schizophrenia’ was put forcefully by American psychiatrist, Thomas Szasz. Szasz (1961; 1991) argued that, from an ethical position, using a medical framework to conceptualise behavioural difficulties was unjustified and unhelpful. He argued that mental illness itself is a myth which obscures important ethical considerations (such as personal responsibility for behaviour), and which serves to bolster the claims of the medical profession that these problems lie within its jurisdiction. A similar case was made by Bannister (1968), who argued that some of the problems inherent in the concept of schizophrenia derived from a doomed effort at extending a medical framework to conceptualise human behaviour:

> ‘It seems likely that the logical confusions inherent in the concept of schizophrenia are one side-effect of the general attempt to subsume behavioural disorders under a framework imported from medicine.’

2.2.2. Scientific challenges to schizophrenia

In addition to ethical questions, serious doubts have also been expressed regarding the scientific standing of the concepts of schizophrenia and psychosis. A clear exposition of this case is also found in the work of Bannister (1968), who proposes that schizophrenia is what he termed a ‘disjunctive concept’, which makes it of little utility to scientific investigations, resting as it does on a ‘Chinese menu’ type criteria for definition. In the case of schizophrenia, this relates to the ‘any two from five’ characteristics as adequate to make a diagnosis, making it possible for people who share none of the five criteria to be grouped together under the same concept. Bannister (1968; p.181) argues that such a concept does not meet the basic requirements to be considered scientific:

> ‘Schizophrenia, as a concept, is a semantic Titanic, doomed before it sails: a concept so diffuse as to be unusable in a scientific context.’

Bannister's argument has been echoed more recently in the work of psychologists such as Richard Bentall. Bentall, Jackson, and Pilgrim (1988) point out that nearly every variable known to affect human behaviour has been proposed to account for schizophrenic breakdowns. They suggest that the concept be abandoned on the grounds that it does not meet basic requirements for a useful scientific construct because it does not satisfy the basic requirements of 'validity' and 'reliability'. The literature relating to the reliability and validity of schizophrenia has been critically reviewed by, among others, Read (2004a), Bentall (2003) and Boyle (1990) who conclude that the concept of schizophrenia is not a valid scientific concept, but little more than an article of faith. Boyle (1990) argues, quite bluntly, that schizophrenia is a 'scientific delusion' which hinders rather than helps understandings and ways of working with 'madness'.

Though criticisms of medical concepts such as schizophrenia are perhaps to be expected from a psychological position, the notion has also come under fire from within psychiatry itself. A recent overview of the past century by one of the foremost psychiatrists in the field of first episode psychosis and schizophrenia, McGorry (1995), pointed out that

> 'It may be sobering to be reminded that "chlorpromazine has turned forty", but it should prompt great concern that the concept of dementia praecox is about to turn 100 without any fundamental change.'

McGorry (1995), echoing Read, Bentall, Boyle and Bannister, argues that the basic categorical model upon which the concept of schizophrenia is based, may in fact be an obstacle to scientific and clinical progress:

> 'The binary model has failed to contribute to any significant clarification of the underlying substrates of psychotic disorder. Indeed, it is likely that its rigidity has inhibited progress in helping to create a "logjam" of confusing research findings.'

2.2.3. Clinical challenges to schizophrenia

The practical and clinical utility of the notion of 'schizophrenia' has also been called into question. From a largely medical perspective, psychiatrists such as McGorry (1994; 1995) point out that within the first few years of a client's presentation to mental health services, there is considerable diagnostic instability, rendering diagnoses like schizophrenia less helpful at this stage. These combined factors led McGorry to propose that the more general term ‘psychosis’ should be employed, rather than schizophrenia, at least in the initial phases of treatment.

Another argument used against the term ‘schizophrenia’ relates to the stigma which has come to be attached to the term, and hence to the person so diagnosed (Link, Struening, Neese-Todd, Asmussen & Phelan, 2001; Sayce, 2000). Birchwood et al. (1988) point out that

> ‘The concept of schizophrenia has become so cemented within the psychiatric (and lay) vocabulary that the label has become attached to the person as well as the disease.’

McGorry’s position, favouring the use of a broader term, such as ‘psychosis’ over ‘schizophrenia’, has gained some support within the clinical and research fields in recent years, evidenced by the fact that specialist services set up to meet the needs of young people presenting with these difficulties have adopted the term ‘psychosis’ in preference to ‘schizophrenia’. Similarly, the report by the BPS (2000) also endorses the use of the term psychosis in favour of schizophrenia. This report defines ‘psychosis’ as:

> ‘An umbrella term for unusual perceptions (e.g. hearing voices), or unusual beliefs. In both cases other people sometimes see the person as to some extent out of touch with reality.’

This report acknowledges that the term psychosis is problematic, though preferable to the concept of schizophrenia, which the authors argue carries with it excess pejorative baggage. Thus, while the term psychosis is perhaps less clearly defined than schizophrenia, it is viewed more favourably because it is considered to have fewer negative associations and less of the historical baggage that comes with schizophrenia. Further, perhaps because the term psychosis is a more general term, which is less clearly defined as a particular condition or syndrome, this, somewhat paradoxically, allows greater attention to be given to the individual symptoms which are subsumed under the heading ‘psychosis’.

It is perhaps not surprising that such an approach finds favour among clinical psychologists, among whom there is a tradition of advocating an approach which focuses on individual symptoms (such as hallucinations, or delusions) rather than putative syndromes (such as schizophrenia or manic-depression). The philosophical and clinical justifications for such an approach are articulated clearly in a classic paper by Persons (1986), and reiterated by Costello (1992).

However it is important to note that the term ‘psychosis’ is certainly not free of negative connotations, being associated with such lay terms as ‘psycho’, which clearly carry pejorative associations. It would be inaccurate to claim that the term is free of any historical baggage whatsoever. Interestingly, the term ‘psychosis’ is reported by Barham (1995) as having originally been used by alienists in the first half of the 19th century, thus giving it a longer history than the term schizophrenia. An example of some of the baggage that comes with the term is to be found in Jasper’s (1962) influential contention that a defining feature of psychosis is that it is fundamentally ‘un-understandable’ and therefore not amenable to psychological intervention.

Thus, we can see that at least some of the criticisms levelled at ‘schizophrenia’ may be equally applicable to ‘psychosis’. Both terms have dubious scientific credentials, they derive from an historical epoch when views of madness were somewhat pessimistic regarding the possibility of recovery, and both have generally negative connotations, often being rejected by patients and clinicians alike.

An interesting contribution to the debate around the issue of diagnoses is made by Gergen and McNamee (2002), who suggest it is useful to consider whose interests are best served by making a diagnosis. More specifically, they suggest that the single most important question is, simply: is the client helped by being classified? They conclude that generally this is not the case, with the drawbacks of being diagnosed outweighing the advantages. The specific drawbacks of being classified that they refer to include the client being disempowered as authority over his or her experience is taken by the ‘expert’ clinician.

2.3. Theories of madness

Having considered some of the conceptual limitations of the concepts of schizophrenia and psychosis, I will now explore some of the literature relating to the possible causes of ‘madness’. While, by and large, theorists have used more formal terms such as ‘schizophrenia’ and, less often ‘psychosis’, given the criticism outlined above, my contention is that we can view these as attempts to make sense of, or explain, ‘madness’. My purpose here is not to provide an exhaustive or comprehensive overview of the literature in this field. Rather, I hope to illustrate the fact that a vast range of theories has been proposed to account for what ‘madness’ really is. My primary concern here is to draw attention to the extent and variety of theoretical explanations that have been, and continue to be, propounded as accounts of what schizophrenia is. As such, I am less concerned with the empirical evaluation of these theories. Suffice it to say, that each theory does have an evidence base which proponents of the theory call upon to support the theory. Of course, from a scientific perspective, the evidence base of a particular theory is of critical importance. What is clear though is that, at the present time (and, since the introduction of the concepts of psychosis and schizophrenia), there is no single theoretical account which has satisfied the needs of the multitudes of researchers and clinicians working in this field. My intention here is merely to illustrate the debate and disagreement which, I believe, typifies this area, not to make a case for adopting any one particular theory.

An interesting historical and local New Zealand perspective on the causes of madness can be found in the 1901 annual report of Lunatic Asylums of NZ which lists the following as the causes of ‘insanity’, for those patients who, over the course of the previous year, had been incarcerated in mental health asylums in the Auckland area: accident, adversity, child-bearing and puerperal fever, cholera, climactic, congenital and hereditary, debility, drink, epilepsy, grief, ill-health, influenza, masturbation, overwork, privation and poverty, senile decay, solitude, sunstroke, syphilis, worry, and unknown causes. This is an impressive list of possible causes, suggesting a rather catholic conceptualisation of insanity in turn of the century New Zealand. In the early 1960s, a report by the Joint Commission on Mental Illness and Mental Health (1961) lamented that:

> ‘Hardly a year passes without some claim, for example, that the cause or cure of schizophrenia has been found. The early promises of each of these discoveries are uniformly unfulfilled.’

Here, we see precursors to Bentall, Jackson and Pilgrim’s (1988) argument that almost every variable known to affect human behaviour has been hypothesised to be a cause of psychosis. However, it is also clear that the particular variables posited as causal factors in madness change over time. This is consistent with Mary Boyle's (1990; chapter 2) position that concepts of madness change in parallel with changing ideas about people and their relationship to the environment.

While it may be true that a very wide range of variables has been implicated as having a causal role in psychosis, attempts have been made to impose some kind of order on the range of theories that have been considered as plausible explanations of madness. Siegler and Osmond (1966; p.1193), in their classic review of the dominant models of madness in use in the mid 1960s, begin with the blunt statement that 'Schizophrenia is disputed territory'. They argue that the then current theories of madness could be categorised as falling within one of six categories: medical, moral, psychoanalytic, family interaction, conspiratorial and social. These models are distinguished in terms of how they conceptualise a range of variables, including diagnosis, aetiology, treatment, prognosis, rights and duties of role of the patient, of the family and of society. Siegler and Osmond suggest that the different models may have uses in the provision of different services based on those models. While they acknowledge that there may be differing evidence bases for the different theories, they argue that it is factors *other* than evidence which determines which theory will be adopted in any particular clinical setting (Siegler & Osmond, 1966; p.1201):

> 'We strongly suspect that objective evidence is not the basis on which the models are accepted or rejected as programmes'

They suggest that other factors, such as how the model functions within a given clinical setting, the moral position of those involved in delivering the service, and the influence of a charismatic individual who promotes this way of working, are important determinants of which model will in fact be adopted in clinical settings.

It is my contention that Siegler and Osmond's (1966) description of schizophrenia as 'disputed territory' remains as true today as it was then. In fact, I will argue that being 'disputed' is an essential and integral aspect of concepts of madness. Before developing this argument further, I will first discuss some of the currently held theories of psychosis, which I have categorised (according to the primary emphasis of each theory) as biological, neuropsychological, psychological, psychodynamic, life event, sociological/anthropological, philosophical/existential, and spiritual. This categorisation is somewhat arbitrary, and for the sake of convenience, rather than reflecting clear cut distinctions in the various models of madness, with some theories incorporating elements from more than one of the domains.

2.3.1. Biological theories

Recent decades have witnessed something of a renaissance and a return to dominance of the biological paradigm in mental health, particularly in the field of psychiatry. However, even within psychiatry, this model of schizophrenia has not achieved universal acceptance, with some notable dissenting voices (for example, Breggin, 1991; Mosher, 2004; Szasz, 1991). Rather than a single biological theory of schizophrenia, what we find is a range of theories, which posit different biological factors as being implicated in the genesis of these experiences, including (but not limited to) genetic theories, biochemical theories, brain structure theories, neurodevelopmental and evolutionary theories.

Genetic theories of schizophrenia posit that there is a significant contribution to the aetiology made by inherited genetic factors. This viewpoint is based upon studies which show higher rates of schizophrenia found in the biological relatives of those with schizophrenia. These studies include simple family epidemiological studies as well as more sophisticated twin and adoption studies which endeavour to disentangle genetic and environmental contributions to schizophrenia. A sympathetic overview of this research is provided by Gottesman (1991), whereas Boyle (1990) and Joseph (2004) provide damning critiques, attacking the methodologies and conclusions of genetic arguments. Harrop and Trower (2003; p.23) occupy the middle ground in this often heated debate, when they suggest:

> 'The best conclusion to draw seems to be that, while there may well be a genetic component, it may be substantially smaller than many studies have estimated.'

Biochemical accounts of schizophrenia look to chemical factors within the brain as significant contributors to aetiology. These theories are sometimes stated with considerable conviction. Fujii and Ahmed (2004; p.714) support their neurobiological theory with the bold assertion that 'schizophrenia and other psychotic disorders are brain disturbances'. However, despite the apparent certainty of their claim, they then go to confess that whatever neurobiological circuits may be implicated in this are not at all well understood. They suggest that the 'success' of biological treatments is evidence in support of their theory. Whitaker (2004) and Ross and Read (2004) question this claim.

Among the biochemical explanations for schizophrenia, perhaps the most notable is the so-called ‘dopamine hypothesis’ (Carpenter & Buchanan, 1995). This theory proposes that schizophrenia is caused by an excess of the neurotransmitter dopamine, or of dopamine activity, in the brains of those with the condition. Evidence to support this theory is based on the effects of dopamine enhancing drugs (which may exacerbate symptoms) and dopamine inhibiting drugs (which have been found to diminish some symptoms). A critique of biochemical theories is provided by Read (2004c).

The structure of the brain (as opposed to the chemistry) has also been implicated by those with a biological leaning as having a causal role in schizophrenia. The predominant theory within this framework is the notion that enlarged brain ventricles are important causal factors of schizophrenia (Johnstone, Crow, Frith, Husband & Kreel, 1979). The evidence base for this theory is partly from post-mortem studies which have suggested that those with a diagnosis of schizophrenia do have enlarged ventricles. However, doubts have been expressed regarding the consistency of this finding as well as some of the oversimplified conclusions which have been reached (Chua & McKenna, 1995; Dean, 2000).

Recent years have seen the emergence of neurodevelopmental theories of schizophrenia, which seem to have acquired some dominance within biological conceptualisations of schizophrenia. Neurodevelopment theories posit that schizophrenia is the consequence of a subtle neurological defect, acquired early in life, which affects brain development and which manifests itself as the brain matures through the symptoms of schizophrenia (Bloom, 1993). This theory is distinguished from earlier neurological theories in that it proposes that the underlying biological defect is non-degenerative in nature. Evidence in support of this theory derives from studies which identify brain abnormalities in newly diagnosed patients that are similar to those found in those who have a longer history of schizophrenia, so lending weight to the argument that the neurological defect is non-progressive (Jaskiw et al., 1994).

Neurodevelopmental theories of schizophrenia are commonly differentiated into 'early' and 'late' theories, based on the assumed timing of the neurological insult. 'Early' theories implicate intrauterine or perinatal neurological deficits (Keshavan, Schooler, Sweeney, Hass & Pettegrew, 1998), whereas 'later' theories propose that this insult is acquired later in life, such as Feinberg's (1982) suggestion that exaggerated synaptic pruning during adolescence is the root cause of schizophrenia. Common to both sets of theories is the notion that schizophrenia is the expression of an underlying, non-degenerative neurological defect, which expresses itself with the onset of schizophrenia, possibly triggered, or amplified by environmental stressors. Pantelis, Yücel, Wood, McGorry & Velakoulis (2003) review the evidence for these theories, and conclude that the weight of evidence supports the hypothesis that:

> 'an early neurodevelopmental insult interacts with either normal or abnormal post-pubertal brain maturation to produce further (late neurodevelopmental) brain structural and functional changes'.

Read, Perry, Moskowitz and Perry's (2001) Traumagenic Neurodevelopmental theory (discussed below: 2.3.7) proposes that the neurological defect may result from early childhood trauma.

Another factor which has been implicated in the cause of psychosis is the use of illicit substances, with cannabis having been perhaps most researched in this area. Although drug use, is, of course, a complex behaviour involving more than simply the ingestion of a biological substance, as these theories tend to focus on the biological component of substance use (as opposed to sociological, or personality factors for example), I include them in this section. The notion most commonly expressed is that cannabis (or other substances) may act as a trigger for underlying predisposition or vulnerability (such as a neurodevelopmental defect). An association between cannabis use and psychosis is well recognised, but doubts regarding the nature and extent of this relationship have been expressed. Evidence to support this relationship is provided by Henquet et al., (2005). In a prospective study they found that, for vulnerable individuals, exposure to cannabis during adolescence and early adulthood increases the risk of subsequent psychosis, in a dose-response fashion. However, an earlier review by MacLeod et al., (2004) concludes that evidence of a relationship between cannabis use and psychological harm is inconsistent and less in extent than sometimes assumed. They suggest (p.1586) that whatever relationship may exist may be a non-causal association

> 'We found no strong evidence that the use of cannabis in itself has important consequences for psychological and social health.'

However, illustrating some of the uncertainty in this field, a recent review of substance use and by Thirthalli and Benegal (2006) concludes 'psychosis in the aftermath of substance abuse is fairly common.'

This does not nearly exhaust the range of biological theories that have been proposed. As noted in the BPS (2000) report:

> 'A complete list of all the factors that have been identified as potential causes of psychotic experiences would cover every aspect of biological functioning.'

By and large biological theories of schizophrenia endeavour to explain the condition with little attention paid to the *content* or social context of the individual's experiences. Though these theories are varied in their focus, they have a common thread of explaining schizophrenia in terms of purported biological pathologies of one sort or another.

As with all models of illness, there are clinical implications which derive from these theories. Biological conceptualisations of madness tend, not surprisingly, to be associated with biological treatment recommendations (such as medicine and electro-convulsive treatment). As such, these models have been criticised for being suspiciously close to the business interests of pharmaceutical industry (Mosher, Gosden & Beder, 2004) an issue also addressed by Sharfstein (2005), president of the American Psychiatric Association.

2.3.2. Evolutionary theories

Closely related to the biological theories, in that biological factors tend to be implicated, are the evolutionary theories. Horrobin (2002) argues that between approximately 80,000 to 140,000 years ago, in the evolution of *homo sapiens* there was a genetic mutation that was associated with increased creativity and imagination, giving rise to the development of artistic and technical skills which were central to the evolution of human societies. Horrobin (2002) proposes that this genetic mutation reflected a prototype of what we now know as schizophrenia, though in a much less pronounced (and much more positive) form than is now known. Horrobin suggests that the genes associated with schizophrenia are of considerable importance in our evolution, but that changes in diet have seen an amplification of the ‘negative’ phenotype of this genotype. Horrobin (2002) calls upon genetic analysis of prehistoric remains, as well as evolutionary biochemistry, in support of this theory.

Jaynes’ (1976) evolutionary theory proposes that the symptoms of schizophrenia (in particular voices) reflect a fairly recent stage in the evolution of human consciousness. Jaynes’ thesis is that the human mind has undergone a significant transformation over the past 4,000 years or so. He suggests that prior to the 2nd millennium BC, mind was ‘bicameral’ in nature, with a very limited capacity for self-reflection, with one’s own thought processes commonly being experienced as a ‘voice’. He proposes that schizophrenia is ‘at least in part, a vestige of bicamerality’ and that before the 2nd millennium BC, ‘everyone was schizophrenic’. Thus, from this perspective the symptoms associated with schizophrenia, were a normal aspect of the way in which the mind functioned 4,000 years or so ago. Those who experience symptoms such as voices, are not in the strict sense ‘ill’, but rather are simply manifesting an earlier state in the evolution of human consciousness.

A more recent theory of schizophrenia which also uses an evolutionary framework is that of Rudegeair and Farelly (2003) who propose that the symptoms of schizophrenia may be a form of dissociation between different psychological functions. They propose that integration of psychic functions is a relatively late evolutionary development and that it is also a function which is vulnerable to disruption by early childhood traumas. Thus, they suggest, childhood trauma may impair the individual’s psychic integration, leaving the individual with ‘dissociated’ states, which are, Rudegeair and Farelly (2003) suggest, the underpinning cause of schizophrenia.

2.3.3. Neuropsychological theories

A theory of schizophrenia which seems to cross the biological – psychological divide is that of Frith (1992; 1994) in that it endeavours to identify not only the purported biological substrate of the condition but also to delineate the associated impairments in information processing and representation. Unlike the biological theories, Frith’s theory pays considerable attention to the content of psychotic experience, aiming to develop a model which encompasses both the form and content of psychotic experience. Frith (1992) assumes that schizophrenia is a meaningful construct, which can be made sense of if we look to higher order cognitive processes, such as thoughts about thoughts ('metacognition' or 'metarepresentation'). Thus, Frith (1992; p.116) argues that:

> 'All the cognitive abnormalities underlying the signs and symptoms of schizophrenia are reflections of a defect in a mechanism that is fundamental to conscious experience. This mechanism has many labels. I shall use the term metarepresentation.'

Frith proposes that schizophrenia can be understood as the consequence of malfunctioning in the brain which leads to breakdowns in certain 'meta-representational' processes, such as the internal monitoring of actions and thoughts (Frith & Done, 1988). Frith (1994) is suggesting that the wide range of schizophrenic symptoms can be seen as resulting from a fairly narrow range of deficits or malfunctions in a few important higher-order psychological processes involved in the 'meta-representation' of information.

An important example of the kind of meta-representational processes that Frith (1994) hypothesizes is implicated in schizophrenia is what he refers to as 'theory of mind'. 'Theory of mind' includes the important social ability to infer what might be going on in other people's minds. Frith (1994; p.147) argues that malfunctioning of this mechanism could underlie apparently disparate symptoms of schizophrenia, such as thought disorder, flattened affect, and delusions.

> 'Many of the signs and symptoms of schizophrenia can be understood as arising from the impairments in processes underlying "theory of mind" such as the ability to represent beliefs and intentions.'

Frith (1992) proposes that we can view schizophrenia in general terms as a disorder of self-awareness, characterised by three principal meta-representational abnormalities which can account for all the major signs and symptoms. These three abnormalities, which Frith (1992) argues are biologically based, being located in the prefrontal cortex of the brain, are:

1. An impairment in willed action associated with an inability to generate spontaneous willed actions.

2. A defect in self-monitoring leading to an absence of awareness of one's own intentions.
3. A disorder in the monitoring of the beliefs and intentions of others.

Although there is some experimental support for some of Firth's notions (reviewed in Bentall, 2003; p.316-319), the biological underpinnings of the theory remain unsubstantiated, nor is there much in the way of clinical evidence to support the utility of this theory to guide treatment.

2.3.4. Psychological theories

I have categorised as psychological those theories which are based upon psychological models of functioning and which primarily implicate psychological processes in the aetiology and/or maintenance of these conditions (although I will discuss psychodynamic models in a separate section as, to some extent, they derive from a distinct intellectual tradition).

From an historical point of view, psychological approaches to psychosis, and in particular cognitive-behavioural perspectives, have blossomed in the last 10-15 years. However, prior to this recent resurgence of interest in psychosis, psychologists did show some interest in schizophrenia in the 1940s and 1950s, generally operating within a behaviourist perspective, for example, with the application of token economies in inpatient settings. There followed a period of relative neglect by psychologists of the so-called 'serious mental illnesses', such as schizophrenia, such that schizophrenia came to be referred to as 'behaviourism's lost child' (Bellack, 1986). With the advent of the cognitive revolution within psychology (Miller, 2003), so too there came a resurgence of interest in psychological approaches to research and treatment for psychosis and schizophrenia. This has been of particular note in the developing area of Early Intervention for Psychosis, where psychologists have played a pivotal role, in both research and clinical settings.

Psychological approaches derive from a quite different perspective from medical perspectives on human distress. In essence, the psychological framework tends to avoid the pathologising approach of medicine. Instead, psychologists draw more from understandings of normal human processes as a way to make sense of unusual or abnormal presentations such as we find in psychosis. Thus, to fully appreciate psychological approaches to psychotic experience it is first necessary to consider the important and distinct aspects of the psychological perspective.

Perhaps the most obvious difference between the medical and the psychological approach is at the level of conceptualisation. As has been noted earlier psychologists in particular have been critical of the assumption that human distress can be helpfully viewed through a medical framework which assumes that symptoms can be grouped together into putative syndromes such as ‘schizophrenia’ (for example, see Bentall 2003; Boyle 1990; Read, 2004a, 2004c). This antipathy between the very concepts of schizophrenia and psychosis, and the tenets of a psychological approach to understanding human behaviour and experience led psychologists to develop a quite different orientation in investigating madness. One such approach has been to look at if and how the experiences associated with ‘madness’ do in fact group together. For example, using cluster analysis, Liddle (1987) found that symptoms can be grouped together in three clusters: positive symptoms (hallucinations and delusions), negative symptoms (poverty of speech, low motivation, etc.) and cognitive disorganization (incongruity of affect, disorganized speech, etc.). This finding has been replicated in other studies (see for example, Toomey, Faraone, Simpson & Tsuang, 1998), although other researches have suggested the three factors could be further sub-divided (McGorry, Bell, Dugeon & Jackson, 1998).

Many, though not all (e.g., Birchwood et al., 1988) of those working within a psychological framework have rejected the syndrome approach inherent within the notion of schizophrenia, and have argued instead that there is more to be gained from investigating (and treating) psychotic experiences at the level of the individual symptom rather than at the level of a putative syndrome. This argument has been made most clearly by Persons (1986) and recapitulated by Costello (1992), both of whom outline a range of reasons for adopting such an approach. Issues of reliability and validity, which have plagued the concept of schizophrenia, are largely side-stepped by this approach which makes no *a priori* assumptions about how symptoms do, or do not, correlate.

The individual symptoms approach has proved a particularly useful paradigm for psychological research into psychotic experiences, such that it is now becoming the dominant model for such research. Another aspect of the focus on individual symptoms (which Bentall, 2003, suggests would be more accurately referred to as ‘complaints’, thus liberating the experience from the medical model), is that it is more consistent with the psychological assumption that these experience lie on a continuum with normal experiences, and hence that normal psychological processes are implicated in the aetiology and/or maintenance of these ‘complaints’.

Evidence to support this contention can be found in research, such as that by Strauss (1969), who demonstrated that both hallucinations and delusions are best thought of as points on a continuum with normal perceptions and beliefs, differentiated by factors such as degree of conviction and preoccupation with the experience. Similarly, research into the existence of hallucinations and delusions has found that such experiences exist more often than one might imagine (and that the medical model implies) in non-clinical populations. For example, Tien (1991) outlines research which suggests that one in ten people may experience hallucinations. Estimates for the prevalence of delusional beliefs in ‘normal’ populations, including research carried out in Dunedin, New Zealand (Poulton et al., 2000) suggest that as many as 20% of the population may meet criteria for holding delusional beliefs, although a large-scale Dutch study found only 3.3% of the population held ‘true’ delusional beliefs (van Os, Hanssen, Bijl & Ravelli, 2000).

An early example of a psychological approach to psychotic experiences is Don Bannister’s investigations into thought disorder, where he proposed that thought disorder can be understood as the consequence of someone having been ‘invalidated’ so often that they go out of the business of making testable (and hence disprovable) statements about the world, instead reverting to statements which are so loose in their meaning as to be impossible to disprove. (Bannister, 1960; Bannister & Fransella, 1966; Bannister, Adams-Webber, Penn & Radley, 1975). Despite this early research of Bannister’s it was some time before investigations of this nature became more commonplace for psychologists. Perhaps somewhat ironically given Bannister’s early work, thought disorder has been largely neglected in much modern research, where the ‘complaints’ of hallucinations and delusions have received far more attention. It is to these that I will now turn my attention.

2.3.4.1. Psychological theories of hallucinations

Bentall's theory of hallucinations (2003, chapter 14) is located firmly within the cognitive tradition in psychology where it is assumed that is not experiences in themselves which cause distress, but rather how the individual evaluates, or appraises, such experiences. Thus, the focus shifts from exclusive attention on the experience to the appraisal processes the individual uses to render the experience meaningful to him or herself. Bentall (2003; p.367) proposes that hallucinations are not, as is often assumed, the result of 'faulty' perceptual processes, but rather 'Hallucinations arise from an error of judgement rather than an error of perception.' The particular judgement implicated, according to Bentall, is the judgement about where an experience originates from - inside or outside the self:

> 'People who hallucinate make faulty judgements about the sources of their experiences, and it is for this reason that they mistake their inner speech or visual imagery for stimuli external to themselves.'

Bentall argues that ascertaining whether or not experiences are internally or externally generated is not something that is a 'given' of the experience; that is, experiences do not come with a label informing us of their source. Rather, Bentall suggests that identifying the source of experiences is a skill, which, like all other skills, develops over time, is subject to individual variation, and can fail under certain circumstances. This skill has been referred to as 'source-monitoring' (Johnson, Hashtroudi & Lindsay, 1993). This source-monitoring theory of hallucinations was supported by Garrett and Silva's (2003) study of the subjective experience of hallucinations, which found that clients' descriptions of hallucinations were congruent with this theory.

Bentall (2003) discusses a range of factors which are important components of the source-monitoring skill, including qualities in the individual (such as expectations and beliefs), aspects of the stimulus (such as how clear it is) and situational factors (such as the degree of urgency or danger involved). A hallucinatory experience is the outcome of failure in the application of this skill when an internally generated experience (such as inner speech) is misattributed by the individual to an external source, who will thus experience it as a voice. In his exposition of the theory, Bentall (2003, chapter 14) provides a detailed overview of research and clinical evidence which lends considerable support.

Other research which has investigated the role of the appraisals of experience in psychosis includes the seminal work by Romme and Escher (1989; 1993; 1996). In a series of investigations into the experience of hearing voices, Romme and Escher showed that these experiences are not always distressing to the individual. They found that an important determinant of whether or not voices would be distressing to the individual was the understanding, or 'explanatory model' (Kleinman 1988) that the individual had for such experiences. For example, those who viewed their voices as guides giving useful advice would be much less likely to experience associated distress than those who viewed their voices as manifestations of a powerful evil force. These findings are similar to those of Chadwick and Birchwood (1994) who point to the role of appraisals of omnipotence and omniscience of voices being associated with distress. This research illustrates the important role played by the client's understanding of his or her experience, a theme that will be discussed in chapter 6.

2.3.4.2. Psychological theories of delusions

As with the research on hallucinations, research in the area of delusions has been well summarised and synthesized by Bentall (2003). As is the case for hallucinations, delusions are seen largely as the product of normal information processing. In particular, processes involved in formation and maintenance of normal beliefs are seen as implicated in the formation and maintenance of delusions. Thus, in an earlier version of the theory we will consider below, Bentall (1994) states that:

> 'The reasoning biases exhibited by deluded subjects might be seen as amplifications of normal mechanisms for coping with threat.'

Bentall's theory of paranoid delusions has developed over a number of years, being modified and expanded in light of the growing body of research and clinical practice in this field. Bentall (2003) suggests that a range of cognitive processes may be involved in the development of paranoid thinking, including causal attributions that the individual makes about experiences. Bentall argues that paranoid people have a characteristic attributional style which renders them vulnerable to paranoia. Research by Bentall and others (Candido & Romney, 1990; Kindermann & Bentall, 1996) suggests that paranoid people have a tendency to make 'external personal' attributions for negative events. That is, they tend to blame negative events (such as not getting a job) not on situational factors (e.g., too many applicants) but rather on other people's deliberate actions (e.g., the government telling the employer not to offer the person a job). Although acknowledging some uncertainty regarding why some people may develop this particular tendency, Kindermann and Bentall (1996) suggest that it may have its origins, at least partly, in experiences which have proved challenging to the individual's self-concept:

> 'Although the developmental origins of the abnormal attributional style of paranoid patients are not understood, it is possible that such a style develops in the context of chronic threats to the self-concept that predate the appearance of psychosis.'

In his recent work, Bentall (2003; p.305) suggests that paranoia may contain a 'nugget of truth', in so far at is may relate, however obscurely, to earlier experiences which the individual has had which contain similar themes to the content of the delusional beliefs. This, to some extent echoes the earlier theory of Maher (1974) that delusional beliefs are attempts to make sense of unusual experiences. In addition to the role of attributional style, Bentall suggests that other factors, such as hyper-vigilance for threat-related material and a difficulty in understanding what other people might be thinking (a 'theory of mind' deficit) may also be implicated in the psychology of delusions.

Other psychological explanations for delusional beliefs include Garety's (1991; 1992) theory which places greater emphasis on the role of probabilistic reasoning, suggesting that delusional patients suffer from a tendency to 'jump to conclusions' on the basis of limited evidence. In a review of the various theories of delusions and the evidence to support them, Garety and Freeman (1999) conclude that there is sufficient evidence to suggest that both attributional and probabilistic biases are implicated in the formation and maintenance of delusional beliefs. Another perspective on delusions is Rhodes and Jakes (2004) idea that delusions are expressions of metaphors which have been 'lost': that is, the metaphorical aspect is no longer conscious to client.

2.3.5. Psychodynamic/Psychoanalytic Theories

As with both psychological and biological explanations for schizophrenia, within psychodynamic accounts of madness we find a variety of different theories rather than a single unified and universally accepted theory. Psychodynamic accounts of human experience can be traced to the works of Freud (1957) and are based, to varying degrees, on his model of the workings of the human mind. Freud developed a comprehensive model of human psychological functioning which stressed the structure of self (ego, id and superego) and posited a range of processes which are in operation as the self develops through time. Freud's emphasis was on inner conflicts and ways of dealing with these conflicts ('defences') both at the time of the initial conflict, and subsequently in an individual's life when these conflicts may re-emerge, often in a disguised form. Freud's view can, somewhat simplistically, be summarised as seeing psychological difficulties as being the expression of conflicts from past experiences.

Freud (1904) himself discouraged psychotherapy of psychosis. Although in his earlier works he had considered this possible, this position was later revised. Josephs and Josephs (1986) point out the Freud was the first clinician to see meaning in psychotic experiences, as illustrated by his Schreber case. Despite this, Freud later went on to argue that psychosis (which he at times referred to as 'narcissistic neuroses') is not amenable to psychoanalytic therapy because the client is unable to form a 'transference relationship', an essential ingredient of successful psychoanalytic therapy (Arieti, 1974). This viewpoint was maintained by classical analysts, although an early pupil of Freud's, Paul Federn (1952) questioned this, and made several attempts to treat psychotic patients, arguing that poor ego boundaries contributed to psychotic problems, with material from the id invading the ego and being projected onto the external world.

A common thread in many of the psychoanalytic conceptualisations of psychosis is that it reflects the individual's attempts to deal with difficult emotions that relate to an earlier stage of development. An early proponent of the psychoanalytic perspective, Melanie Klein (1946), made significant contributions to the analytic conceptualisation of psychosis. She suggested that the basis of psychosis can be found in early development and reflects the use of particular defence mechanisms. In particular, she introduced the concept of 'projective identification', which she describes as the 'splitting off parts of the self and projecting them on to another person', a process she viewed as implicated in the development of the 'paranoid-schizoid position'. This position was developed by Bion (1956) who argued that this defence mechanism was a core feature of schizophrenia.

Also operating within a psychodynamic framework, Sullivan (1956) suggested that schizophrenia can be explained as an adaptive strategy by the client in trying to deal with the cumulative effects of trauma, which threaten to throw the client into panic and terror. He viewed schizophrenia as a defensive strategy for avoiding fragmentation and chaos, and for maintaining a meaningful view of the self, even if that is at some cost to the individual (who retreats into madness). A similar view is espoused by Shapiro (1991), who argues that self-destructive behaviour in schizophrenia reflects an attempt to reverse self-fragmentation secondary to overwhelming affect.

Searles (1961) agrees that schizophrenia is characterised by fragmentation of experience, which results in a loss of continuity and connection, although he proposes that it is intense fear of change (derived from parental restrictions on autonomy) which is the genesis of psychosis. Modern analysts, such a Symington (2006) suggest that the emotions of shame may be important. He argues that shame fuels the projective process, such as ‘projective-identification’. He suggests that psychosis reflects an ‘inner jelly-like chaos’ which derives from the ‘total absence of inner government’.

Adopting quite a different perspective, Fenichel (1945) suggested that schizophrenia may reflect a particular sensitivity on the part of the individual. He argued that people with a diagnosis of schizophrenia are acutely sensitive to the subconscious of others, but they then tend to exaggerate what they pick up through this sensitivity.

London (1980) notes that one of the weaknesses of psychoanalytic theories of schizophrenia relates to scientific evaluation, with there having been few scientific studies evaluating the validity of the constructs or the efficacy of psychoanalytic therapies. While there have been claims that the psychodynamic perspective on schizophrenia is dead (see for example Mueser & Berenbaum, 1990), it is clear that these suggestions of the demise of this model have been somewhat premature. There is a vast and growing psychodynamic literature on psychosis. More recent models of madness which can be subsumed under the psychodynamic umbrella include Karon’s (1999) view that schizophrenia is an expression of chronic terror and the defences utilised by the individual to live with this terror. Overviews of psychodynamic therapy of schizophrenia can be found in Hingley (1997) and Silver, Koehler and Karon, (2004). Psychodynamic theories of psychosis have been consistent in their efforts to explore the meaning of psychotic experiences (Hingley, 2006; Silver et al., 2004) and to find helpful ways of working psychotherapeutically with those who experience psychosis.

2.3.6. Communication and family theories

Though less prominent now than in the 1950s and 1960s, theories of schizophrenia which focussed on styles of communication have nonetheless had a significant impact on the literature, particularly in the areas of systemic conceptualisations and family therapy of schizophrenia. Among the earliest proponents of theories of this sort was Gregory Bateson (Bateson, Jackson, Haley & Weakland, 1956, Bateson, 1973). Bateson argued that schizophrenia results from the individual being brought up in a family environment characterised by a particular style of communication, wherein the child is repeatedly exposed to a 'double bind' situation which renders the individual vulnerable to schizophrenia. A 'double bind' is a form of communication which operates on at least two logical levels, and contains contradictory commands, or requests, thus rendering it impossible to fully comply with. Bateson argued that repeated exposure to such communications leads to problems in understanding the communications and motivations of others (more specifically, to difficulties in discriminating between the literal and the metaphoric aspects of communication). This will result in 'faulty' metacommunication skills in reading the behaviour of self and others which, in turn, leads to the range of symptoms associated with schizophrenia. This deficit, according to Bateson, is the direct consequence of being in a particular family situation characterised by 'double bind' communications. Bateson et al., (1956; p.258) argue that:

> 'The child grows up unskilled in his ability to communicate about communication and, as a result, unskilled in determining what people really mean and unskilled in expressing what he really means.'

In support of this view, Wynne and Singer (1963) found that families of those diagnosed schizophrenic consistently score higher than 'normal' families on measures of 'communication deviance'. Further empirical support for the role played by family communication is found in the UCLA Family Project, which followed families prospectively for 15 years and found that both expressed emotion (hostility, criticism and emotional over-involvement) and ‘communication deviance’ are predictive of schizophrenia (Doane, West, Goldstein, Rodnick & Jones, 1981; Goldstein, 1987).

Though these theories came to be associated with theories which ‘blame’ the family (and in particular the mother) for causing schizophrenia (Johnstone, 1999), and hence dropped out of fashion when such approaches came under fire, we can see a more enduring influence of the theory in clinical approaches to schizophrenia which focus on the importance of styles of communication within the family, such at is found in the literature on expressed emotion (Goldstein, Rosenfarb, Woo & Neuchterlein, 1994; Vaughn & Leff, 1976) as well as systemic approaches to madness (see Aderhold & Gottwalz, 2004 for a recent review of this literature).

2.3.7. Life event theories

The family communication theories outlined above point to the importance of the interpersonal environment the individual finds him or herself in. In the current section I will consider accounts of schizophrenia which have implicated life events (such as childhood trauma) in the aetiology of schizophrenia. I have already referred to Rudegeair and Farerlly’s (2004) theory which identifies trauma as critical; for convenience I have located this under ‘evolutionary’ theories, though it could, clearly, also be subsumed here. It is worth pointing out that theorists from a wide range of perspectives (e.g., psychodynamic, psychological etc.) have argued that life events play an important role in psychotic experiences.

The role of life events in the aetiology of mental health problems is a topic which has generated, and continues to generate, considerable controversy. Both sides of this debate can be traced to the work of Freud. Freud’s earliest (circa 1896) theory on this matter argued that early childhood sexual experiences are a crucial aetiological factor in the development of mental health problems in later life (Freud, 1962). Famously and controversially, Freud revised this theory a few years later to suggest that the early sexual experiences he had considered of such importance were fantasies the child had created, rather than actual experiences. This shift in Freudian theory has been the subject of much analysis in recent years where it is often argued that Freud first uncovered, only to subsequently deny, the important role of actual sexual abuse in the development of mental health problems in later life: see Masson (1984) for a critical review of this change in Freud's theory. Though Freud's interest was more in the neuroses than the psychoses, we can see in this about-turn a parallel in the current literature, where the role of sexual abuse and other adverse events in childhood, as contributory factors to the causes of psychotic experience is hotly debated.

In the realm of theories of psychosis and schizophrenia, we find an early example of emphasis being given to the role of life experiences (not limited to sexual abuse) by Harry Stack Sullivan (1956; 1962) who encouraged his patients to see their difficulties as being related to life experiences. Pinpointing a more specific relationship, Frieda Fromm-Reichmann (1948; 1958) argued that the symptoms of psychosis can be seen as the client repeating early traumas and past interpersonal relations, which come to manifest themselves in a somewhat distorted form in present relationships. She argued that such traumatic early interpersonal relationships set the client on a solitary path, where trust is particularly difficult, leading to the loneliness of the schizophrenic position.

Interest in the role of early traumatic experiences in schizophrenia has been the subject of considerable empirical investigation over the past 5-10 years, with mounting evidence that people who have psychotic experiences are more likely than the general adult population to have been subject to abuse (sexual, physical, and/or emotional) as children (Bebbington et al., 2004; Janssen et al., 2004; Read, 1997; Read, Goodman, Morrison, Ross & Anderhold, 2004). However, as in Freud's day, the literature in this field is imbued with controversy, which has not yet been resolved by empirical investigations. Recent large scale studies (Bebbington et al., 2004; Janssen et al., 2004; Spataro, Mullen, Burgess, Wells & Moss, 2004) reached quite different conclusions about any putative relationship between psychosis and early childhood abuse. While the study by Janssen et al. (2004) concludes that 'childhood abuse predicts psychotic symptoms in adulthood in a dose-response fashion', Spataro et al. (2004) argue that their results 'do not support an association between child sexual abuse and psychosis'.

Methodological differences in these studies may account for at least some of the inconsistencies in findings. Spataro et al.'s (2004) study includes only those cases of sexual abuse which came to the attention of the authorities at the time, which are unlikely to be representative of all cases of childhood sexual abuse. Another potential weakness of this study, acknowledged by the authors, is that the average age of subjects at follow up (in the 20s) may have underestimated the incidence of psychosis, which commonly does not emerge until the mid 20s. Similarly, criticism can be levied at the Janssen et al. (2004) study. While this is a large scale study (n=4045), their conclusions about the relationship between abuse and psychosis are based on only seven participants who reached their 'need for care' criteria level of psychotic disturbance. Bebbington et al.'s (2004) research was also large scale (n=8580), with the evidence convincingly pointing to a positive relationship between psychosis in adulthood and a range of 'victimization experiences' (sexual abuse, bullying, violence, being taken into care, etc.), with the association being strongest in the case of those who report sexual abuse.

At present, there is a lack of consensus in this field regarding the nature of the relationship between early trauma and psychosis in adulthood, which continues to generate the kind of controversy aroused by Freud's original exposition of this theory. A helpful discussion of the range of theories that might be proposed to account for this association is provided by Bebbington et al. (2004).

Other investigations which hope to shed light on the nature of the relationship between trauma and psychosis, include those which have considered particular relationships between abuse and severity of psychiatric disturbance (Read, 1998) and also associations between different types of abuse (sexual and physical) and particular symptoms (hallucinations, delusions and though disorder; Read, Agar, Argyle & Anderhold, 2003). Though the literature delineating relationships between specific forms of abuse and specific psychotic symptoms is tentative rather than conclusive, it does nonetheless provide hope that if such specific relationships are indeed found consistently, this may allow advances to be made in identifying particular mechanisms that may be implicated in the development of psychotic experiences.

Such is the interest in the relationship between trauma and psychosis that an entire issue of Acta Psychiatrica Scandinavica (Nov., 2005) was dedicated to this matter. This provides an updated review of the literature in this field (Read, van Os &

Morrison, 2005) and further consideration of possible mechanisms (biological and neurodevelopmental) to explain the relationship trauma and psychosis. Bak et al., (2005) put forward the notion that early trauma may predispose people to experience more distress associated with psychotic experiences through diminishing coping responses.

An example of how the literature in this field can encompass more than one conceptualisation of schizophrenia is found in the Traumagenic Neurodevelopmental Model (Read et al., 2001). The writers propose childhood abuse is an important causal factor in the development of schizophrenia and argue that this is entirely consistent with findings showing abnormalities in the brains of adults diagnosed with schizophrenia. Though biological correlates of schizophrenia are commonly used to support the idea the schizophrenia is biologically caused, Read et al. (2001) argue that many of the brain abnormalities found in schizophrenia are also found in the brains of those who have been abused as children. That is, they suggest that the experience of abuse causes particular abnormalities in the brain which render people vulnerable to travelling down a neurodevelopmental pathway which may lead to psychotic experiences such as those found in schizophrenia. Read et al. (2001) acknowledge that other factors are also likely to be involved in the aetiology of such a complex picture as schizophrenia, cautioning against overly simplistic models which posit a single (usually biological) factor as *the* cause of schizophrenia.

While my focus in this section has been mostly on sexual abuse as a possible causal contributor to schizophrenia, this is not alone in terms of life events which have been implicated in schizophrenia. Among the other life events which have been found to be associated with schizophrenia are: physical abuse and bullying (Janssen et al., 2004); poverty (Faris & Dunham, 1939; Harrison, Gunnell, Glazebrook, Page & Kwiecenski, 2001); belonging to an ethnic minority (Hutchison et al., 1996); and recent stressful experiences (Birley & Brown, 1970). A recent overview and integration of this literature is provided by Read, (2004d). Other variables which have been considered important in causing schizophrenia include the notion that urban environment may cause psychosis (van Os, 2004). Sundquist, Frank and Sundquist (2004) discuss evidence consistent with this view and consider the possibility that factors such as poor social networks and lack of support may contribute to the condition. We can see that in addition to showing a relationship between trauma and psychosis, there are many other factors which have been implicated and investigated as important factors in professional explanations of schizophrenia.

The theories considered above have derived largely from clinical disciplines, whether they be primarily medical in their orientation, or more inclined to a psychotherapeutic perspective. However, this does not exhaust the range of theories that have been proposed as explanations of what schizophrenia is. Other disciplines have also investigated schizophrenia, and come up with quite different conceptualisations of schizophrenia. I will now consider some of these theories.

2.3.8. Sociological/anthropological theories

The theories discussed so far (with the exception of family/communication theories) have in common that they take a largely individualistic approach to schizophrenia. By this, I mean that they take as their starting point the assumption that schizophrenia can be understood by looking to the individual who has this diagnosis, and identifying what it is that is unusual about this individual that explains how it is that he or she has developed this complaint. By contrast, sociological and anthropological approaches tend to adopt quite a different starting position, in that their focus is much more on the social context within which a diagnosis of schizophrenia may be made. As such the social and cultural practices involved in the process of identifying someone as ‘deviant’, and then labelling the person as mentally ill, are given greater prominence in sociological and anthropological accounts of schizophrenia.

Of course, an important aspect of anthropological investigations into ‘madness’ is to look at the local, indigenous ways of making sense of such behaviour and experiences. However, in this section I will attend only to professionals’ (or academics’) theories of schizophrenia. Indigenous views of madness will be given more attention in the chapter 5, when lay theories of madness are considered.

A recent example of using an anthropological perspective to shed some light upon the nature of psychosis is provided by Harland, Morgan and Hutchinson (2004). They argue that we must attend to the nature of self if we are to understand the mechanisms through which an individual (whatever their biopsychosocial vulnerabilities) actually becomes psychotic. They draw on anthropological and phenomenological investigations of 'self' to illustrate their argument. Writers such as Littlewood (1991) and Eisenberg (1977) have argued that to understand schizophrenia, we must look not only at those so diagnosed, but also at the very process of diagnosis itself, not overlooking the frameworks adopted by those who do the diagnosing. Littlewood (1991) draws our attention to the fact that any complex behaviour can be viewed in a range of ways, and how it is that we view the behaviour will be influenced by a range of factors, including culturally embedded points of view. Littlewood point out that notions such as 'schizophrenia' are not 'natural facts', about which we are compelled to agree, but rather reflect a particular way of construing experience, which reflects our own interests, or those of the culture/sub-culture to which we belong. Though it might be argued (and indeed often is) that the various models of schizophrenia are supported by empirical evidence, it is important to recognise that this 'evidence' is not independent of the model adopted in the first place. As Eisenberg (1977) points out:

> 'Once in place, models act to generate their own verification by excluding phenomena outside the frame of reference the user employs. Models are indispensable but hazardous because they can be mistaken for reality itself rather than as but one way of organizing that reality.'

Both Eisenberg and Littlewood seem to be stressing that our models of madness and the evidence we may call upon to support these models are not independent of one another. That is, particular ways of viewing schizophrenia will lead to particular research endeavours, designed to gather particular types of evidence (and thereby ignore other evidence) which in turn are used as support for the theory. The point being made is that we must recognise that other factors, such at those outlined by Littlewood, are also implicated in our models of madness and we would do well to recognise this.

In addition to the philosophical/epistemological critiques of Littlewood and Eisenberg, within the sociological tradition there is also attention given to how and why it is that individuals come to be identified as deviant, and the impact that this has on the person. This work, which has its roots in classic works such as those of Goffman (1961) and Becker (1963), has come to be referred to as 'labelling theory', focussing as it does on the process and impact of being labelled. Looking at the social context and functions of identifying people as 'deviant', writers, such as Becker (1963), argue that deviance is actually created by the social group and the rules adopted for deciding who is 'inside' and who is 'out':

> 'Social groups create deviance by making rules whose infraction constitutes deviance, by applying those rules to particular people and labeling them outsiders.'

Ivan Illich (1973; p.56) argues that this process serves a function of social control, whereby those who do not fit easily into conventional social categories are rendered less threatening to society by being categorised as deviant:

> 'People who look strange or behave oddly threaten any society until their uncommon traits have been formally named and their uncommon behaviour has been slotted into a recognised role. By being assigned a name and a role, eerie and upsetting deviants are turned into well-defined and established categories.'

Clearly one such category of deviance, and one that has received considerable attention, is that of mental ill-health in general, and schizophrenia in particular. In addition to the process through which individuals come to be labelled, sociologists have also examined some of the effects of such labelling, arguing that there is an iatrogenic effect, whereby the individual so labelled will be treated differently by others and will come to see him or herself differently as a consequence of this labelling process. Thus, it is argued, an individual, once labelled as, say schizophrenic, may come to see themselves in this way, and this will have the effect of amplifying the original deviant behaviour and excluding for the individual alternative behaviours (Turner, 1987). The individual comes to be stigmatized by the label 'mental patient' which in turn will determine how others react to person. Should the person accept this label, then he or she will act accordingly, thus reinforcing the social role of 'mental patient' (Doherty, 1975). This process has been labelled entering into a 'career of deviance' through 'role-playing' the sick person. Scheff (1984) suggests that once an individual is labelled 'ill' this can lead to a self-fulfilling prophecy, in which the process of accepting the label of illness can actually have an impact on the disease process itself, as he found in his study of TB sufferers. Scheff (1984) found that those patients who more readily accepted the rules of the hospital ward made a slower recovery than those who rejected these rules. Similarly, there is some research into the impact on the individual of accepting the labels of 'mental illness' or 'schizophrenia': those who accept such labels have been shown to fare worse in certain measures of mental health, such as dependence (Morrison, Bushell, Hanson, Fentiman & Holdridge-Crane, 1977) and sense of control and associated depression (Birchwood, Mason, MacMillan & Healy. 1993).

Another interesting study into the impact of labelling is the infamous study by Rosenhan (1973). His study, which involved 'stooges' falsely reporting having heard a voice uttering a single word, demonstrated how easy it was to be labelled as schizophrenic, and also how difficult it was, at that time at least, for the pseudo-patients to lose the label once so diagnosed, despite showing no further signs or symptoms of mental ill-health. A recent replication of this study (Slater, 2004) reported similar findings, despite supposed increased reliability and validity of psychiatric diagnoses.

2.3.9. Philosophical/Existential theories

Given the profound, and at times profoundly confusing, aspects of the experiences associated with schizophrenia, it is perhaps not surprising to note that we can also find theories of schizophrenia which have a distinctly philosophical orientation. Also, the historical overlap between psychology and philosophy means that, for many of the earlier writers in this area (such as Jaspers, Freud, and William James) distinctions between philosophy, psychology and psychiatry were far from clear cut. For example, though Karl Jaspers is generally regarded as one of the fore-fathers of modern psychiatry, he spent most of his working life as a philosopher. In his classic text (Jaspers, 1963; p.309), he points out that:

> 'in psychotic reality we find an abundance of content representing the fundamental problems of philosophy.'

Philosophical theories may endeavour to account for schizophrenia in philosophical terms, and/or may focus on the philosophical implications of having such experiences. Though much of modern psychiatry and psychology pays little heed to the philosophical aspects of psychotic experiences, there is nonetheless a significant, if also marginalised, literature which addresses these issues. Perhaps one of the most vocal and influential recent writers in this tradition was the Scottish psychiatrist, R.D. Laing, a major figure in the 'anti-psychiatry' movement of the 1960s and 1970s, who himself had personal experience of psychosis (Clay, 1996). In addition to his philosophical/existential position discussed here, Laing was also an important contributor to the communication theories discussed above (Laing & Esteron, 1970). Laing (1960; 1967) argued that schizophrenia can be seen as the manifestation of existential despair, reflecting a division in the patient's psyche, which is brought upon by the conflicting demands of living in a world which alienates us. For Laing, madness is viewed as a kind of voyage, through which the person comes to more fully appreciate the nature of existence. Schizophrenia, to Laing (1967; p.93) was 'a natural way of healing our own appalling state of alienation called normality'. Laing suggested that schizophrenia reflects a kind of 'ontological insecurity' where the individual feels uncertain about his or her very way of being in the world and that appropriate 'treatment' for those suffering from schizophrenia is to provide the individual with an environment which allows him or her to work through these philosophical crises (Laing, 1967).

Others who have written in the philosophical tradition include the Finish psychiatrist, Siirala (1961) who argues that people diagnosed schizophrenic are, in some ways, prophets who express the malaise in society. That is, Siirala sees schizophrenics as both victim of a harsh society, and prophets (to whom nobody really listens) who have a particular sensitivity to our collective sickness. This 'collective sickness' is the accumulated evil acts committed by members of a society, which have come to be hidden from view for, and by, 'normal' people. He argues that those working with schizophrenics have a responsibility to reveal to society the prophecies of patients, given that these are, according to Siirala, insights into the madness that exists not only within the individual psyche of the client, but rather within the society to which the client belongs. Arguing along similar lines, Arieti (1974; 1979) proposed we should view schizophrenia as more than simply an unfortunate illness that happens to afflict some members of the human race. Rather, he argues, the experiences that are characteristic of schizophrenia are such that they can provide us with unique insights into human nature. Of schizophrenic experience Arieti (1979; p.220) proposes 'we can learn from it about human life in general and the human predicament.'

More recently, Louis Sass (1992) has further developed the philosophical conceptualisations of madness, drawing on the works of both Heidegger and

Wittgenstein. Sass (1992) proposes that we can comprehend schizophrenia as a complex, and perhaps convoluted attempt by the individual to grapple with issues relating to the very nature of Being itself (that is, with 'ontological' issues). Sass suggests that schizophrenia reflects a particular 'way-of-being-in-the-world' that indicates a shift in how the individual deals with the very frameworks we use for making sense of the world, such as the nature of 'self' and the nature of 'reality' (Bracken & Thomas, 1999; Sass, 2004). Sass and Parnas (2003) elaborated this theory, proposing that disturbances of self may be the central feature of schizophrenia. They suggest that this conceptualization can help unify an otherwise disjointed concept (schizophrenia) and also suggest that this theory may help identify prodromal schizophrenia by identifying the subtle changes in self that may precede the condition itself.

The focus on the role of self in schizophrenia is also considered by Ladrine (1992; p.405), who suggests that psychiatric symptoms, especially those associated with schizophrenia, are 'violations of Western cultural assumptions about how the self ought to be experienced'. A similar perspective is explored by Fabrega (1989b). Lysaker and Lysaker (2004) add a further perspective, when they suggest that schizophrenia results from what they refer to as 'disturbances in dialogical capacity'. This notion is based on the philosophical position of self as 'subjective multiplicity', as proposed by Nietzsche (1966) and others, and proposes that schizophrenia results from a breakdown within the individual's relationship between different 'selves'.

2.3.10. Spiritual theories

Spiritual theories of schizophrenia in the modern age can be traced to the works of Carl Jung, who, like R.D. Laing, had a personal experience of a psychotic breakdown (see Jung, 1995). Also like Laing, Jung has been an influential figure in this area, though one who has been marginalised by mainstream theorists and clinicians. One wonders if somehow having a personal experience of psychosis, as both these writers have, in some way contributes to being seen somewhat as 'outcasts' by their professional peers. Drawing heavily on Eastern philosophical and theological writings, Jung (1936) proposed that schizophrenic psychosis can be viewed as the result of the disintegration, or fragmentation, of consciousness brought on by a failure to recognise the psychic importance of the spiritual realm of experience. Similarly, William James (1902) considered there to be a close relationship between 'mysticism and insanity'.

There has been a recent resurgence of interest in Jung's work and more specifically in spiritual conceptualisations and spiritual implications of psychotic experiences. For example, the Australian Jungian analyst Maureen B Roberts (2000) argues that 'schizophrenia is an extremely introverted, psycho-spiritual mode of perception, or way of relating to the world'. Roberts suggests that schizophrenia is a state of consciousness involving what she refers to as 'extreme empathy', in which the normal boundaries between self and other have broken down. Another attempt to examine the relationship between psychosis and spirituality has been developed by British psychologist Isabel Clarke. Using the personal construct framework of George Kelly (1955), Clarke (2000a; 2000b; 2001) proposes that psychosis and spirituality are alike in being a unified area of human experience, both of which reflect attempts by the individual to make sense of the world without use of their usual constructs for navigating reality. Clarke (2000b) argues that the differences between psychosis and spiritual experiences have been exaggerated and further, that what differences there are, reside in the *experiencer* rather than the experience. This perspective has been elaborated by New Zealanders Randal and Argyle (2005), who suggest the normal process of spiritual development is a gradual one, but certain individuals may experience sudden 'growth spurts' in their spiritual development which can give rise to a 'spiritual emergency'. They argue further that phenomenologically there is little to distinguish what is classed as 'spiritual emergency' from what is considered 'psychosis'.

Another, more explicitly spiritual theory of psychosis is proposed by Tobert (2001) who, developing Grof and Grof's (1986) notion of 'spiritual emergency', suggests that psychotic experiences, as so classified in Western cultures, may in fact be expressions of the person having mystical experiences, from the 'non-physical dimension', where they accidentally 'tap into' aspects of consciousness which are rarely recognised in the West.

Other spiritual theories which have been proposed to account for psychotic phenomena include De Bruijn's (1993) suggestion that voices may result from ‘psychic sensitivity’. Elferrich (1993) notes that voice hearing is at times associated with near-death experiences, and goes on to propose that this may reflect an interconnection of the consciousness of the living person and the dead. In a similar vein, Bosgo (1993) suggests voices may be result of genuine, but unrecognised parapsychological abilities, such as telepathy.

Finally, in this section, we must also consider the work of British psychologist, Peter Chadwick, whose writings cover both professional and personal perspectives on schizophrenia, Chadwick himself having been diagnosed with the condition (Chadwick, 1992; 1997). Chadwick explores the strong spiritual aspect of the experience for the individual, arguing that this is a crucial part of psychosis. Echoing Siirala (1961, see above), Chadwick (1997; p.172) suggests that direct experience with psychosis may provide us with unique and important insights into the nature of existence:

> ‘It may be that many insights had at the outer limits of sanity, shining like a sun to the receptive mind, will yet transform our world and save the minds of others who still live without hope.’

Given the range of theories that have been proposed to account for schizophrenia (only some of which have been considered here), it should come as no surprise that there are also theories which have made some attempts to integrate some of the various conceptualisations. It is to these that I will now turn.

2.3.11. Stress – vulnerability models

The most widely promulgated of these theories are the ‘stress-vulnerability’ models of schizophrenia. Developed from a framework first articulated by Meehl (1962), the notion of ‘stress-vulnerability’ as a model for schizophrenia, was first explicitly expressed by Zubin and Spring (1979) and later expanded upon by Neuchterlein and Dawson (1984). Essentially, stress-vulnerability models propose that episodes of psychosis can be understood within a heuristic framework which recognises contributions from both ‘vulnerability’ factors and from ‘stress’ factors. Neuchterlein and Dawson (1984) suggest that certain characteristics of individuals may serve as more enduring ‘vulnerability’ factors and environmental ‘stressors’ may precipitate psychotic periods in such vulnerable individuals. It is worth noting that within this model as originally outlined by both Zubin and Spring (1977) and Neuchterlein and Dawson (1984), 'vulnerability' factors include pre-existing, enduring characteristics, which are products of both genetic and non-genetic variables (including early physical and social environmental influences). We can see the model as an attempt to conceptualise episodes of schizophrenia in terms of enduring characteristics of the individual which render that individual vulnerable and more transient stressors in the environment which act as triggers for episodes in such vulnerable individuals.

This model of schizophrenia is rather unusual in that is it has achieved a degree of consensus among clinicians and researchers. However, on closer inspection, we may note that this model is in fact open to a variety of interpretations regarding what constitutes a 'vulnerability' factor. For example, there has been some disagreement around whether 'vulnerability' refers specifically to inherited biological factors, or whether other factors (such as being abused as a child) should also be considered as part of the 'vulnerability' that an individual may have to psychosis (see Read et al., 2001). Interestingly, the model is commonly referred to in medical texts as the 'stress-diathesis' model, with the more medical and biological 'diathesis' ('constitutional predisposition toward a particular state or condition and especially one that is abnormal or diseased': Merriam-Webster online dictionary) replacing the more general notion of 'vulnerability' of the original expositions. This is a subtle, yet significant, alteration in the original argument, which is rarely, if ever, acknowledged as having an impact on what the model conveys.

Whatever position one may adopt regarding what is and is not 'vulnerability', we can ask to what extent the 'stress-vulnerability' is in fact a theoretical explanation of psychosis or schizophrenia. It seems that this model simply states that those who have episodes of psychosis must have those factors (whatever they may be) that render the individual vulnerable to psychosis, along with those factors which trigger this vulnerability. That is, the model proposes that only those people who have an underlying (inherent, constitutional or acquired) vulnerability to psychosis are vulnerable to psychosis, and that among those individuals, only those whose vulnerability has been activated (through 'stressors') will become psychotic. We can see that there is a certain tautology to this argument: only those who *can* develop psychosis will do so, and only when their propensity for doing so is actualized. Such an argument could be proposed for every aspect of human behaviour. It is perhaps not at all surprising that this framework has achieved a degree of consensus. Though it has proven to be a fairly useful framework within the clinical setting (for example, by helping clients identify their own ‘triggers’) we can see that this is not so much a theoretical explanation for what ‘madness’ is, but rather is a broad, all-encompassing framework (or what Bentall (2004) refers to as a ‘meaningless generalization’) that may have some clinical utility, even if it falls short as a theoretical conceptualisation of schizophrenia.

2.4. Schizophrenia as an ‘essentially contested concept’

We can see that in the literature on schizophrenia, we find a dizzying array of accounts for what the experience is and which factors may be aetiologically implicated. It is not possible at the current time, based on empirical evidence alone, to arrive at any conclusion regarding which conceptualisation of schizophrenia is the most reliable, valid, or informative. The confusion in this area is exemplified by Crow (1984) who, using a somewhat twisted logic, proposes that the lack of clear evidence for any particular theory of schizophrenia is good grounds for considering his ‘viral’ theory, despite the fact that, as he acknowledges, there is little direct evidence to support this theory either.

It is recognised, even in mainstream psychiatric textbooks, that the literature on schizophrenia is characterised by this plurality of theories, competing for dominance. For example, in a chapter from one of the standard texts of psychiatric medicine (McGlashan & Hoffman, 1995; p.957) we find the following quote, acknowledging this very diversity:

> ‘Schizophrenic madness has had more explanations thrown at it and been the object of more attempts to render it meaningful than has any other mental illness.’

Also, from the same text (Karno & Norquist, 1995; p.903), in a chapter on the problems of studying the epidemiology of schizophrenia, we find a suggestion that the personalities of theoreticians have played a role in this debate:

> ‘The clinical diagnosis of schizophrenia has been a veritable battleground of competing personalities and concepts throughout most of this century.’

It is important to reiterate that the two quotes above do not come from a critical anti-psychiatry text. Far from it: they come from a mainstream psychiatric textbook. We see then that here is consensus about one thing, namely, that schizophrenia has been, and continues to be, subject to a wide range of explanations. Despite an abundance of empirical investigations into all aspects of schizophrenia, this situation shows no signs of abating. From a more critical position, Whitaker (2002; p.291), after reviewing theories of schizophrenia and the available evidence, concludes:

> 'Thus, if we wanted to be candid in our talk about schizophrenia, we would admit to this: Little is known about what causes of schizophrenia.'

This points to the importance of factors other than simple empirical data in keeping this controversy regarding schizophrenia alive. This point is made succinctly by the psychiatrist-anthropologist, Littlewood (1991; p.699), who states:

> 'Schizophrenia, like left handedness, can be perceived in a variety of ways depending on our own frame of reference, our personal identification and sympathies, our compelling social urgencies.'

The point Littlewood seems to be making is that the notions of schizophrenia held by researchers and clinicians depend on and reflect a whole range of personal and social factors which influence which particular model of schizophrenia will be adopted.

It has been suggested (e.g., BPS, 2000) that some of the difficulties which come with the term schizophrenia may be averted if we use instead the concept of psychosis. Whatever value there may be in this proposal, it seems that it will not solve the predicament I have outlined earlier, as definitions of psychosis have proved equally variable. Even within the DSM IV-R (APA, 2000; p.297) it is noted that 'The term psychotic has historically received a number of definitions, none of which has achieved universal acceptance.' That this situation is not merely historical is made quite apparent when we find, in the very same manual (which is, we should remember, an effort to standardise such terms) this rather vague attempt at a definition (p.297): 'In this manual the term psychosis refers to the presence of certain symptoms.' This quote is followed immediately by the following, which seems to be midway between a confession and an acknowledgement of defeat, given the purpose of the book:

> 'The specific constellation of symptoms to which the term refers varies to some extent across the diagnostic categories.'

So, even within a single text, which has the express purpose of standardising definitions of terms such as psychosis, we once again find inconsistencies. There would appear to be no good reason to assume that term 'psychosis' offers any hope of resolving the difficulties I have outlined which permeate the literature on schizophrenia. It is my contention that both terms are subject to having various definitions, explanations and attempts to render them meaningful, making it unlikely that any single definition will achieve universal acceptance.

How then are we to respond to this situation? I will now outline my response to this dilemma, where I will argue that the multiplicity of competing theories on the nature of schizophrenia (and psychosis) may not be incidental, nor simply reflect a stage in the evolution of the concepts (as has often been argued), but rather may be an *intrinsic* quality of the concept itself. Certainly, given that the concept has been imbued with controversy since its very inception, and that this controversy shows no signs of abating, on logical grounds alone there is a good case to be made that this is a quality of the notion of madness itself, regardless of which particular term (schizophrenia, psychosis, madness, and so on) that we may choose to adopt.

It seems that empirical data alone is unlikely to resolve the debate which surrounds the notions of schizophrenia and psychosis. At the very least, looking at the history and current state of conceptualisations of madness, and the evidence base that is used to bolster these competing conceptualisations, we find no evidence to suggest that some form of consensus is about to be established. Quite the contrary: notions of madness are as keenly contested today as they ever have been. The scientific method may have led to somewhat clearer requirements regarding what is to be considered as 'evidence', but this has not prevented the various competing notions of madness from developing a body of evidence supporting the theory. Each of the theories of schizophrenia that I have outlined above has a body of empirical evidence which advocates of the theory call upon in support of their particular theory. I want to suggest therefore that a conceptual rather than an empirical approach to the notions of schizophrenia and psychosis may in fact shed more light on the dispute. To this end, I think it appropriate that we turn once again to philosophy, and in particular linguistic philosophy, in order to consider what kinds of concepts 'schizophrenia' and 'psychosis' are.

I want to propose that given the plethora of explanations for what schizophrenia is and the absence of any kind of consensus among researchers or clinicians in this field, we might well consider the possibility that schizophrenia is what the philosopher W.B. Gallie (1955/56) referred to as an 'essentially contested concept'. This concept of Gallie's fits firmly within the tradition of linguistic philosophy, based on one of the fundamental notions of Wittgenstein that if we want to understand the meaning of a term we should look not (or not only) at putative definitions, but rather we should look at the *usage* of the term. To quote Wittgenstein (1953; p.220) himself on this topic: 'Let the use of words teach you their meaning.'

2.4.1. Gallie's notion of essentially contested concept

Writing in the 1950s, Gallie (1955-56; p.169 and 1964, chapter 8) proposed that

> 'There are certain concepts which are essentially contested, concepts the proper use of which inevitably involves endless disputes about their proper uses on the part of their users'

His argument is based upon the notion that it is usage that determines meaning in language, and he proposes that there are certain terms which are used in such a way that the meaning of the very term is contested, and that, therefore, this is an *integral* part of the meaning of the term. Gallie (1955-56; p.172) goes on to propose that these terms are used in an explicitly competitive fashion:

> 'To use an essentially contested concept means to use it against other uses and to recognize that one's use of it has to be maintained against these other uses.'

As a philosopher, Gallie was concerned with concepts such as 'beauty', 'justice' and 'democracy', which have dogged Western philosophers since at least the time of Socrates. He proposed that these concepts may usefully be considered as essentially contested concepts. In the original expositions of the concept, Gallie (1955/56; 1964) argued that there are five conditions of 'contestedness'. These were, briefly, that the term is (1) appraisive in nature, (2) internally complex in character, (3) that explications of the concept can emphasise different components of the complexity, (4) that the appraisive aspect of the concept can be modified in the light of changing circumstances and (5) that those who use the term recognise the contested nature of the term, and have some appreciation of competing uses of the term.

These conditions would seem to be well met by the concept of schizophrenia: it is a complex, appraisive concept, which has been used in such a way that emphasis is placed on different components of the concept. As we have seen, it has changed to meet different circumstances, and also those who use the term do so in a way which implicitly recognises that it is indeed contested, in that they acknowledge the existence of other theories of schizophrenia, even if alternative theories are summarily dismissed. However, there is one aspect of Gallie's criteria which is not so consistent with the notions of madness. Gallie argues that essentially contested concepts (ECCs) are not only appraisive in nature, but further that they are positively appraised. To quote Gallie (1964; p.161) once again:

> 'The concept in question must be *appraisive* in the sense that it signifies or accredits some kind of valued achievement.'

Clearly, it would be difficult to make a case that schizophrenia is such a 'valued achievement'. Unfortunately, Gallie does not explain why he believes ECCs must be positively appraised concepts, which makes it difficult to evaluate his inclusion of this as part of the criteria. If we accept Gallie's argument that terms such as 'beauty' or 'justice' meet the criteria for being considered an ECC, then one would assume that their opposites (say 'ugliness' and 'injustice') must, surely, also be ECCs. Thus, I would like to argue that ECCs are, as Gallie argues 'appraised concepts', but that this appraisal can be either positive or negative in nature. If we accept this modification to Gallie's original criteria, then it seems that 'madness', in whatever fashion we may refer to it, meets the criteria for being an ECC (as, of course, does its opposite, 'sanity', an equally contested concept).

In sum, what I am proposing is that we consider schizophrenia as an ECC, which is to claim that the disputed nature of the concept is neither accidental, nor transitional, but rather reflects a central component of the very meaning of the concept. This is to suggest that the controversy and debate which surround notions of madness are integral to these notions. That is, 'madness' is something which, in Western societies at least, we inevitably dispute the 'true and proper' meaning of. Further, disputing the true and proper meaning of the term constitutes the meaning of the term. This conceptualisation is, I believe, a radically different way of making sense of madness, which operates at quite a different level of logical analysis. Rather than developing a new theory of madness, or adopting an already developed theory, this approach is an endeavour to develop a 'meta-theory' which looks at how terms for madness function in the professional literature in this area, and to construe this as being central to the meaning of the term. That is madness is, quite simply, something about the meaning of which we argue, inevitably, and interminably. This argument constitutes and sustains the meaning of madness, which suggests that this debate cannot be resolved. Though not expressed in these terms, this is a position expressed by a few other writers in this field. Estroff (2004; p.284), for examples, suggests that:

> 'Disagreement and contestation about meaning, reality, and identity may represent the quintessence of schizophrenia.'

Further, Leudar and Thomas (2001; p.208) following their review of historical and current accounts of voice hearing, conclude that 'hearing voices has always been an experience with a socially contested meaning.' Outside of the strictly philosophical domain, Gallie's concept of essential contentedness has been used, albeit rarely. Of most relevance to the current discussion, McKnight (2003) suggests that the practice of medicine itself is a prime candidate for being considered an ECC, pointing out (McKnight, 2003, p262) that we cannot simply define the problem area to resolve this dispute as this begs the question given that definitions are what is contested:

> 'To claim that a concept is essentially contested is to claim that disputes over its use are not resoluble even in principle.'

Other examples of applications of ECC include Heaney's (1996) proposal that we can view both 'power' and 'knowledge' as examples of ECCs, Christensen and Dorn's (1997) proposal that 'social justice' is an ECC and Pell's (1999) suggestion that 'race' is best seen as being essentially contested. Discussing the notion of 'race' as an ECC, Pell (1999; p.2) suggests that:

> 'There is no way in principle to ever resolve debate about these moral concepts because they embrace a number of different and competing conceptions.'

2.4.2. Implications of viewing schizophrenia as an ECC

Though this may seem, initially at least, a somewhat pessimistic position to adopt as it points to the impossibility of the debate regarding the meaning of 'madness' ever being resolved, I want to propose that adopting this position may, in fact, enhance our understandings of how concepts such as 'schizophrenia' and 'psychosis' operate in our culture and thereby enhance our understandings of people diagnosed with schizophrenia and psychosis. In addition, recognising these terms as ECCs may actually provide clarity which will in turn improve the quality of the debate. This is a point made by Gallie (1964; p.188) himself when he argues that:

> 'One desirable consequence of the required recognition in any proper instance of essential contestedness might therefore be a marked raising in the level of the quality of arguments in the disputes of the contestant parties.'

It is reasonable to ask how this might be achieved – that is, how it is that viewing notions of madness as ECCs may enhance the debate. Gallie does in fact outline a range of implications which emerge from recognising a concept as an ECC and discusses how this might improve the quality of the debate. These can be summarised as:

a. Recognition and acceptance of plurality.
b. Acknowledgement of the cultural, social, and psychological factors which contribute to the position in the debate that individuals, groups, or institutions adopt.
c. Drawing attention to the purpose and function of the debate.

Before outlining these positions more fully, I would stress that this is not a mere philosophical or linguistic point. Notions of madness inform not only research into such experiences, but also significantly influence the kinds of clinical services that individuals who find themselves so labelled receive. The 'contestedness' of schizophrenia is not something which is found only in philosophical treatises on the nature of madness. It is something which permeates most, if not every, clinical encounter between those so diagnosed and their clinicians. As such, I believe that enhancing the debate around the nature of madness will provide us with not only greater conceptual clarity, but ultimately, and more importantly, the potential to enhance our ability to provide sensitive, respectful, and helpful clinical services to clients with a diagnosis of schizophrenia.

2.4.2.1. Recognition of Plurality

One of the most obvious implications of accepting that a given term is an ECC is to recognise that there is a multiplicity of ways in which the term can be defined and used. If we come to see that a given concept is essentially contested, we are, by definition, accepting that there are a number of ways in which this term can be and is used. Gallie (1955-56; p.193) goes further than this, by suggesting that recognising, and to some extent accepting (rather than simply trying to refute or disprove), competing uses of the term may actually enhance our understanding of our own, as well as our rival's position:

> 'Recognition of a given concept as essentially contested implies recognition of rival uses of it (such as oneself repudiates) as not only logically possible and humanly "likely", but as of permanent potential critical value to one's own use or interpretation of the concept in question; whereas to regard any rival use as anathema, perverse, bestial or lunatic means, in many cases, to submit oneself to the chronic peril of underestimating the value of one's opponents' positions.'

Gallie suggests that failure to recognise valid uses of the concept other than one's own particular use will encourage futile debate around which particular use is the correct, or best use of the term. Ironically, and presumably co-incidentally, Gallie (1964; p.189) makes this point using the language of psychiatry, suggesting that those who hold that their use of the term is the correct use may be delusional:

> 'So long as contestant users of any essentially contested concept believe, however deludedly, that their own use of it is the only one that can command honest and informed approval, they are likely to persist with argument and discussion in the hope that they will ultimately persuade and convert all their opponents by logical means. But once let the truth – i.e. the essential contestedness of the concept in question – out of the bag, then this harmless if deluded hope may well be replaced by a ruthless decision to cut the cackle, to damn the heretics and to exterminate the unwanted.'

So, if we recognise a term as an ECC this makes it easier for us to consider alternative uses of the term without feeling the need to refute them. In the area of schizophrenia, this could have very important implications in clinical settings, where, commonly, different clinicians may bring different, often competing, and sometimes contradictory, perspectives on schizophrenia to the clinical setting. Similarly, and perhaps more importantly, clients also, of course, have their own understandings of their experiences, and these are often quite different from professional or clinical understandings (clients' understandings will be discussed in chapters 4 and 6). The client's view is often lost beneath the arguments of the 'experts'. Were clinicians able and willing to allow for a plurality of perspectives on schizophrenia, they may find it easier to work with clients who hold a view quite different from their own. This is a position espoused by Gergen and McNamee (2002) who propose that within mental health, acceptance of a multiplicity of possible explanations is preferable to diagnosis because it allows and embraces the voices of various parties, thus empowering the voices of the client.

2.4.2.2. Acknowledgement of social, cultural, and psychological factors

Another related implication of adopting the view that schizophrenia is an ECC is to draw our attention to other factors that may contribute to the position we adopt vis-à-vis the ECC. If we have a range of potential perspectives we can adopt in regards to the ECC, then we may need to look at which factors influence, either consciously or subconsciously, the position we find ourselves taking. That is, if we want to understand why a particular individual adopts a particular notion of schizophrenia, we must look not only at the notion adopted, but also at factors within or acting upon the individual which draw that particular person to that particular perspective on psychosis. Of course, this analysis can operate at other levels as well as that of the individual; we might also find it fruitful to ask why certain groups, or institutions, or cultures, at certain times in history, promote and defend particular views on how schizophrenia is to be perceived and explained. Gallie (1955-56; p.192) puts it thus:

> 'At any given stage in the history of the continued uses of any essentially contested concept, it will no doubt be necessary to call upon psychological or sociological history or the known historical facts of a person's or group's background to explain their present preferences and adherences.'

This might more explicitly draw our attention to a whole range of factors which influence the position, or positions, we adopt in construing schizophrenia. Among other things this might help elucidate some of the underlying assumptions (or what the sociologist Gouldner (1970) calls 'background assumptions') which may underpin our position. Of course, the range of such factors that we might investigate is myriad, but may include things like socio-political interests, economic interests, the role of gender, social class, cultural orientation, personal history with madness, religious leanings, and philosophical assumptions regarding the nature of personhood. Investigating if and how factors such as these may influence how each of us (researcher, client and clinician alike) makes sense of madness may be an interesting source of study in its own right as well as something which could make an important contribution to our ways of understanding and relating to (or 'treating') those who are so diagnosed. This approach obliges us to look at the role of the person (or group) construing and not only at the person being construed. Rather than simply explaining schizophrenia, or madness, as an illness that resides solely within the individual so identified, we may come to see that how we choose to view schizophrenia, from the range of perspectives on offer at any given time, is, at least in part, a reflection of our own particular history, interests and assumptions about the nature of life. Further, if we find ourselves released from the dogma of trying to explain what schizophrenia 'really' is (a debate which has not yet yielded a satisfactory answer) we may instead be able to consider more pragmatically which way of viewing schizophrenia (if that is the term we still use) is helpful for *this* particular client at *this* particular time.

2.4.2.3. Drawing attention to the purpose and function of the debate

A further implication of viewing schizophrenia, or any other concept, as an ECC is that this may draw our attention to why such debates are perpetuated, or what particular functions these debates may serve. Although this is not a point made directly by Gallie, it is, I believe, implicit in his discussion of such concepts. This point is made more explicitly by Pell (1999):

> 'Part of understanding what it means to be an essentially contested term is understanding the social purposes served by debate about moral or evaluative terms.'

This argument suggests that ECCs are primarily moral and evaluative in nature. Though we may not agree with this fully, there does seem a case to be made for there being a moral component to judgments about who is and is not 'mad'. This point is made clearly, and with some humour, by Bentall (1992) in a paper where he points out that if all moral judgments are withdrawn from psychiatric diagnoses, this does not allow us to make a clear distinction between these diagnoses and experiences such a 'happiness'. The point he is making is that certain considerations, moral in nature, must also inform the psychiatric diagnostic system, and indeed, inform our judgments about what we consider to be ‘abnormal’.

Whether or not we accept the argument that there is a moral aspect to making such a diagnosis, viewing schizophrenia as an ECC would allow us to question what purpose or function the contestedness may serve. Might it be that this contestedness allows for flexibility in our definitions of madness, which, given the changing nature of society, may indeed be of greater benefit than having a static, unchanging, and unquestioned definition? Also, if we see schizophrenia as an attempt to define ‘insanity’, then clearly this cannot take place in isolation from our definitions of ‘sanity’. Might it be that for our society to function effectively and to be open to change, both these notions need to be negotiated, and renegotiated under changing circumstances? No doubt there are many other questions which might emerge from considering what purposes and functions the contested nature of any concept may serve, and whose interests might be best served.

I hope I have now outlined a good enough case for why schizophrenia, madness, psychosis, or whichever term we may prefer, can be fruitfully thought of as an essentially contested concept. I believe that this position entails quite a radical reconceptualisation of our notions of madness, and that this reconceptualisation has implications for both research and clinical practice in working with people who receive these diagnoses. Among the more obvious clinical implications would be recognition that madness can be viewed in a number of different ways, and that the position that any individual adopts is not determined entirely by the evidence available to support that particular perspective. How we view madness reflects, in part at least, aspects of our own personal, cultural, and socio-historical position in the world. Thus, we may be forced to conclude that there is not one schizophrenia, but rather there are many. At least, there are many ways of construing schizophrenia, based at times on quite different assumptions, and reflecting quite different interests.

One of the most striking things about the professional literature on schizophrenia, which I have shown to be characterised by dispute and debate regarding the very meaning of the term, is the almost complete absence in the professional debate of the perspective of those who have most immediate familiarity with those experiences that are considered constitutive of madness. That is, of course, those who have themselves been viewed as ‘mad’. In the following chapter I will look at lay understandings of health matters, before discussing clients understandings of psychosis (chapters 4 and 6).

3 Lay understandings: theory

> 'The worst affliction of all is, and continues to be, that one does not know whether what one is suffering from is an illness of the mind, or a sin' (Kierkegaard, quoted in Jaspers, 1963; p.425)

Having considered professional conceptualisations of madness, I will now turn my attention to lay understandings of mental health problems and psychosis/schizophrenia in particular. I will first discuss theoretical and conceptual issues relating to the nature of 'lay understandings'. In chapter 4, I will discuss research into lay understandings of health related issues. The quote above, from Kierkegaard, draws attention to one of the themes which will be discussed later in this chapter, namely, the importance of making sense of one's own experience, and, in this quote, the struggle between construing one's suffering as 'illness' or 'sin', which, as we will see in the Results section, was an important consideration for participants of this research.

3.1 Theoretical issues in lay understandings

Before discussing 'lay understandings' in any detail, it is necessary to first clarify what is meant by the term. Scientific (or professional) accounts of phenomena have been contrasted with the kinds of explanations offered by the non-experts (ordinary, or lay people), which will include those directly affected by the particular experience as well as members of the general public. Thus, 'lay understandings' tends to refer to the ways of understanding a given phenomenon held by those who are not part of the official 'expert' community of scientists, or professionals/clinicians in the particular field. Lay perspectives on a whole range of experiences (such as law, economics, statistics, education, spirituality, etc.) have attracted the attention of social scientists. In fact, there is a small literature dedicated primarily to investigating the nature of lay understandings themselves. Furnham (1988) summarized the research in this area and examined some of the main differences between lay and scientific theories.

In terms of differentiating lay and scientific theories, Furnham (1988) suggests that lay theories are largely implicit and informal, contrasting with the explicit and formal nature of scientific theories. Further, he notes that lay theories tend to be more tolerant of ambiguity and inconsistency than are scientific theories. Another important consideration is the function served by lay theories. Hewstone (1983) proposes that lay theories serve a variety of functions including providing a sense of control, maintaining self-esteem, and self-presentation in public situations.

While the approach of contrasting lay and scientific theories does help clarify some of the differences between these perspectives, it is important to recognize this can over-emphasise the differences between the two. Ultimately, both lay and scientific theories reflect our attempts to make sense of experience, though there may be subtle differences between the form and style that these theories take. Kelly's (1955) metaphor of 'man-the-scientist' cleverly suggests that lay people and experts alike are in the business of making sense of experience in such a way that allows them to anticipate future events, and that very similar processes are in operation allowing both experts and lay people to develop and test theories about the nature of things. While lay theories may be less formalized than scientific theories, it may well be that they serve essentially the same purpose: to render experience meaningful and to help us anticipate the unfolding of events.

Other important differences between lay and scientific theories are their relative status within society, and the claims made by scientific theories to be neutral, value-free and objective. There is an assumption that lay theories reflect the interests and values of the people who hold the theory, whereas the theories held by scientists are assumed to be free of such influences.

As Furnham (1988; p.105) points out, medicine is 'the area where lay theories have the most important consequences'. Given the very nature of medicine, where patients' accounts are inevitably a central part of the medical encounter, it would seem impossible to overlook the role that such accounts have. This is illustrated by research such as that of Hampton, Harrison, Mitchell, Prichard and Seymour (1975) who found that 80% of diagnoses in primary care settings are derived from the patient's history alone. However, it is my contention that personal, subjective experience of mental health problems has been largely relegated to the place of information which the clinician uses in making his or her diagnosis, rather than being viewed as having integral value in the debate regarding the nature and meaning of the experience. That is not to suggest that patients' accounts of their experiences have been entirely overlooked, but rather their voices have been somewhat marginalized. For example, Lupton (1994, chapter 4) in discussing the history of lay perspectives on medicine suggests that patients' views of their experience have over time come to be viewed as of less relevance within the medical encounter, a trend amplified by the increasing dominance of the biomedical perspective in medicine from the beginning of the 20th century.

An early example of the call to see patients' accounts of their illness as of more central importance to the clinician is found in the works of Giorgio Baglivi (1704), who suggests that for medical training, acquiring knowledge from reading books is less important than learning first-hand from the 'the narratives of the patient'. This is consistent with the more general philosophical position of writers such as Natanson (1968) and Polanyi (1958) who argue that in our understandings of the world, first-hand lived experience has precedence over the derivative world of science.

This phenomenological perspective is brought vividly into the world of medicine by Toombs (1992), a medical sociologist, who uses both her own lived experience of multiple sclerosis and extensive empirical investigations to illustrate and explore the different phenomenological positions of the physician and the patient. Toombs (1992; p.49) argues that there is a fundamental difference in how the physician and patient approach the experience of illness. This difference resides, first and foremost, in the nature of the relationship that each has to the illness:

> 'The physician and patient apprehend illness from within the context of separate worlds, each world providing its own horizon of meaning.'

Toombs (1992) argues that while the physician attends to signs and symptoms of disease, the patient views the very same signs and symptoms more in terms of their effects on everyday life. Further, and perhaps of greatest importance, the physician is trained to see the illness as a 'typified instance of a particular disease state', whereas the patient has the experience of what for him or her is a 'unique personal event'. Thus, patient and physician have, inevitably, quite different ways of rendering the 'object' (in this case signs and symptoms) thematic, or meaningful. Toombs (1992) provides a helpful discussion of how the different positions adopted by physician and patient, clinician and client can contribute to communication difficulties in medical encounters. This fundamental difference in the relationship to the experience is encapsulated nicely by Epstein's (1995; p.54) comment that 'every medical history turns its patient into a case of a disease'. Both Epstein (1995) and Toombs (1992) relate their work to Foucault and the exercise of power (see chapter 1).

How then might we view knowledge that derives from these two distinct perspectives, the lay and the professional/clinical, on illness experience? Implicit in much of the medical literature is the notion that the knowledge of the physician or the scientist is superior to that of the patient. This position is strongly criticised by Kleinman (1988; p.242) who urges that we should see the knowledge of lay people as different from, but not necessarily inferior to the clinician's knowledge when he notes that 'laymen possess alternative forms of knowledge, not merely insufficient scientific knowledge'. Similarly, Dingwall (1976) warns us against the 'medicocentric' position of evaluating lay models only in terms of medical models. He proposes that lay models should be studied in their own right, and not viewed as inadequate medical models. These are principles upon which the current research is based: the principle that clients' first-hand lived experience puts them in a *different* but certainly not epistemologically *inferior* position to scientists and clinicians, and that therefore, the knowledge that clients have of their experience has a valid and significant contribution to make to the human endeavour of making sense of the experience of psychosis.

3.1.1. Identifying an experience as 'illness'

Much of the literature in the area of clients' understandings of their conditions makes the assumption, usually implicit, that clients of medical services will necessarily view their experiences as signs of illness, albeit from a perspective that may differ from that of the clinician. However, the individual may not only have a different notion of the nature of the illness from that of their doctor, but may not construe the experience as illness at all. This is, perhaps, especially the case in the area of mental health care where, commonly, clients' and clinicians' understandings of the experience differ at even this most fundamental level. Implicit within the assumption that clients will see their experience in medical terms, is the notion that viewing the experience as a medical disease is somehow a simple, immutable and unchanging 'fact', rather than being but one way of construing the experience. This ‘medicocentric’ position fails to recognize that which experiences are considered to indicate the presence of ‘illness’ is of a changing nature even within the professional medical literature,. Certain experiences, though essentially unchanged in their presentation and phenomenology, which were at one time considered signs of illness are no longer seen as such. For example, Englehardt (1992) discusses two examples of experiences once considered as illnesses. These are masturbation, which until as late as 1933 was classified as a disease, as well as the impressive sounding ‘drapetomania’. The latter was a purported disease entity in 19th century USA southern States, invoked to explain the behaviour of slaves who tried to run away. A more celebrated and recent case of a condition being no longer classified as an illness is that of homosexuality, which until 1980 was considered a psychiatric condition and treated as such in the standard psychiatric diagnostic books of the time (Raskin & Lewandowski, 2002). Debates such as these are not purely historical. There are ongoing debates regarding the status of certain diagnosis, about whether these are genuine illnesses or not, including borderline personality disorder (Adshead, 2001), alcoholism (Malzman, 1991) and schizophrenia (Szasz, 1988).

Clearly, we see here examples of what is considered an illness changing over time. As Jones (2003; p.2) notes, ‘Being sick is not a *fact,* it is a social definition’. Though a full discussion of the factors which influence professionals in classifying experience as disease or otherwise lies outside the bounds of this thesis, examples such as these illustrate that the concept of disease, even among professionals, is subject to change and that experiences classified at one time as illnesses may be seen quite differently in another time or place.

This leads us to consider which factors may be implicated in how lay people go about identifying particular experiences as signs of illness or disease. Overviews of the literature in this field are provided by Calnan (1987, chapter 7) and Jones (2003). According to Dingwall (1976), identifying an experience as ‘illness’ is a complex process, with emphasis being on how the person construes his or her body in relation to social action; when there is some kind of interference with ‘normal’ functioning, the person, using their own lay knowledge of medicine, may view that interference as signs of illness. Similarly, Friedson (1970) argues that when ordinary routine activities are interfered with by a bodily condition, it is likely that this will be seen by the individual as signs of illness. Kleinman (1988) offers a similar perspective when he suggests that as individuals we have some notion of normative bodily processes which, when disrupted, lead us to think of an experience in terms of illness. Each of these definitions has as a central component some form of malfunction of physical processes, which are less likely to be present in the case of mental health difficulties.

Other writers, such as Locker (1981), have focused more on the role that perceived responsibility has on a condition being viewed as 'illness'. Locker (1981) suggests that making an illness attribution for an experience is a moral judgement, which relates to notions of personal control and responsibility for the condition. Another factor of relevance is the availability of other, non-illness explanations for a condition. Blaxter (1983), based on his research into working class women's accounts of their health concerns, suggests that a condition will be seen as illness when the person can come up with no other explanation.

Clearly, the process of coming to see any experience as indicative of illness is complex, with many different factors playing a role. This complexity is reflected in models that have been developed to try to account for this process, such as Fabrega's (1974), which posits that there are four interlinked systems (biological, social, phenomenological, and memory), and nine different stages involved in how a person comes to view an experience as 'illness' and then to seek treatment.

3.1.2. The disease/illness/sickness distinction

At this point, it is important to clarify our terms; in particular, the concepts of 'disease' and 'illness', which hitherto in this thesis have been used interchangeably. A very useful distinction which has been made (initially from the sociological and anthropological literature in this field) is between the related concepts of 'illness', 'disease' and 'sickness'. Illness refers to the individual's subjective experience of the condition; disease is the biological (or sometimes psychological) malfunction underpinning the individual's condition; sickness (developed from Parsons' (1951) notion of the 'sick role') refers to the socially sanctioned roles allowed to those who are seen as suffering from a disease. The illness/disease distinction has received most attention within anthropological and medical literature, with sociological researchers giving somewhat more attention to ‘sickness’, or the social roles available to those who are ill. As the focus of the current research is on how clients understand their experience, our concern here is primarily with the illness/disease distinction. This distinction was made originally in medical anthropological writings by Fabrega (1974) and developed further by Eisenberg (1977) who described both illness and disease as models, used by the lay person and the clinician respectively, for making sense out of the chaos of the phenomenological world of ill-health. Eisenberg (1977; p.11) makes the distinction thus:

> ‘illnesses are experiences of disvalued changes in states of being and in social function; diseases are abnormalities in the structure and function of body organs and systems.’

This distinction has been readily and widely adopted within this field, being explained in simpler terms by Helman (1981; p.548) who, reflecting on the usefulness of this distinction within general practice, states ‘Disease is something an organ has; illness is something a man has’. Or, equally simply, as explained by Kleinman (1988; p.5) illness is ‘what the patient feels when he goes to the doctor’, disease is ‘what he has on the way home from the doctor’s office’. Kleinman (1993; p.38) expands on the definition of illness to include psychological and biological malfunction as well as social factors implicated in the experience of illness (thus subsuming the notion of ‘sickness’ as defined above as an aspect of illness):

> ‘In the language of our model, disease denotes a malfunctioning in, or maladaption of, biological and/or psychological processes. Illness, on the other hand, signifies the *experience* of disease (or perceived disease) and the societal relation to disease. Illness is the way the sick person, his family and his social network perceive, label, explain, valuate and respond to disease’.

The illness/disease distinction has come to occupy a central position within the research looking at clients’ understandings of their medical complaints. However, within this distinction we see evidence of the assumption noted above that the client will construe his or her experience primarily within a medical framework. The concept of ‘illness’ carries with it medical associations and the contrast with ‘disease’ (as defined above) suggests that there is a definite and identifiable biological malfunction underlying the clients’ experience. There is a tension, found even within

Kleinman's work, between wanting to elevate the clients' experience to being epistemologically on a par with that of the clinician, and at the same time subsuming both client's and clinician's perspective within the medical framework of the clinician. For example, Kleinman (1993; p.44) suggests that reducing conflict between clinician and client understandings 'should exert a positive influence upon patient adherence to the medical regimen' then only a few lines later notes that 'All clinical realities and the explanatory models they entail can be shown to be culture-specific, including those of biomedicine'. This does not seem entirely consistent with his earlier statement about the importance of getting patient 'adherence' to the medical advice.

These assumptions regarding the ubiquity of the medical perspective are not ones that can be made within the field of mental health where, as already mentioned, clients may not construe their experience as 'illness' at all, and the case for identifiable biological underpinnings of the client's experience is unproved and best regarded as hypothesis rather than fact. Clearly, both terms, illness and disease, bring with them assumptions regarding the medical nature of the experience being considered. As already noted, Bentall (2004; p.197) suggests 'complaint' may be a more neutral term, free of medical associations, in referring to what it is that brings a client into a mental health centre. This echoes an earlier suggestion by Zola (1972) that 'trouble' is a useful way of referring to clients' difficulties. While such terms may indeed be preferable, they too are not completely free of difficulty in that some clients of mental health services (particularly those being treated involuntarily) may not even agree that they have a 'trouble' or a 'complaint'. Perhaps this disagreement regarding suitable terms for the client's experience reflects the 'contested' nature of the meanings of experience in this area, as discussed in chapter 2. Despite these limitations, the illness/disease distinction has proven a useful one in so far as it has drawn attention to the range, complexity and the intrinsic interest in how the client makes sense of the experience that health professionals may construe as disease.

3.1.3. Clinical implications of 'illness'

One of the most obvious and perhaps most important consequences of distinguishing the client's understanding ('illness') from the clinician's perspective ('disease') is to highlight the clinical significance of the client's understanding of his or her experience, an often neglected component of the clinical encounter. Medicine, with its increasing reliance on technology and it's assumption of expertise as residing solely within the medical practitioner has sometimes tended to see the client's understanding as largely irrelevant (or worse, sometimes an obstacle) to the treatment of the disease. Kleinman (1988) notes that the failure to attend to the client's illness meanings is 'a fundamental flaw in medicine'. Kleinman (1986; p.150) argues forcibly that medicine cannot afford to continue to overlook the meanings of the experience to the client as this is a central feature of real life clinical encounters:

> 'The meaning and experience of illness must be part of any investigation into illness that conceives of that subject in any way commensurate with real life.'

This position is echoed by other commentators, such as Good and Good (1981; p.81) who argue that 'The cure of disease without a concomitant healing of illness has been a major failure of modern medicine'.

Kleinman (1988), in his research into patients living with chronic medical conditions, points out that the client's personal narrative helps 'make chaotic, wild, natural occurrences more domesticated, ritually controlled, mythologized', thus giving shape to an otherwise fearsome and painful reality of living with such a condition. Kleinman also notes that the client's narrative is not simply descriptive, for the client, of his or her experience, but that it is, in fact, constitutive of the experience of illness. The illness experience will also shape how and when the client seeks treatment, as well as the client's evaluation of the treatment offered. As Fitzpatrick (1984; p.11) notes:

> 'If health care is sought, the definitions that the lay person brings to bear on his or her illness constrain the kinds of help sought and the perceptions of benefit gained from treatment.'

Another important aspect of the client's understanding of the experience is the direct impact this can have on the individual. In addition to shaping the client's views on treatment, the illness experience will also to a large extent determine how the client feels about the condition. As Epstein (1995; p.19) comments 'human lives are shattered by the explanatory stories we tell as well as by the physical difference and illness'. The suffering of the individual is not, as a pure biological perspective on health may assume, wholly attributable to any putative underlying biological condition, but is shaped also by how the individual makes sense of that condition. In other words, both illness and disease contribute to the individual's suffering, and both must, therefore, be taken into consideration by health services if the alleviation of suffering is their aim. Within the realm of physical health, this is an important focus of Health Psychology.

The relationship between 'illness' and 'disease' is a dynamic one, where each can, and does, have an influence on the other. One such illustration of this dynamic relationship is expressed by what has come to be referred to as Leventhal et al.'s (1997) 'Symmetry Rule'. This rule states, basically, that there is symmetrical relationship between the individual's perceptual experience and the diagnostician's label. This relationship is symmetrical in that when we have an unusual physical (or mental) experience, we will look for some kind of explanation (such as a label, or diagnosis) for this experience; similarly, when we are given a diagnosis, we will seek perceptual evidence in support of this label. As explained by Leventhal and Diefenbach (1991; p.260):

> 'a person who suffers from a set of symptoms will seek to label the symptoms, and person who is labelled (i.e., diagnosed) as having an illness will expect to experience specific symptoms.'

Leventhal et al. (1997) discuss this rule further and outline empirical investigations which support their thesis. For example, research shows that when people are given false feedback regarding blood pressure and the lack of a pancreatic enzyme, they later report symptoms that are consistent with, and specific to, the faulty feedback they have received. This supports the notion that people will seek perceptual evidence when they are given a disease label. This 'symmetry rule' may be worth considering in the area of psychosis where the medical model has traditionally predicted a poor prognosis, with little hope of recovery. Such a prediction may, from this perspective, actually have a negative influence on the prognosis.

Though Leventhal's rule may point to a symmetry between perception (of the client) and label (of the clinician), this is not to imply that there is balance, and in particular a balance of power, between the clinician and the client. In fact, research in this area has shown quite convincingly that there is a clear imbalance of power in this relationship and that the medical view of the clinician tends to dominate the lay perspective of the client. In an influential analysis of patient-doctor medical interviews, Mishler (1984) concluded that within the medical interview there are two distinct voices speaking from two distinct perspectives. The patient's voice speaks from first-hand lived experience, which Mishler calls 'the voice of the lifeworld', whereas the clinician speaks from a biomedical framework, or in Mishler's terms, 'the voice of medicine'. Mishler's (1984; p.99) analysis of these medical encounters led him to conclude that there is a struggle between the voice of the lifeworld and the voice of medicine and that, typically the voice of the lifeworld is suppressed :

> 'The patient has a story to tell: its theme is a lifeworld problem. In telling her story she is interrupted by the physician speaking in the voice of medicine.'

A similar point is made by Taussig, (1980) who notes that the clinician's ability to explain and offer treatment in the medical encounter brings with it the power to control the encounter (though, as discussed by Aderhold & Gottwalz (2004), such dominance may not lead to a significant change in actual beliefs). Writers such as Mishler and Taussig draw attention to the importance of power differentials in medical encounters, and how this differential can be seen in which of the two distinct perspectives (the voice of the lifeworld, or the voice of medicine) is likely to dominate the dialogue. Calnan (1984) argues that it is in those clinical situations where there is greatest uncertainty (regarding diagnosis, treatment etc.) where there is greatest potential for tension in the doctor – patient relationship. This clearly has implications for mental health, within which there is greater uncertainty than other areas of health care.

All of this points to the great importance of what the experience means to the client as a central factor which must be accommodated within health care delivery. After all, as Jones (2003; p.4) reminds us:

> 'It is not usually the symptom (or even its severity or persistence) that matters to the individual. It is the meaning of the symptom'.

If we accept that there is validity in this position, then clinical services must take cognisance of this fact. This is the position adopted by Good and Good (1981) who argue that the client's subjective reality is an unavoidable aspect of medical care, and needs to be properly attended to if we are to provide a clinical service designed to meet clients' needs. Good and Good (1981) outline such a service, which they describe as utilizing a 'meaning-centred approach' to clinical work, in which there is greater focus on understanding and interpreting symptoms, rather than purely on reducing them to putative biological substrates. Medicine, must, therefore, include the study of illness and of disease, for a medicine that focuses exclusively on the disease end of this relationship does so at the expense of the very people it is designed to assist: the clients. As Kleinman remarks (1988: p.253) ‘The purpose of medicine is both control of disease process and care for the illness experience’.

Thus, we must see that the client’s experience is as much an area of clinical concern as whatever disease process may be implicated in the ‘complaint’. Kleinman (1988; p.17), reflecting on his research into patients suffering from chronic physical conditions (but applicable to all areas of health care), considers the role of the clinician vis-à-vis the client’s experience to include:

> ‘Legitimating the patient’s illness experience – authorizing that experience, auditing it empathically – is a key task in the care of the chronically ill.’

As we will see in the discussion which follows, how the client understands his or her experience has clinical implications which provides a strong case for the importance of clients’ understandings. However, there is also a case to be made that attending to the client’s understanding is an ethical requirement of clinical practice. This point is made by Fulford and Hope (1993; p691) who, in discussing medical ethics, state quite simply that ‘understanding the patient’s actual experience is the basis of sound medical ethics.’

3.2. Models of lay understanding

If we accept that lay understandings of health difficulties are an important factor that must be taken into account in both research and clinical practice, we are then faced with the question of how to investigate these understandings. What kind of theoretical framework will be helpful in such investigations? In this section, I will consider efforts that have been made to develop some kind of conceptual structure in this field. These efforts can be divided into those directed at creating some form of taxonomy of lay understandings of illness and those that have focused more on identifying the processes involved in developing a personal understanding of one’s experience. As we shall see below, the latter approach has, in recent years at least, had greater success in terms of generating research in this area.

The general assumption behind both taxonomic and process approaches to lay understandings is that individuals' understandings of their experiences are not random or disorganised accounts, but rather, as Levanthal, Meyer, and Nerenz (1980; p.16) put it:

> 'The patient's symptoms, his beliefs about their determinants, and his beliefs about treatment form an organized and more or less coherent theory of illness. The degree of organization will vary from person to person as will the ability to verbalize the organization.'

As we shall see below, this is an assumption which is supported by empirical investigations. Where taxonomic and process approaches differ from each other is in how they endeavour to look at the similarities among ways in which individuals make sense of illness experiences. Taxonomic approaches construct broad categories to capture the nature of lay understandings (where the focus is more on the content of the client's understanding), whereas process approaches aim more to identify and articulate the psychological processes involved in making sense of illness experience.

3.2.1. Taxonomy of understandings

Weinstein, (1972) proposes that clients' understandings can be grouped according to the factors most implicated by the client as causative of their condition, suggesting that there are 8 broad domains of life that clients implicate in their understandings: economic, social, personal, emotional, family, traumatic events, drugs and alcohol, and miscellaneous. Weinstein (1972) then goes on to subsume these lay understandings within a framework of professional understandings of mental illness (using terms such as 'organic illness', 'affective disorders' and 'behavioral' to classify patients' understandings), perhaps betraying a general weakness of taxonomic approaches: that they assume that the taxonomic approach of professionals can simply be extended to subsume clients' understandings of their experience.

Other taxonomic approaches have been less specific in terms of the content of clients' perspectives, looking instead at broad metaphorical frameworks that lay people use in conceptualising illness. For example, Herzlich (1973) posits three ways lay people conceptualise illnesses: as a destructive force, as an occupation, or as kind of liberator. Chrisman (1977) suggests that there are four common categories of folk models of illness: illness as invasion, as degeneration, as mechanical failure and as loss of balance. Yet another framework is proposed by Helman (1984), who argues that lay theories of illness place the cause of ill-health in one of four regions of the world: the patient, the natural world, the social world, or the supernatural world.

Investigators who have been more explicit about the metaphorical nature of clients' understandings include Pfifferling (1981) who argues that there is a broad range of commonly used metaphors for construing illness (as challenge, as enemy, as punishment, as weakness, as relief, as strategy, as irreparable loss, and as value). Pfifferling (1981) suggests that clinician sensitivity to the client's metaphorical framework may help clinicians understand client behaviour. Similarly, the celebrated work of Susan Sontag (1989) examines how metaphors render disease more meaningful and looks at the role of metaphors used in lay illness models in general and lay models of HIV/AIDS in particular. Sontag's (1989) discussion includes consideration of some of the implications of commonly adopted metaphors and how such stereotyping of the nature of the illness and the personality of the sufferer can and does impact on the individual, by, for example, attributing moral responsibility to the sufferer, so generating stigma associated with the condition. This stigma, derived from the culturally sanctioned metaphors of the times, may be internalised by the individual, who may come to see him or herself in self-stigmatising ways. As Sontag (1989; p.3) puts it

> 'It is hardly possible to take up one's residence in the kingdom of the ill unprejudiced by the lurid metaphors with which it has been landscaped.'

An interesting discussion of the broader context within which metaphors of illness can be placed is provided by Lupton (1994, chapter 3). Lupton points out that lay metaphorical representations of illness (such as mechanical, military, sporting) found in both literature and in personal accounts of illness, do not develop *de novo* in a vacuum, but rather they correspond in some ways to the dominant medical discourses of the times, thus demonstrating the powerful influence of the medical perspective.

Although taxonomic approaches, such as Sontag's (1989) and Lupton's (1994) have contributed interesting and illuminating perspectives on the role of metaphor in lay understandings, these approaches have had limited impact on research dealing with clinical manifestations of clients' understandings of illness. It may be that the taxonomic approach operates best at the sociological level, with its relevance to specific clinical encounters being less obvious.

3.2.2. Process models

I will now consider two related approaches to lay understandings which have generated more research and which seem to have more immediate and obvious implications for clinical practice. I will refer to these as 'process' approaches because, in contrast to taxonomic approaches, they aim to identify the psychological processes that individuals use in trying to make sense of illness, rather than the focus being on categorizing clients' understandings according to content.

3.2.2.1. Health Belief Model

One of the earliest and most influential of the process models is the Health Belief Model (HBM). This approach grew from within the broader framework of Social Learning Theory (Bandura, 1977; Kurt Lewin 1951) and was developed in the 1950s in the USA in response to disappointments with public health initiatives. Janz and Becker (1984) describe the HBM as conceptual framework for understanding health-related behaviour. The HBM proposes that we must look at the client's understanding of health and illness. King (1983) points out that subjective perceptions of health and illness rather than 'actual or objective medical facts' determine health behaviour.

Researchers have endeavoured to specify and measure components of subjective perceptions that influence health-related behaviour. Factors which have been specified (from King, 1983; Janz & Becker, 1984; Furnham, 1988) include: Health Motivation; Perceived Susceptibility; Perceived Severity; Benefits and Costs; and Cues to Action (events which trigger health-related perceptions in the individual). The HBM shares much in common with Rotter's (1966) notion of 'locus of control', a concept incorporated within the HBM where 'health locus of control' and 'mental health locus of control' have been found to have some (Hill & Bale, 1980).

Janz and Becker (1984) review 46 studies which show the usefulness of the HBM in a range of medical conditions including diabetes, uptake of influenza vaccination and early detection of conditions such as cancer. Other studies have found that health beliefs can predict participation in screening for breast cancer (Calnan, 1984a) and compliance in alcohol treatment (Rees, 1985). Janz and Beker (1984) conclude that there is substantial support for the usefulness of the HBM in understanding and predicting health-related behaviour. Despite this optimistic conclusion, the HBM has come under criticism from some quarters and it appears that its dominant role has been usurped by research into explanatory models (discussed below). Good (1986) argues that the HBM operates with an overly rational notion of human beings, who are viewed as behaving to meet health needs within a framework of 'subjective utilitarianism'. Good notes that the model assumes biomedical knowledge is the norm, against which other behaviour is viewed and regarded as 'deviant' and needing explanation. Both Good (1986) and Furnham (1988; p.113) argue that the HMB tends to omit the context of health behaviour and factors (such as social support networks, the broader cultural context, and doctor-patient communication) which also influence health-related behaviours. The HBM has had only limited impact in the area of mental health, possibly because it accommodates research into public health initiatives more readily than it does investigations into other areas, such as mental health, where different notions and concepts are required to investigate client's understandings.

3.2.2.2. Explanatory Models

Perhaps reflecting the 'interpretative turn' within the social sciences (see chapter 1) more recent investigations into client's understandings of illness experiences have concentrated more on the meanings that this experience has to clients and the broader context within which these meanings are constructed. This research has investigated the client's 'explanatory model' for illness experience.

The name most commonly associated with the concept of 'explanatory model' (EM) is that of Arthur Kleinman, who has written extensively about EMs, particularly in relation to chronic illness, although Kleinman's work (see for example Kleinman 1986; 1988; 1993) also includes a broader discussion of the range of applications and implications of EMs. The notion of EM can be seen as the clinical application of an anthropological concept and research tool (Good, 1986).

Kleinman (1988; p.121) defines an EM as 'the notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process.' Kleinman proposes that illness experiences must be rendered meaningful by the individual and that this is done, essentially, within a particular cultural context. Kleinman (1988; p.55) argues that developing meaning for an illness experience helps turn a 'wild, disorganized natural occurrence into mythologized, controlled, cultural experience'. Within the EM framework, context and culture take a central position. Kleinman (1993; p.30) describes the concept of EM thus:

> 'The model is an attempt to understand health, illness and healing in society as a cultural system, and to compare such systems cross-culturally.'

EMs are not simply beliefs that one has about an experience of illness, but are much broader than this, being frames, provided by one's culture, that render such experiences meaningful by locating them within a particular cultural context Good, 1986). In addition to being a useful concept for cross-cultural comparisons of illness meanings, Good (1986; p.165) points out that the EM concept can also be helpful for making comparisons within a given culture:

> 'Explanatory models provide a means of exploring patients' understandings of their conditions, for explicitly comparing and contrasting the perspectives of clinicians and patient.'

EMs are the individual's personal myth about the illness experience, and thus fit well within the narrative or storytelling framework. EMs can be construed as a story that the patient and significant others construct and tell to give coherence to the events and course of suffering. These 'stories' are derived from a particular cultural context, are often tacit rather than explicit, and may at times be contradictory and may shift in content. EMs are not merely descriptive of the experience of illness, but can be constitutive in that the EM does not merely reflect or describe illness experience but also contributes to the experience of symptoms and suffering. As stated by Kleinman (1988; p.9):

> 'The meanings communicated by illness can amplify or dampen symptoms, exaggerate or lessen disability, impede or facilitate treatment'.

3.2.2.2.1. Dimension of EMs

Five distinct dimensions have been identified as the essential elements of EMs (Leventhal et al., 1997). These five elements are as follows:

1. Identity: the nature of the symptoms and any label, or name, which may be given to the experience.

2. Time line: the anticipated course of the condition.
3. Consequences: the practical implications for the individual.
4. Causes: the individual's notions of what caused the condition.
5. Controllability: the individual's beliefs regarding whether or not, and by whom, the condition may be controlled.

There is remarkable consistency in the research literature on the existence of these five dimensions of EMs, both cross-culturally, and at different historical epochs. For example, Blaxter (1983a) studied Scottish women's ways of talking about the experience of illness and found that 74% mentioned their beliefs regarding the causes of their illnesses. In a large-scale empirical study based on the analysis of over 1,600 respondents who had had a recent illness experience, Lau, Bernard and Hartman (1989) found support for the presence of the above five dimensions in respondents' accounts of their illness experience. They point out that while these five dimensions are useful ways of conceptualising how illness is construed, individual descriptions of illness do not usually contain all five elements: that is, there is some variability in which elements are found and in the emphasis placed on the different elements by individuals. The element found most commonly in clients' accounts was that of identity, with over 90% of participants having labelled their illness experience. Lau et al. (1989) also found strong evidence for the generality of these components in lay representations of common illnesses. In another study of EMs, Bishop, Briede, Cavazos, Grotzinger and McHahon (1987) asked their research participants to generate descriptions of symptoms of illness. They found that 91% of the content of what participants said about symptoms could be accounted for under one of the five dimensions. They argue that this is strong evidence for the existence and widespread generality of these components in people's schemas of illness, or EMs. Studies using a more longitudinal methodology have found evidence of the relative stability of illness schema for somatic symptoms (Lau et al., 1989; Robbins & Kirmayer, 1991).

Schober and Lacroix (1991) provided historical analyses of lay understandings of illness using writing from the 17th to 18th century (as well as from ancient Greece) and concluded that these historical accounts are also consistent with the EM model, which leads them to ponder the possibility that the EM model may reflect a universal cognitive framework. Schober and Lacroix (1991; p.17) seem somewhat surprised by their own findings when they conclude that:

> 'What is striking about lay medical thought which found expression in 17th and 18th century writings in that the cognizing about illness appears to have taken place within the bounds of a cognitive structure compatible with that of contemporary lay illness models.'

While there may be some consensus regarding the importance of the five dimensions of EMs, there have also been calls to broaden the study of illness perceptions to attend to other aspects of the illness experience. In an overview of research into illness perceptions, Weinman and Petrie (1997; p.6) comment:

> 'There is clearly a consensus about the five dimensions of illness perception but there is a growing awareness of other processes which need to be incorporated into explanatory models. For example, in addition to assessing illness perceptions, there is a need to understand people's views about the treatment or advice they are given.'

The clinical implications and significance of the client's EM has been stressed by researchers in this field. While more detailed research into EMs will be discussed in chapter 4, some of the more general clinical implications are worth noting at this point. Kleinman (1988, chapter 2) notes, for example, that there is a clear relationship between the client's EM and what treatment options the client will consider and possibly pursue. Similarly, EMs perform the important function of enabling a person to communicate information to others regarding their experience, and that locating the otherwise inchoate experience within an EM symbolically allows the individual some sense of control over symptoms, thus preventing feelings of helplessness vis-à-vis the experience.

Correspondence, or conflict, between the EM of the clinician and the client's EM has also been investigated. Kleinman (1980) notes that incongruence between clinician and patient EMs negatively correlates with variables such as compliance, satisfaction, use of services, and treatment response. Kleinman (1993) suggests that at times these differences reflect institutionalised conflicts between lay and professional perspectives, which may inadvertently be fostered by the way in which an institution is run. This conflict can impede health care and therefore points to the importance of health care providers being, at the very least, cognisant of the EMs of their clients.

The importance of the clinician's EM in influencing the nature of clinical services is discussed by Stein (1986), who found that physician's EMs are not drawn exclusively from a narrow biomedical framework, but rather include a mixture of both lay and scientific factors. According to Stein (1986) this is evidenced by the pervasive categorisation by physicians of patients as being either 'sick people' (those with a 'real disease') or 'trolls' (those deemed not to have a genuine biomedical disease), and the role that this informal categorising of patients has for the kind of service they will receive. Stein's (1986) study points to the importance of the clinician's EMs, and the need for clinicians to have awareness of their own complex EMs and how these may impact on their interactions with clients. Clearly, the EM of both the physician and the patient is of importance in determining what kind of intervention, if any, will be sought by the patient, what kind of service will be offered by the clinician, and equally importantly, what kind of relationship will be established between clinician and client. Good and Good (1981; p.185) argue that patients' EMs have such a great impact on health-related behaviour that 'teaching patients to confront their own networks of illness is a basic clinical task'.

The notion of EM has come under some criticism from Young (1981; 1982) who suggests that this approach, like that of the HBM, runs dangers associated with making a 'rational man' assumption. Young argues that the both the EM and HBM approaches tend to be overly cognitive in their orientation, neglecting the contribution of non-cognitive factors to our understandings of illness experience. Young (1981) suggests that some of the findings of the EM research may be an artefact of the research assumptions and methods used by those who adopt this framework. He suggests that there is a danger of looking too enthusiastically for cognitions, which may result in these being produced by the exchange between researcher and respondent. Young also suggests the EM approach makes assumptions regarding the importance of language and reason, and this may also lead to a tendency to overlook the 'objective social order' as a critical determinant of medical behaviour. That is, Young suggests that the model neglects social realities faced by those receiving health care as well as the influence of emotions, and how these impact on a person's response to illness.

Young's (1981; 1982) points do seem reasonable, namely that both emotional responses and social realities are factors which contribute to the EM which and individual will develop. However, they are certainly not fatal blows for the EM approach, which can readily extend to cover both these aspects (indeed, Kleinman's work commonly makes reference to both the social context and the contribution of emotion to the client's EM). Research looking into clients' understandings of illness experiences will be considered in more detail in the next chapter. In the final sections of this chapter I will discuss measures of illness experience that have been developed, and briefly consider literature relating to the sources of clients' understandings.

3.2.3. Measures of patients' understandings

Though many investigations into illness understandings (like the present one) do so within the framework of a qualitative methodology, a number of quantitative measures have been developed and used as instruments for investigating illness experiences. Scharloo and Kaptein (1997) review measures used in studies of chronic somatic illness and note that the most used method of investigation is that of the semi-structured, or open-ended interview approach. One of the limitations of both questionnaire and structured interview approaches is that measures designed to capture beliefs about a specific condition may be limited in their usefulness to that particular condition.

Examples of quantitative measures of illness experience include Jenkins' (1966) questionnaire which uses 16 semantic differential questions to represent components and dimensions of illness experience, and Hill and Bale's (1980) Mental Health Locus of Control and Mental Health Locus of Origin Scales, which use six-point Likert scales to measure sense of control and beliefs regarding the origins of mental health difficulties. Turk, Rody and Salovey's (1986) Implicit Models of Illness Questionnaire (IMIQ) is a 39-item questionnaire, looking at a variety of variables including cause, cure, and sense of personal responsibility. The Illness Perception Questionnaire (Weinman, Petrie, Moss-Morris & Horne, 1996) is a patient-completed questionnaire designed to measure the five components of EM, and has been shown to help predict of levels of distress and disability. Other measures include the Beliefs about Medicines Questionnaire and the Personal Models of Diabetes Interview (both in Weinman & Petrie, 1997). The Symptom Interpretation Questionnaire (Robbins & Kirmayer, 1991) lists 13 common somatic symptoms and aims to identify whether individuals make physical, emotional, or environmental attributions for these symptoms.

Interview schedules include Lacroix's (1991) Schema Assessment Instrument, an open-ended interview protocol used to obtain ratings on various dimensions of illness-related cognitive schemata. Lacroix (1991) reports that this is a reliable measure and a good predictor of return to functioning, which has also been used for comparing patient and clinician illness schemata on dimensions of severity, prognosis, aetiology and content. The Short Explanatory Model Interview (Lloyd et al., 1998) is a structured interview schedule which explores and rates cultural background, nature of presenting problem, help-seeking behaviour, interaction with clinician, and beliefs about mental illness. This interview uses clinical vignettes to elicit beliefs, and can be applied cross-culturally as its structure allows a flexible approach that doesn't impose Western concepts on respondents (e.g., 'healer' can be used instead of 'physician'). The Explanatory Model Interview Catalogue (Weiss et al., 1992) is a semi-structured interview protocol designed to elicit general and specific beliefs about illness in the patient's own terms, which has been used to study cultural meanings in leprosy, and associated mental health difficulties.

3.2.4. Sources of patients' understandings

I will now consider the sources lay illness beliefs and some of the factors, both social and individual, which have been identified as having a role to play in determining which particular understanding of illness an individual may adopt. Fitzpatrick (1984; p.11) points out that how we understand illness experiences is limited by the explanations available to us within our cultural context which 'fundamentally shapes and influences the way the illness is experienced.' This inseparability of our EMs from the cultural context in which they arise is a point made also by Kleinman (1988; p.5):

> ‘Local cultural orientations organize our conventional common sense about how to understand and treat illness; thus, we can say of illness experience that it is always culturally shaped.’

Culture, therefore takes a central position in influencing our ways of understanding illness and in providing the range of ways of making sense of illness available to us. Clearly though, given the variation that exists within cultures, other factors are also involved. As Good and Good (1981; p.176) comment:

> ‘The meaning of illness for a sufferer is grounded in – though not reducible to – the network of meanings an illness has in a particular culture.’

One way in which culture may shape the kinds of understandings available is through media portrayals of different forms of illness. Sontag (1989) has explored how the media has influenced stereotypes of those infected by the HIV virus. Wahl (2003) provides a detailed analysis of media representations of mental illness and the impact these can have, despite that fact that they may be grossly inaccurate. Lupton, (1994) proposes that technological developments within a culture also influence the range of ways in which illness is construed. She argues that we commonly use technological metaphors to make sense of illness, and as technology changes, then so to do the frameworks available to us to make sense of illness. Lupton (1994) argues that metaphors of illness and health permeate literature, and that these have a significant effect on lay illness understandings (for example, military metaphors for cancer, and computing metaphors for viral infections). Also, within Western cultures at least, it is important to recognise that lay perspectives are far from independent of professional, scientific explanations for illness. The medical profession has a powerful voice within Western culture, and as such is able to exert some influence over lay understandings. As Calnan (1987; p.9) points out:

> ‘Lay knowledge itself may consist of images or stereotypes that have been generated through official ideology and have been taken on by lay people. Thus, because of the power of western medical monopoly and medical ideology, lay ideas, assumptions, and knowledge may have been shaped, at least in part, by its ideas and concepts.’

The more immediate social context also has an impact on how experiences are interpreted. Moss-Morris and Petrie (2000) comment on examples which illustrate this, such as mass ‘outbreaks’ of psychogenic conditions within confined social quarters, (e.g., naval barracks). Other social factors which influence the EM an individual adopts include gender, cultural orientation, age, and social class. By way of illustration, I will discuss some of the literature pertaining to the role of social class. Radley (1995) argues that middle class people tend to view illness in more mentalistic terms, while working class are more likely to see illness in physical terms, which, Radley suggests, reflects different ‘ways of being’ and in particular different ways of bearing illness which, he argues, relate to different social ideologies and social practice. Radley’s (1995) argument is consistent with research carried out by Blair (1995) who found that working class participants focused more on physical explanations for illness, whereas middle class participants were more focused on the psyche. Blair (1995) relates his findings to Bernstein’s notions of ‘restricted code’ and ‘elaborated’ codes as working and middle-class ways of relating to experience. Blair (1995) found that these differences in ways of discussing illness also corresponded to differences in notions of how to avoid illnesses (with working class participants preferring relaxation and ‘taking things easy’, whereas middle class people advocate ‘expressing feelings’) and differences in notions of what would be appropriate treatment (with working class people being more inclined to physical treatments). Blair (1995; p.45) notes that working class people tend to feel less in control of illness and concludes ‘Distress cannot be understood without reference to the contexts of its experience and expression’.

In addition to broad social factors, individual factors also influence our EMs. For example, taking a personal and philosophical approach to psychology, White (1993) argues that implicit metaphysical assumptions underpin our every belief, inference and judgement, and as such also underpin our understandings of illness experience. Another individual difference which has been proposed as influencing illness interpretations is the tendency towards ‘introspection’. Hansell and Mechanic, (1986) argue that increased introspectiveness is associated with increased reporting of both physical and psychological distress. Also, our own particular history of illness experience is important as interpretations of illness are influenced by our past illness experiences. Robbins and Kirmayer (1991; p.1040) report that empirical investigations show that:

> ‘Previous physical illness and psychiatric problems influence the manner in which new symptoms are interpreted. Patients with a greater burden of acute or chronic physical illness reported more somatic attributions. Patients with a history of chronic psychiatric problems reported more psychological attributions and fewer environmental or normalizing attributions.’

Moss-Morris and Petrie (2000) also comment on the influence of previous illness episodes in influencing the meaning an individual gives to a specific experience. They found this to be the case for both those who had had a heart attack and people with a diagnosis of Chronic Fatigue Syndrome, where previous illness experiences influenced how physical changes were understood (a finding consistent with Leventhal’s symmetry rule).

To conclude, we have seen that lay understandings of illness experiences play a central role in how the individual understands and responds to experience, and that there have been a number of models developed to conceptualise lay understandings, along with a range of methods of investigation, both qualitative and quantitative. The explanatory model approach has been particularly fruitful in terms of generating theory and research and has clear clinical utility. A wide range of social and individual factors have been demonstrated to influence EMs. I will now move on to focus more specifically on the role of lay understandings in psychotic experiences.

4 Lay understandings of psychosis: research

Having considered general conceptual and theoretical issues pertaining to lay understandings of illness experiences in the previous chapter, the next two chapters will focus on lay understandings of psychoses. The present chapter will consider the position of clients' understandings of psychotic experiences within the scientific literature. The following chapter will look at the general public's (including family and care-givers) understandings of psychosis. A discussion of the importance of the subjective experience of psychosis will be presented in chapter 6. The present chapter will begin by arguing that there has been a relative marginalisation of the client's understanding within the clinical literature, before moving on to look at arguments and evidence that points to the clinical significance of clients' understandings.

4.1 Marginalisation of the client's understanding

Within the clinical and scientific literature, research into clients' understandings of their experiences of mental ill-health has occupied a peripheral role. Lally (1989) points out that within mental health there is a general lack of research into patients' perspectives. In the area of psychotic experiences, this lack of research seems even more pronounced. Molvaer, Hantzi, and Papadatos (1992) conclude that 'research dealing with patients own attributions for their illness has been virtually non-existent', a conclusion very similar to the one reached more recently by Drayton, Birchwood, Hallet and Trower (1998), who complain 'There is a paucity of research concerned with the individual's psychological adaptation to psychosis.'

This neglect of research into clients' understandings of their experience is somewhat curious, when we remind ourselves that within mental health care diagnosis depends almost entirely on the clients' description of their experience (as opposed to being derived from biochemical tests, which may be diagnostic in other areas of medicine: see Newnes, 2002). It seems almost as if the client can be (indeed *must* be) relied upon to provide a history and description of his or her experience, on which the diagnosis will rest, but, once the client has provided this information, he or she is then viewed as having little to contribute towards understanding his or her own experience. The paradox here is that while diagnosis depends upon seeing the client as a valuable, indeed necessary contributor to the process, once the client has been diagnosed with a psychotic illness, this *ipso facto* seems to render him or her unable to contribute to the discussion regarding what this condition means.

Though there is, as the above writers have bemoaned, a general lack of research in this area, a few notable and influential writers have made a case that this area is an important clinical and research consideration that ought not to be overlooked. In his classical text Jaspers (1963) dedicated an entire chapter to the patient's attitude to his illness and made some effort towards developing a classification of the individual's ways of understanding and responding to psychotic experiences. Jaspers (1963; p.417) argued that

> 'Much can be learned from *patients' own interpretations*, when they are *trying to understand themselves*.' (Italics in original)

Another early and influential text which drew attention to the importance of clients' understandings was by Mayer-Gross (1920, quoted in Dittman & Schuttler 1990). In this text, Mayer-Gross considers the opinions of people diagnosed with schizophrenia and suggests a classification for how the individual responds to their experience. Mayer-Gross (1920) proposes that there are five ways in which the client responds to the experience: 'despair', 'renewal of life' (seeing the experience as offering this), 'shutting out' (as if nothing happened), 'conversion' (where the psychosis is viewed as a revelation) and 'integration' (of the experience into the notion of self). More recently, Sims (1988; 1994) argues that a full and proper assessment of the client's difficulties must involve a detailed phenomenological exploration of the client's subjective experience, and an empathic appreciation of the same. Sims (1994; p.445) makes the point that within clinical practice 'There is a great need to acknowledge, have respect for, and use in treatment, the patient's *own* experience.' It is within this spirit that the present research was undertaken.

One of the ways in which the neglect of the client's experience is manifest is in the lack of a well-developed language to refer to, describe, or categorise clients' responses to their own experience, which leaves us in the kind of predicament described by Wittgenstein (1922) where our lack of language limits what we can say. This point is identified as an obstacle to research in this area by Kleinman (1988; p.28), who notes:

> ‘Clinical and behavioral science research also possess no category to describe human suffering, no routine way of recording this most thickly human dimension of patients’ and families’ stories of experiencing illness.’

It seems reasonable to ponder why it might be that we find this neglect of the client’s understanding within mental health research and practice. One explanation for this neglect is proposed by Mechanic (1972), who points out that in mental health care it is more difficult to separate the attribution from the entity about which the attribution is made. That is, the client’s understanding of the experience, and the experience itself, given that they are both essentially psychological processes, are difficult to disentangle, and, perhaps as a consequence of this, the client’s understanding of the experience tends to be overlooked, subsumed, or rendered invalid, by the experience itself. It’s as if having hallucinations makes it impossible for one to consider what such experiences might mean: the first-person perspective is effectively eliminated.

Kleinman (1988) locates the problem more squarely within the realm of modern medicine and medical training. He argues that the biological focus within medicine and the kinds of practice that this engenders precludes inquiry into the meaning of the experience. A similar position is taken by Jennings, Callahan and Caplan (1988), who argue:

> ‘The emergence of biomedicine’s remarkable effectiveness in curing disease has apparently been accompanied by a relative neglect of patients’ experience of disease.’

Kleinman (1988; p.17) suggests that the tendency to overlook the patient’s perspective is developed in medical training where clinicians ‘have been taught to regard with suspicion patients’ illness narratives and causal beliefs.’ Equally critical of the neglect of the client’s position, though proffering another take on why this might be so, is Mosher (2001; p.389), who suggests that clinical approaches to people who are distressed, and particularly those who are psychotic, may have been developed to allow others to keep the troubled person at a distance:

> ‘When looked at contextually, these interventions seem to be designed to allow the rest of us to avoid having to deal with these persons’ humanity – that is, their subjective experience of psychosis and its effect on us.’

How then might we overcome this tendency to neglect the subjective experience of the troubled individual? I believe that this both entails, and is an inevitable consequence of, the kind of interpretative turn discussed in chapter 1, particularly if this incorporates greater respect for and attention to the importance of observations from the first-person position (see chapter 6) and paying more than lip-service to the notion of 'authoring' (discussed in chapter 1). We may need to heed Mosher's (2001) implied point, that approaching the subjective experience of a troubled soul may in itself be distressing to some and that therefore appropriate training and support will be necessary.

4.2 Why clients' understandings are important

Why then should clients' understandings of their experience of illness be considered important? I believe that this question has both an ethical and an empirical answer.

4.2.1 Ethical arguments

The ethical position is stated very simply but forcibly by Fulford and Hope (1993; p691), who argue that 'understanding the patient's actual experience is the basis of sound medical ethics': attending to the patient's understanding is a *sine qua non* for ethical medical practice. In a more general sense, the phenomenological philosophical position, as espoused by the likes of Husserl (1962), operates from the starting point that immediate experience is necessarily unique and that to be human is to interpret or 'thematise' ones experience: to be human is to make one's unique sense of one's own unique lived experience. Failure to treat another individual as having this capacity is to fail to treat that person as fully human; surely not a basis upon which an ethical medical practice could be based. Though Husserl's concern was more with the human condition in general rather than the more specific domain of medicine, his perspective has been adopted within medical research by the likes of Toombs (1992) and Kirmayer (1988). This position is summarised nicely by Kirmayer (1988; p.82):

> 'Caring begins with accepting the phenomenal reality of the patient's suffering, including its moral significance to the patient and others. Accepting the patient as person leads to a willingness to explore the personal meanings of distress beyond the theories of biomedicine.'

In short, I believe that there is an overwhelming ethical argument for acknowledging the importance of the client's understanding of his or her experience of psychosis, and that to fail to do so would be to fail to meet one of the first requirements for building an ethically sound medical practice.

4.2.2 Clinical/empirical arguments

In turning attention to the empirical literature, I will, where possible, draw from literature that relates specifically to psychosis. However, the relative dearth of literature in this area means that I will also have to draw from literature that has investigated relationships between other health-related complaints and clinical variables. For convenience, I have arranged the literature in this area under the following headings: relationship issues; help-seeking behaviour; cause and outcome; other clinical variables.

4.2.2.1 Relationship issues

When considering the client's understanding of his or her experience, it is important to note that this does not exist in a vacuum; clinicians too have explanatory models for the client's difficulties. Client and clinician, may, to varying degrees have explanatory models which are congruent with each other, or which may be in conflict. What are the clinical implications of the congruence, or lack thereof, between client and clinician explanatory models? Bannister (1985) investigated this very issue in relation to the psychotic experiences of patients in hospital. He found that congruence between patient and medical staff on notions of the causes of psychotic breakdowns was associated with good outcomes for the patient. He also found, however, that clinician-client agreement on what constitutes appropriate treatment bore no relation to the outcome. Based on these findings, Bannister (1985) warns of the risks of clinicians adopting a narrow biomedical perspective which may make it difficult for them to understand or appreciate the client's perspective and may blind the client to the personal significance of the experience and the need to reflect on this experience. Some support for Bannister's argument can be found in the Soteria House project (Mosher, 2001) where good outcomes were found for clients who had had psychotic experiences. Staff exploration and validation of the clients' perceptions were central to these successful outcomes. Within the recent British Cognitive-Behavioural approaches to psychosis, great emphasis is placed on clinician and client endeavouring to reach a joint understanding of the client's experience, which is seen as an important step in developing a helpful clinical relationship (see Bentall, 2003; BPS, 2000).

In the domain of physical health, there is considerable research which shows that conflict of explanatory models (EMs) between client and clinician can be an obstacle to health care. Kleinman (1988; p.122), in his study of those living with chronic conditions, argues that conflict of EMs is not at all uncommon and that 'the evidence shows that these conflicts do indeed impede health care'. Kleinman gives clinical examples to illustrate his argument, and notes, in passing, that clinicians' inattention to the EMs of their patients and families signals disrespect to those concerned. By contrast, congruence of EMs will lead to a far more successful clinical relationship. Kleinman (1993; p.45) comments that

> 'When the EMs of patients, families and practitioners are alike, there will be improved communication, fewer problems in clinical management and better patient adherence and satisfaction.'

Though one might reasonably assume that the clinician has some responsibility to endeavour to understand the client's perspective, there is some research which suggests that, in fact, clients tend to have a better understanding of the clinician's perspective than vice versa. For example, Cohen, Tripp-Reimer, Smith, Soforman and Lively (1994), studying clients' and clinicians' models of diabetes found, ironically, that clients had greater awareness of their clinician's model than the clinician had of the client's model. The researchers attribute this difference to the excessive focus on physiological mechanisms by staff, whereas clients were more interested in symptoms and social complications associated with diabetes. A similar finding was noted by Helman (1986) researching staff and patients in a psychosomatic disorders clinic. Where clients and clinicians held different models of the complaint, clinicians had limited knowledge of patients' EM, and this was especially so in relation to notions of aetiology and the causes of exacerbations of symptoms. This difference was more pronounced when clients were from less educated backgrounds, which draws our attention to socio-economic factors which impact on clinician-client relationships. Helman (1986) warns that simply because clinician and client agree on diagnostic labels for the complaint, this is no guarantee that there will be agreement on aetiology, and this apparent agreement may give a false impression of consensus, obscuring differences regarding the meaning and implications of the diagnostic term. Stein (1986) suggests that counter-transference can be analysed in terms of clinicians EMs and how these lead to clinicians classifying patients as either legitimate patients (‘sick people’), or malingerers (‘trolls’).

Calnan (1987) suggests that some areas of medicine may be more prone than others to clinician-client discordance of understandings. In particular, he suggests that in those areas of medicine where there is greatest uncertainty (in diagnosis, outcome, or aetiology) there is greatest potential for such discordance. Calnan (1987) gives cancer and epilepsy as examples where this uncertainty is most pronounced. Clearly, the whole area of mental health is similarly imbued with uncertainty regarding crucial clinical variables (such as aetiology, prognosis, appropriate treatment etc). It would seem then, by Calnan’s criteria at least, that the field of mental health in general, and psychosis in particular is one where there is every likelihood that the clinician and client will bring quite different EMs to the clinical encounter, and that this will engender the kinds of difficulties noted above. We should not expect that the uncertainty regarding the cause of psychosis will inhibit the psychological search for a causal explanation: as discussed by Bentall (2003, chapter 10) the tendency to make causal attributions for anomalous experience is a universal trait. Sound advice is offered by Prince and Reiss (1991) who note ‘psychiatrists should deal with their patients’ attempts at explaining symptoms by negotiation and compromise’. However, as pointed out by Kleinman (1988), Helman (1986), and Cohen et al. (1994), increasing reliance on biomedical perspectives may make this unlikely, and may in fact set the scene for disagreement in EMs between clinicians and clients in the mental health field. Lothian and Read (2002) note that issues of considerable significance to the client (in their research, the contribution of abuse to mental health difficulties) may be ignored if clinicians rely too heavily on narrow conceptualisations of mental illness. Larsen (2004) reports that within early intervention for psychosis services, staff acknowledge an interest in ‘mystical’ models of psychosis, but only in informal settings, a finding which suggests that staff themselves may experience some conflict between professional and lay perspectives on psychosis.

4.2.2.2 Help-seeking behaviour

We can see that once the client is involved with mental health services the degree of congruence between client and clinician understandings is likely to have an impact on the relationship they develop, which will in turn play a central role in the health care received. However, even before this point is reached, the client's understanding of his or her experience will play a role in whether or not treatment will be sought in the first place. In the domain of mental health, the understandings of family members and care givers may also play an important role as it may be they who seek medical assistance for the client. When a person (or his or her family) does in fact seek medical help for their complaint is an area of particular interest in the area of psychosis, where there is increasing emphasis on early intervention; explanatory models held by those concerned will have an impact on their help-seeking behaviour (Steel et al., 2006).

Within physical health, research has shed some light upon when an individual will seek help for physical complaints. Research shows that how the individual understands his or her experience is a crucial variable in determining whether and when medical help will be sought. Lau et al. (1989) found that the individual's EM for bodily complaints is consistent across time and for different illness experiences, and that the EM is a good predictor of whether or not the person will visit a doctor when feeling unwell. Similarly, Bishop (1987) found that a GP is more likely to be consulted if an individual construes his or her symptoms as being physically, rather than psychologically, caused. Another important factor in determining whether or not professional help will be sought is the availability of alternative ways of explaining the experience. Cowie (1976) reports that the decision to seek medical help occurs when a person and significant others are unable to account for symptoms within their framework of everyday knowledge.

While such research is derived from the domain of physical health, it seems likely that similar factors will also play a role in influencing when help will be sought for mental health problems such as psychosis. Once the person does in fact reach mental health services, we then have the question of whether or not the individual will engage with the service, and whether the treatment offered will be followed (or, in medical parlance, whether the individual will 'comply' with treatment). Once again, we find that both these variables are influenced by the client's understanding of their condition. In terms of engagement with services, Tait, Birchwood and Trower (2003) found that following a psychotic episode, clients who have a dismissive attitude to their experience, seeing it as having little personal relevance to them or, who 'seal over' (this concept will be discussed in more detail below) tend to have lower engagement with mental health services, whereas those who adopt a more 'integrative' attitude to their experience are much more likely to engage with services.

A number of studies have shown that whether or not clients accept the treatment offered to them by health services is influenced by the client's EM for their condition. In the area of mental health, Budd, Hughes, and Smith (1996) found that clients' beliefs are a good predictor of whether or not the client will comply with taking anti-psychotic medication. Such findings are also commonly reported in other areas of mental and physical health. For example, Heurtin-Roberts and Reisin (1992) found hypertension patients' EMs are significantly related to compliance with treatment. Of course, this is not at all surprising, as Helman, (1981) remarks 'Only if the prescribed treatments make sense to the patient will they be taken as directed'.

The failure of clients to comply with the advice given to them has led to the development of a therapeutic intervention designed to target non-compliance. Perkins (1999) suggests that patients who believe the risks of taking treatment outweigh the potential benefits are unlikely to continue using the prescribed medication and are therefore good candidates for 'adherence therapy'. This is a therapeutic approach which has as its primary goal increasing client compliance with medical advice. However, such an approach appears to assume from the outset that the client's non-compliance is irrational, and so in need of 'treatment' itself. In addition, it pays scant regard to the right of the client to decline treatment, nor does it encourage the exploration with the client of his or her EM. A more enlightened approach is recommended by Leventhal, Diefenbach and Leventhal (1992), who suggest that exploring the client's theory of illness can help shed light upon the reasons for non-compliance, and as such, rather than being something which should be subject to further 'treatment' through 'adherence therapy', non-compliance can be explored in an open and respectful way by clinicians, to help minimise potential conflict between the client and the clinical service. An interesting twist on the non-compliance literature is provided by Van Putten, Crumpton and Yale (1976) who found that for a portion of in-patients who are non-compliant with anti-psychotic medications, this may be the result of a conscious, deliberate choice reflecting the client's preference for the psychotic state over the 'treated' state. Here again we see potential for conflict between clinician and client if there is a failure to recognise that for some clients, at least some of the time, the psychotic state may actually be preferred to the medicated state.

Taken together, this research points clearly to the importance of one aspect of the relationship between client and clinician: the degree of conflict or congruence between the explanatory models they hold for the client's compliant. This will have a crucial impact on the nature of the relationship developed between the parties to the clinical encounter and hence on clinical outcomes. There is also an extensive literature which looks at the relationship between the client's explanatory model itself (as opposed to in relation to the clinician's EM) and various important clinical variables. I will now turn my attention to this literature.

4.2.2.3 Cause and outcome

A study with quite profound implications was carried out by Escher, Romme, Buiks, Delespaul and van Os (2002). This was a three year follow-up study of children who hear voices, designed to establish which children will go on to reach 'caseness' (defined in their study as needing the care of mental health services) over this three year period. They found that the progression from hearing voices to needing mental health care input was in large part associated with the child's and parents' appraisals of the voices rather than the voices themselves. That is, children or families who at the initial assessment had a more negative appraisal of the voices, seeing them as more problematic and indicative of pathology, were, over the course of the next three years, much more likely to reach 'caseness' levels, requiring input from mental health services. They found also that negative appraisals of the voices were more associated with passive coping styles. Clearly, this is an area which requires further investigation and which may have great importance in the area of early intervention, and potentially, prevention. Similar findings have been reported in the area of physical health, where Cope, David and Mann (1994) found that beliefs about viruses may be implicated in the development of chronic fatigue, by predisposing the person to prolonged disability.

While such research points to the possibility that the individual's understanding is implicated in whether or not their experience will develop into a diagnosable condition, there has been far more research into the relationship between the client's understanding of, and attitude to, their condition and the course or prognosis of the condition once diagnosed. The client's understanding within mental health is often subsumed within the concept of 'insight', which will be discussed below. Of more relevance and, I believe, more usefulness to the area of clients' understandings of psychotic experiences are the twin concepts of 'sealing-over' and 'integration' as first articulated and developed by McGlashan, Levy and Carpenter (1975), and Levy, McGlashan and Carpenter (1975). The recent revitalisation of psychological approaches to psychosis has seen a resurgence of interest in these concepts. McGlashan and his co-workers use these terms to refer to the individual's attitude to and response to psychotic experiences. Those who 'seal over' tend to have fixed, usually negative views of their psychotic experiences, and tend to dismiss these experiences as having little or no personal significance; they put little effort into trying to develop an understanding of the experience, which is largely encapsulated and dismissed as irrelevant. By contrast, 'integrators' express interest and curiosity about the experience, which they tend to see as having personal relevance. Integrators view their psychotic experiences as being somehow related to the ongoing patterns of their life and look to learn from this about themselves, seeing it as an opportunity to develop and grow. Integrators take a more open and flexible attitude to the experience, and are more likely to accept some personal responsibility, as well as see the experience as being linked to other life experiences such as trauma, guilt etc, whereas 'sealers' do not see a relationship between the psychotic experiences and prior life problems, and may dismiss the whole experience as meaningless.

Though sealing-over and integration are sometimes discussed as if they are distinct response styles, McGlashan, Docherty and Siris (1976) point out that they are best thought of as opposite ends of a continuum. McGlashan et al. (1976), through illustrative case studies, show how the same individual can fluctuate between sealing-over and integrating. They suggest that factors influencing the stance an individual adopts include the response of others around them (including clinicians) and use of medication, which may promote sealing-over. Larsen (2004) describes a small-scale study looking at how clients relate to their experience and found that clients adopt both sealing-over and integration responses to their experience, and that which stance is adopted relates to the particular context within which the client is discussing the experience.

Tait et al. (2004) elaborate further on the original model, investigating the response of clients who have had a first psychotic episode. They identified four distinct response styles: in addition to the two original states of sealing-over and integration, they report that some individuals show a more ‘mixed’ response, combining elements of both sealing-over and integration, with one tendency being more pronounced. They also found that response to psychosis predicts engagement with service (with ‘integrators’ being more likely to engage) and, further that this also relates to attachment style (with ‘sealer-overs’ having a history of poor attachment and insecure identity). Bell and Zito (2005) studied response to psychosis in those diagnosed schizophrenic and found a connection between response style and more general aspects of the person such as cognitive flexibility and interpersonal relatedness. They also note cultural differences, with non-white clients being less likely to be integrators.

As McGlashan and others have pointed out, it is not only client attitudes to psychosis that can be conceptualised as reflecting a sealing-over versus an integrative approach: clinicians’ understandings can also be considered along this continuum. Professional theories which emphasise biological factors would seem to fit more on the sealing-over end of this continuum, whereas those which locate the psychotic experience within the life experience of the client (such as psychodynamic, traumatogenic, and psychological perspectives) are more integrative in their orientation. This may have some implications for the ways in which the client responds to the experience and also for the course of the client’s condition. One largely neglected study, with quite startling results, was reported by Whitehorn and Betz (1960). They found that attitude held by the clinician towards the psychotic client and his or her experience was highly significant in influencing the outcome. Clinicians who adopted a flexible, curious attitude to the client’s inner world achieved positive outcomes for 75% of their clients, which contrasted sharply with only 27% positive outcomes being achieved where clinicians had dogmatic, inflexible, authoritarian approaches to the client's experience. The magnitude of this difference in outcomes for clients (75% versus 27%) is quite remarkable, comparing favourably with any difference found between interventions and control groups, including the use of anti-psychotic medications. Though this study is, inevitably, flawed in its methodology (with no clear control group, and measures of both clinician style and outcome in need of refinement), it is nonetheless disappointing that it has not led to further investigations to replicate or refute these findings. This research points to the role of the clinician's attitude to psychosis being an important factor in determining outcome.

Research into the relationship between client attitude to psychosis and outcome of the condition, though not conclusive, suggests that integrators fare better than those who seal over. McGlashan and Carpenter (1981) looked at inpatients with a diagnosis of schizophrenia and found some relationship between attitude to illness and outcome, with those who were less pessimistic about their experience tending to have better outcomes. Looking specifically at integration and sealing-over among those who have had mental health difficulties, McGlashan (1987) found that there was a tendency for integrators to have better outcomes. This finding was also evident, though less powerful, among those who had a diagnosis of schizophrenia.

More recent research (Birchwood, Iqbal, Chadwick & Trower, 2000a, 2000b; Drayton et al., 1998) has found a clear relationship between attitude to psychosis and post-psychotic depression, with those who seal-over being far more at risk of depression in the post-psychotic period. Birchwood et al. report that in their sample, all clients who became moderate to severely depressed following a psychotic episode had adopted a sealing-over response to their psychosis, with *none* of the integrators becoming depressed to this degree. This is quite persuasive evidence of the significance of client attitude to psychosis as being an important variable in course and outcome. Drayton et al. (1998) suggest that client attitude to psychosis and recovery styles may be related to early attachment experiences, such as trauma, and they note that post-psychotic depression bore no relation to insight. This proposal found some support in Tait, Birchwood and Trower's (2004) study, which found that 'sealer-overs' reported higher rates of childhood abuse from parents, suggesting that 'sealer-overs' may have lower psychological 'resilience' to deal with difficulties.

Bannister (1985) found that among patients on their first admission to psychiatric hospitals, those who adopted what Bannister calls 'internal' theories of mental illness (that is, 'internal' to the client's life, such as relationships, social skills, childhood experiences) were more likely to recover than those who attributed their illness to external forces (such as physical injury, distressing world events). Warner (1994), reviewing empirical studies in this area, argues that those who accept a medical diagnosis of their condition may conform to the stereotype of incapacity and worthlessness, leading to poorer outcomes. Considering the now well-recognised, though poorly understood finding that in non-industrial societies those meeting Western criteria for a diagnosis of schizophrenia tend to have better outcomes than those who live in wealthier, more industrialised societies, Waxler (1979) proposes the possibility that this difference may relate to the different understandings of mental illness found in those societies; this thesis is also discussed by Kirmayer and Corin, (1990).

One model which may help conceptualise the relationship between EM and outcome for psychosis is proposed by Lafond (1998), who draws parallels between the normal process of grieving and response to mental illness, and argues that it is crucial to consider how the person is responding to their experience, particularly for clients having their first psychotic episode. Whatever model one may adopt to conceptualise the research findings, it seems clear that client and clinician understandings of, and attitude to, psychotic experiences *do* have an impact on the course and outcome of the condition. This conclusion is consistent with that reached by Weinman and Petrie (1997; p.5) in their overview of the literature in the general field of illness perception and outcome, who summarise the research findings thus:

> 'There do appear to be some consistent relations between different illness perception dimensions and different health outcomes.'

A persuasive personal perspective on this is provided by May (2002; 2003) who argues from his own personal experience of psychosis and his clinical experience as a psychologist that developing a personally meaningful EM ('an enabling personal narrative') is a crucial part of recovery. He notes in passing that being diagnosed 'schizophrenic' was particularly unhelpful as it did not allow such a narrative.

4.2.2.4 Other clinical variables

I will now look at studies which have focussed on relationships between clients' understandings and other important clinical variables. I will provide an overview which, hopefully, is illustrative of the range of variables that have been shown to be influenced by clients' understandings.

4.2.2.4.1 Impact/distress

An important though at times overlooked aspect of psychotic experience, is the extent to which this distresses the client. The tendency to overlook this may reflect the assumption that psychotic experiences are inherently and inevitably distressing to the individual. Research, such as that by Romme and Escher (1989), demonstrates that this is not always the case. They found that significant numbers of voice-hearers have a neutral, or even positive relationship with their voices and that the degree of distress associated with voices is related to the understanding that the person has of the experience, as opposed to being attributable only to factors inherent in the voice-hearing experience itself (such as the content of the voices). Those who understood their voices in a 'benevolent' framework (for example, seeing the voices as being a part of the self, or a guiding spirit) were less likely to report distress than those whose EMs were more 'malevolent' (e.g., seeing the voices as being from a powerful negative source, such as the Devil). Thus, the understanding that one has of psychotic experience mediates the degree to which this experience is distressing. Given that one of the primary goals of mental health services is to alleviate client distress, it is clear that one must, at least some of the time, attend to client understandings of the experience to achieve this goal.

4.2.2.4.2 Self-stigmatisation

The notion of self-stigmatisation refers to the tendency that an individual may have to internalise negative social stereotypes of illness, an issue which is particularly pronounced in the area of mental health, where such negative stereotypes are pervasive. Clearly, whether or not one internalises such negative stereotypes will relate to how one understands one's experience. That negative social stereotypes of mental health problems are pervasive in western society is demonstrated by numerous studies (which will be discussed in more detail in chapter 5). For example, Giovannoni and Ullman (1963) studied attitudes to mental patients and found that both non-patients and patients held extremely negative views of ‘the mentally ill’. Gilman (1988) suggests that this process may reflect our ways of representing illness within Western culture and proposes that in the case of mental illness this can be described as ‘othering of the mad’. Gilman suggests that this ‘othering’ reflects our attempts to distance ourselves from our human fear of our own psychological collapse. However, he goes on to argue that when we then become subject to that process (that is, when we are labelled ‘mad’) we are likely to internalise our cultural ways of representing disease: we become ‘the Other’ we have feared. Wahl (2003; p.106) reports that as many as 95% of those diagnosed with mental illness have internalised negative notions of mental illness (derived from media representations, Wahl suggests) and that this causes significant damage to self-esteem. Some have suggested that the medical conceptualisation of mental health problems may make a significant contribution to self-stigma. Reviewing studies of the disease model of mental illness, one of the conclusions reached by Mehta and Farina (1997) is that those adopting an illness model for mental distress report increased stigma from other people as well as increased self-stigma in the shape of a negative self-concept. Ritsher and Phelan’s (2004) review of the literature in this area reaches a similar conclusion, noting that the process of internalising negative stereotypes of mental illness is associated with demoralization, lowered self-esteem, and unemployment. In their own study into psychotic patients, they found that internalised stigma is particularly common for this population, and that ‘alienation’ (the subjective experience of feeling not a full member of society, with ‘spoiled identity’) was a major component of this, and is associated with poorer outcomes and more depressive symptoms.

Qualitative studies have proved useful in developing an understanding of the processes involved in having self-stigmatising views on one’s condition. In the domain of chronic physical ill-health, Charmaz (1991) found that over the course of illness, people go from initially accepting illness labels, to later fighting against these as they become associated with threats to the sense of self. Charmaz views this struggle as an attempt to hold on to a positive self-concept and continuity of identity both of which are threatened not only by the chronic condition, but also by the negative stereotype associated with this. In the realm of mental health, Ridgway (2001) identified a similar process of struggling against being subsumed by one’s diagnosis. Reporting on a qualitative analysis of recovery narratives for those who have had mental health difficulties, Ridgway (2001) found a common theme in these narratives is reducing the sense of internal stigma and an important part of this is seeing that the condition does not define the self. Knight and Bradfield (2003) undertook a small-scale but in-depth grounded theory study (with only 3 subjects) of the experience of being diagnosed with mental illness. They report that participants in their study characterised being diagnosed as akin to a feeling of being ‘robbed’ of one’s emotional state and subjectivity as this is reduced to a biochemical imbalance, which feels ‘as if self is replaced by diagnosis.’ Participants described feeling as if they ‘embody’ the diagnosis and come to identify the self with the label, generating feelings of anxiety and expectations of rejection. May (2002) speaks about the importance of challenging the prevailing notion that mental health problems are to be seen only as ‘disabilities’. He suggests that this can be challenged through seeing positives in the experience and recommends celebrating the uniqueness and resilience of those who have been through the mental health services. He refers to organisations in the UK, such as the Hearing Voices Network and Mad Pride, which are challenging cultural stereotypes by promoting a more positive perspective on the experience of mental health difficulties.

4.2.2.4.3 Depression/sense of entrapment

Related to self-stigmatisation, and as already noted, research by Birchwood (1999; 2000a, 2000b) has shown that depression following a psychotic episode is associated with how the individual evaluates the experience of psychosis. Birchwood shows that suicidal thinking and depression are associated with the individual internalising social stereotypes about schizophrenia (through acceptance of the diagnosis), and having a low sense of control over illness. Birchwood, Mason, MacMillan and Healy (1993) describe a ‘sense of entrapment’ associated with particular ways of viewing the experience of psychosis, which can leave the individual feeling helpless vis-à-vis the condition.

4.2.2.4.4 Coping mechanisms

The application of coping mechanisms to deal with psychotic experiences has received considerable attention over recent years (for example, Carr, 1988; Falloon & Talbot, 1981; Tarrier, 2002). Research in this area shows that clients develop and utilise different ways of coping with their experiences of psychosis, some ways being more effective than others. These findings have been adopted clinically, where clients are often instructed in the use of different coping strategies. However, such interventions commonly overlook another important finding from this research: that clients do not develop or apply coping strategies randomly, but rather, the coping strategies clients are willing to use, are those which make sense *to the client* in terms of the client's own understanding of psychosis (Carr, 1988; Falloon & Talbot, 1981). Thus, client's EMs have an important influence on which coping strategies will be applied, and clinical interventions aimed at teaching clients new coping strategies must also consider if and how such strategies fit within the clients' EMs. Similar findings have been reported in the area of physical health. Leventhal, Easterling, Coons, Luchterhand and Love (1986) found that for cancer and hypertension patients, patients' EMs determine the coping strategies they will adopt. Kemp, Morley and Anderson (1999) note a similar relationship between illness representation and coping with epilepsy, with EM and coping style being congruent with one another. In the area of hearing voices, Romme and Escher (1993; p.8) note that if voices are seen by the individual as simply an 'illness', this prevents any form of identification with the voices, which they see as a necessary condition for effective coping.

4.2.2.4.5 Return to work/functional impact

Another important variable related to ill-health is the impact on the individual's functioning. One measure of this is the ability to return to work subsequent to the episode of ill-health. Again, we find that within mental and physical health, the individual's understanding of and attitude to their condition has an impact on the likelihood of a return to work. Weinman and Petrie (1997) found that following a myocardial infarction, patients' EMs predicted how long it would take them to return to work. Similarly, Beckham, Burker, Lyttle, Feldman and Costakis (1997) report that for patients with cancer, expectations about control of symptoms were related to, and predictive of, subsequent functioning. Within mental health Warner, Taylor, Powers and Hyman (1989) studied 54 patients who had had a psychotic episode and found that those who viewed their experience as a form of 'mental illness' had lower self esteem, felt more stigmatised, *and* that this was associated with lower social and occupational functioning.

4.2.2.4.6 Patient satisfaction

Callan and Littlewood, (1998a, 1998b) investigated factors associated with client satisfaction with mental health services and found that clients' satisfaction is greatest when there is concordance between the client's and clinician's EMs.

4.3 Insight

Before ending this chapter, it is necessary to consider the concept of insight. Insight occupies an important role within the psychiatric literature. This concept demonstrates that within mental health attention is indeed given to clients' understandings of their experience. It is true the notion of 'insight' (at first glance at least) appears to counter my argument that within mental health the client's understanding is largely neglected. I will now discuss this topic, and argue that the notion of insight, as currently used in both research and in clinical practice, does not attend to what the client believes about his or her condition, but looks primarily at whether or not the client adopts the same position as that of his or her clinician (or researcher) and, as such, is sometimes merely an extension of the biomedical perspective rather than a genuine attempt to explore what clients think.

4.3.1 Historical factors and definitions

Historical analysis (Berrios & Markova. 1998) of the concept of insight show that the exact meaning of this term changes over time, reflecting changes within the culture and dominant philosophy in mental health care. Markova and Berrios (1992) note cultural specificity to the concept of insight, pointing out that the term exists only in North and West-Germanic languages, and go on to suggest that the dominance of these languages within Western mental health research may have caused what they term an 'ontological mirage': the belief that because there is a term for the concept, it must therefore refer to something which exists universally, in all cultures, rather than reflecting the specific interests and orientation of a particular, and fairly small, language group.

An early attempt at definition of the term is found in Jaspers (1963) who described insight as residing within the client's attitude to his or her experience, and argued that clients have insight into their condition when they show 'the correct attitude to the experience': that is, recognising the experience as showing pathology in mental functioning, and understanding the experience. Jaspers (1963; p.421) believed that psychotic experiences were ‘un-understandable’ and that the patient developing insight (or understanding) was, therefore, ultimately not possible:

> ‘In psychosis there is no lasting or complete insight. Where insight persists we do not speak of psychosis but personality disorder’

The term ‘insight’ has a long tradition within the psychodynamic framework, and we can see changes in how the term is used even within Freud’s work. In his early work Freud related the term to the recovery of repressed memories, while in his later work he saw insight as consisting of integrating aspects of the id into the ego (Rosenblatt, 2004). More generally within the psychoanalytic tradition, the term is used to refer to the notion of having a deep awareness of self and appreciation of the meaning of one’s experience. A classic and much quoted exposition of the psychodynamic notion of insight was provided by Lewis (1934) who, echoing Jaspers, defined insight as consisting of the ‘correct attitude to a morbid change in oneself’. This ‘correct attitude’ is possible only if the client has both an awareness of change in the self and an understanding of what change this change means.

Similar notions are found in more recent, medically-oriented definitions of insight. Fulford (1998) reports that, medically, insight refers to a client having awareness of symptoms and recognition that these are symptoms of an illness, an understanding of the causal origins of the illness, along with an appreciation of the seriousness of the condition and the willingness to comply with treatment. Other writers such as David (1990) and Greenfield, Strauss, Bowers and Madelkern (1989) have also broken insight down into component parts. For example, David (1990) identifies three related dimensions, which he argues together constitute insight: a recognition that one has an illness, compliance with treatment, and the ability to label mental events (such as hallucinations and delusions) as pathological. David and others have developed measures of insight based on these component parts.

4.3.2 Insight and other mental health variables

Despite Jasper’s (1963) claim that insight is impossible within genuine psychosis, there has been quite extensive research which has investigated the nature and extent of insight in different clinical presentations such as delusions (Garety, 1998) and bipolar disorder (Pallanti, et al., 1999). Other researchers have considered the relationship between measures of insight for those with diagnoses of schizophrenia and other clinical variables such as quality of life (Doyle et al., 1999) and outcome (Schwartz, 1998).

Within the psychiatric literature, there is an implicit assumption that insight is a 'good thing' and that those who have insight are likely to fare better as far as treatment and outcomes are concerned. However, this assumption has been called into question by research which shows that insight (meaning seeing one's experience as indicative of a mental illness) can be associated with worse outcomes for clients. Studying the relationship between measures of insight and symptom severity, Doherty (1975) found that denial of illness was actually associated with better outcomes and fewer severe symptoms, whereas those who accepted that they had an illness were likely to have more severe symptoms. Dixon and King (1998) found that denial or unawareness of symptoms by patients diagnosed with schizophrenia was associated with less subjective depression for the client. Dixon and King (1998; p.95) caution that 'attempts to increase insight among such patients, if successful, may result in increases in depression'. Similarly, in a qualitative study of previously hospitalised patients with psychotic experience, Lally (1989) found that those patients who reject the diagnostic label (thus, demonstrating a 'lack of insight') are less likely to be engulfed by their experience and maintain a healthier self concept. Morrison et al. (1977) found that psychiatric clients with medical views of mental illness (the 'correct attitude') tended be more dependent on mental health services, whereas those who rejected a medical conceptualisation and adopted a more psychosocial view of their experience were likely to be more independent. Research such as the above forces us to question what might be meant by the 'correct attitude'. Clinically, it would appear that 'insight' can be associated with higher levels of severe psychotic symptoms and depression, lower self esteem, and greater dependence. Surely, a requirement of an attitude being considered the 'correct' one would be that it is associated with better, not worse, outcomes for clients.

4.3.3 Critique of insight

Other questions have been asked about the validity of the concept of insight. Johnson and Orrell (1996) found that psychiatrists' judgements of insight (based on case vignettes) were influenced by patients' ethnicity, with patients who were described as ‘white’ being considered to have more insight into their condition. This finding points to one of the many factors which may influence clinical assessments of insight. Johnson and Orrell (1995) discuss the social aspects of insight, and point out that these are often overlooked or considered irrelevant. They argue that there is a variety of cultural and personal factors which influence how a patient will see a problem, and the concept of insight does not permit these factors to be considered.

Although these clinical critiques of insight are, of course, significant, for the purposes of the current discussion, far more damming is the critique of the very concept of insight. Defined by both medical and psychodynamically-oriented practitioners as having the ‘correct attitude’ to one’s condition, this begs the question of *which* attitude is the correct one (if indeed there is such a thing as the ‘correct attitude’). In practice, what notions of insight tend to address is the extent to which the client’s understanding corresponds to that of the clinician. However, knowing that the client does not share the clinician’s understanding of their experience gives us little information about what the client actually believes. Kirmayer and Corin (1998; p.212) provide a thoughtful and compelling overview of insight, discussing the role of cultural factors as well as the changing understandings within medicine. In discussing the usefulness of the concept, they point out that:

> ‘If the notion of insight is meant to characterise the patient’s position towards the illness, criteria other than mere conformity to the medical model must be used.’

They go on to argue that if all we do is consider the extent to which the client views his or her experience in medical terms, this elevates the clinician’s position, while devaluing the client’s understanding (Kirmayer & Corin, 1998; p.195):

> ‘The psychiatric concept of insight privileges the professional explanation of events in terms of disorder or disease over the patient’s lived experience.’

In a discussion of the meaningfulness (or otherwise) of the literature relating to insight Beck-Sandler (1998) reaches a similar conclusion, namely that it is the concept itself which is flawed:

> ‘It is the concept of “insight” itself, not just the assumptions which follow from it, which is fundamentally flawed.’

Beck-Sandler (1998) comments also on some of the statistical qualities of insight, pointing out that it has poor construct validity, and that is has been variously defined in different studies, reflecting the interests of the particular researchers. He concludes that the concept provides little information about clients' attitudes to and understandings of their experience, and argues that the concept of explanatory model is far better suited to investigations in this area as it goes much further towards exploring the complexity of how clients understand their experience and the needs clients may have in this regard. Perkins and Moodley (1993) go a step further in their rejection of insight by arguing that the concept reflects arrogance on behalf of those who use the term (assuming, at it does, that the researcher's or clinician's perspective reflects the 'truth' of the matter) and it risks alienating service-users who may choose to view their experiences differently. Along similar lines, Leudar and Thomas (2001) suggest that within standard psychiatric accounts, the notion of insight requires that the client ignores his or her experience and leaves the business of making sense of this to the 'experts'.

Thus, for the purposes of the present research, the concept of insight has limited relevance, and certainly much less than the notion of explanatory model, which allows far greater exploration of what the client actually believes. Evaluating the client's perspective purely, or primarily, in terms of whether, and to which extent, it agrees with one's own perspective (and, as far as current usage of insight is concerned, this is usually a biomedical framework) limits the clinician's ability to appreciate the client's formulation in its own terms. Bannister's (1985; p.14) comments sum this up perfectly:

> 'Insofar as the patient's formulation is seen as itself symptomatic of illness, it is not listened to seriously, nor is it interrogated in a way which would help the patient reflect and elaborate.'

Having now discussed the place and importance of the client's understanding within the clinical field, I will now move on to discuss research which investigates members of the general public understand those experiences that are labelled 'psychotic'.

5. General public and cross-cultural understandings of psychosis

In this chapter I will consider research into beliefs about psychosis held by members of the general public, including family members of those who have psychotic experiences, before considering understandings of psychosis from a cross-cultural perspective. As we will see though considering research in this area, general public understandings of psychosis are characterised by a wide diversity of ways of conceptualising the nature of madness.

5.1. General public understandings of psychosis

How the general public view mental illness is an area that has been subject to considerable research over recent years. Attitudes of the general public towards mental illness are clearly of more than merely academic significance, as these attitudes will have some impact on how people who are considered to be mentally ill are seen by and treated by other members of the society within which they live. Research into the attitudes of the general public to mental illness can be traced to the classic studies carried out by Nunnally (1961), who reported on survey research that he carried out in USA between 1954 and 1959. In this research, Nunnally looked at what the public think about 'mental illness' and 'the mentally ill', reporting that the views held by the general public are characterised by fear, distrust and dislike, and that the mentally ill are commonly seen as lacking will power. Nunnally notes that the public differentiated between the then generally used terms of neurotic and psychotic, with those who were viewed as psychotic being seen as relatively 'worthless' and more unpredictable in their behaviour.

A decade later, Rabkin (1972) reviewed the research carried out since Nunnally's seminal work and notes that the public were consistently found to have negative views of the mentally ill. In addition, research reported that those who themselves had been diagnosed as having a mental illness commonly espouse negative attitudes towards people with mental illness. However, research by Crumpton, Weinstein, Acker and Annis (1967), comparing the views of 'normals' (that is, those with no diagnosed mental illness) with the 'mentally ill', found that both held negative views about 'mental illness', but that they differed in that 'normals' tended to view mental illness in terms of sickness and danger, whereas those who had experienced mental illness tended to view these experiences in moral terms (such as seeing those who are mentally ill as criminals or sinners).

Though it is difficult to gauge the attitude towards mental distress held in previous generations, Grant (2001) endeavoured to capture views towards mental health problems held in New Zealand in the 1940s and 1950s. Making use of what historical records were available (such as those published in local medical journals, government reports, newspaper and magazine articles, and autobiographical works such as Janet Frame's), Grant (2001) concludes that attitudes to mental illness in New Zealand were similar to those found in the USA by Nunnally (1961), being characterised by a general fear of the insane, with stereotypical negative views being commonplace. In addition, Grant (2001) notes that within families the way of responding to having a member with mental health difficulties was to try to conceal this, as it was associated with shame and embarrassment for the family.

More recent investigations have considered not only attitudes to mental illness, but also understandings of the causes of mental distress. Read and Haslam (2004) review research carried out in various parts of the world (including England, Ireland, New Zealand, Australia, Canada, Germany, Turkey, India, and USA) and conclude that the general public strongly prefer psychosocial understandings of psychosis, and show a similar leaning towards psychosocial interventions for mental health problems of this nature. These findings show that the public have a quite different perspective on mental illness from the dominant medical paradigm which tends to place emphasis on biological rather than psychosocial factors (Read, Haslam, Sayce & Davies). Examples of this research include Eisenbruch's (1990) survey of beliefs of mental distress, using the Mental Distress Explanatory Model questionnaire on a sample of 260 US college students. Eisenbruch reports that this sample generally held multiple beliefs about mental illness, sometimes incorporating both naturalistic and supernatural components simultaneously. Furnham and Bower (1992) report that when asked to explain the type of behaviour which is considered diagnostic of schizophrenic, most British people believe that this behaviour is symbolically meaningful, rather than being signs of illness. They also note that the most commonly reported explanation for schizophrenia was childhood trauma and that psychotherapy was considered the most appropriate treatment.

Jorm et al. (1997) report that the public give psychosocial explanations for both depression and schizophrenia, with, once again, childhood events being commonly offered as explanations for conditions such as schizophrenia. This is a finding which clearly causes some chagrin for Jorm et al. (1997), who complain that the general public lack 'mental health literacy', presumably because the views they hold are not in accord with biological framework preferred by the authors. Similar findings are reported by Chung, Chen, Lam, Chen and Chan (1997) on research carried out in Hong Kong. They compared attitudes of the general public, patients, and relatives of those with mental illness. Again, they note that the public veer towards psychosocial explanations, which the authors attribute to 'lack of awareness', and they suggest that this indicated a need for 'psycho-education'. A number of large-scale studies carried out by Angermeyer and colleagues in Germany report a similar preference for psychosocial explanations for schizophrenia among members of the general public, as well as those who themselves have this diagnosis (Angermeyer & Matschinger, 2005; Angermeyer & Matschinger, 1994; Angermeyer, Klusmann & Walpuski, 1988).

We see then that the general public in numerous parts of the world tend to view psychosis and schizophrenia in psychosocial terms, where factors such as trauma, recent life events, and stress are seen as likely causes of the condition, and psychosocial interventions are considered appropriate. This perspective contrasts with the dominant paradigm of medicine with its emphasis on biological causation and treatment. I will return to this difference below when discussing stigmatisation: for the time being it is sufficient to note that members of the public favour psychosocial explanations.

5.2. Family members' understandings

Researchers have also investigated how mental illness is viewed by those who have someone diagnosed as mentally ill within the family. Pollock (1995) reports on a qualitative study comparing the attitudes of families who had a member with mental illness (schizophrenia or depression) and families with a member who had multiple sclerosis. Pollock (1995) reports that families who had a member diagnosed as having schizophrenia tended to think of this as being caused by some intrinsic deficit within the individual who was viewed as having been born with the condition. 'Attitude of mind' was seen by families as being the main mechanism open to an individual for fighting their condition. Families who had a member with multiple sclerosis or with a mental illness other than schizophrenia viewed the ‘attitude of mind’ of the individual as being crucial to allowing them to deal with their difficulties. However, schizophrenia was seen within the family as a condition which affected the core of the ‘self’, so rendering the individual unable to fight it.

Angermeyer and his co-workers in Germany report on a number of large-scale interview studies in Germany. Consistent with other findings, Angermeyer et al. (1988) found that family members also favoured multifactorial, predominantly psychosocial explanations for psychosis, with the most frequent explanations being ‘recent psychosocial stress’. They note that while profiles of both patient and family groups were similar, there was nonetheless discordance between patient and family when these were compared pairwise: that is, concordance was noted on a group level, but not when individual patients and their families were compared to each other. Another interesting finding is reported by Angermeyer and Matschinger (1996b), who found that relatives of people diagnosed with schizophrenia differed in their explanations from members of the general public. Family members were found to be more likely than members of the general public to see biological factors as causing schizophrenia. The most common explanation offered by families was a ‘weak constitution’, although other factors, such as genetics, unconscious conflict, and psychosocial stress were also rated, as was God/fate. Discussing the discrepancy between these findings and others, Angermeyer and Matschinger (1996b) point out that the family members in their sample may not have been a representative sample as they were drawn from self-help organisations which may tend to promote a more medically-oriented view. By contrast, Phillips, Yongyun, Stroup and Lihua (2000) found that in China, families attributed 84% of the cause of schizophrenia to factors other than biology. They also note a difference between urban and educated families, who tended to posit internal causes (that is, within the patient), whereas rural and less educated families were more inclined to offer external explanations (such as spirits or mystical forces).

5.3. Other factors which influence understandings of mental illness

In addition to the differences of understandings found between the general public and those who have a family member with a diagnosis of schizophrenia, other factors have been identified which seem to have some bearing on attitudes to mental illness. Farina (1981) reports that gender has a role to play. Research suggests that although men and women express similar attitudes and beliefs towards mental illness, women tend to behave more sympathetically towards those considered mentally ill. A similar finding is reported by Arn, Ottosom and Perris (1971) in Sweden.

Age is another factor which influences attitude to mental illness. Weiss (1985) studied attitudes of children between the ages of 7 and 14 and reports that as children get older, they become better at distinguishing mental illness from other forms of illness, coming to see the mentally ill as more similar and less inferior to themselves, and to consider mental illness as less of a threat to society. However, a later study by Weiss (1986) found that negative attitudes to mental illness are evident in kindergarten and reports that these didn't change with age, with the mentally ill being seen as crazy, and generating fear and disgust.

Another commonly considered variable is that of personal exposure to people who have had a mental illness. Angermeyer and Matschinger (1996a) report that people who have some kind of personal contact with a mentally ill person tend to hold more positive views, with greater exposure being associated with people being less anxious about mental illness and expressing less desire for distance. Education level has also been implicated in attitudes to mental illness, with Clark and Binks (1966) finding that among adults, better educated people had more liberal, accepting attitudes towards the mentally ill.

There is some evidence which shows that attitudes to mental illness are, to some extent at least, malleable. Fisher and Farina (1979) carried out a study of beliefs about mental illness held by students and found that these attitudes were influenced by the content of courses students were exposed to. Students were given classes which emphasised either a social learning or a biosocial view of mental illness; students' views of mental illness shifted in the direction one would expect, veering closer to the views espoused in their lectures. Interestingly, Fisher and Farina (1979) report that the classes seemed to have an impact on how students responded to their own personal distress, with students in the biosocial class being more likely to feel helpless in the face of personal difficulties and use external coping strategies (such as drugs and alcohol).

5.4. Information about mental illness

The role of information about mental illness clearly has a role to play in attitudes held towards those who suffer from mental health problems. This information can come from a variety of sources, some more formal (such as university classes) than others (such as mass media portrayals of mental illness). Wahl (2003) looked at public images of mental illness, as portrayed through movies, books, newspapers and other mass media. He comments on the typical representation of mental illness being one which is both inaccurate and likely to encourage negative attitudes. He notes that the general impression of the mentally ill conveyed through mass media is one of unpredictability and dangerousness, both being exaggerated in media portrayals as compared to the actual levels of dangerousness for this population.

The language used to describe mental health problems can also have an effect on how people think about such difficulties. Investigating what impact a diagnosis may have on attitudes, Angermeyer and Matschinger (1996c) carried out an experiment in Germany in which they gave case history vignettes to members of the public to read. They found that if vignettes included a diagnosis of schizophrenia (with all other information remaining the same) there was then an increased tendency for people to explain the behaviour described in terms of biological factors, and to expect poorer prognoses. They note that those with higher education were more influenced by the use of the term schizophrenia than those with lower education.

5.5. Stigmatisation and destigmatisation programmes

This brings us now to an important consideration in terms of attitudes to mental illness: are some attitudes more associated with stigmatisation of those who have mental health problems? The research findings in this area point quite clearly to there being a relationship between the understanding one has of the causes of mental illness and the degree to which those with mental health problems are stigmatised. Reviews of the research in this area by Mehta and Farina (1997), Read and Haslam (2004) and Read et al. (2006) all conclude that biological models of mental illness are associated with increased stigma (from self and others) and increased discrimination against those with mental health difficulties. Mehta and Farina (1997) found that holding a disease perspective of mental health problems had an impact on behaviour, with US college students who were told that their partner in a learning task was performing poorly because of mental illness treating their partner more harshly, in comparison to being told that their partner's poor performance was due to social stressors.

Dietrich et al. (2003) looked at this issue cross-culturally and found that in a variety of cultures biological notions of mental illness are consistently associated with a desire for greater social distance from those considered mental ill. Reflecting on the import of their findings for efforts to reduce stigmatisation, they comment (p.354):

> 'Our study raises concerns that promulgating biological concepts among the public might not contribute to reducing social distance desired toward people with mental disorders.'

This is an issue of some importance as, commonly, programmes designed to reduce stigmatisation operate within the medical framework, encouraging the view that mental illness is 'an illness like any other illness'. Indeed, this is a perspective embraced by some destigmatisation programme in New Zealand. As summarised in a recent NZ Mental Health Commission report critiquing this view (Yee & Lapsley, 2004; p.5):

> 'The medical model argues that people with a mental illness should not be stigmatised or discriminated against since they are blameless victims of their illness, just like people with a physical illness. Biological foundations of mental illness are emphasised in this approach, which often sees educating the public about mental illness as a key strategy.'

Read and Haslam (2004) are critical of the impact of destigmatisation programmes which promote this notion, pointing out that research shows that a medical perspective on mental illness is associated with more, not less, discriminatory attitudes and behaviour towards those who are diagnosed as mentally ill. Research suggests that whatever claims one may make about the intentions of those who promote a medical model of mental illness, this perspective is associated with increased discrimination, perhaps because this view suggests that those who suffer from mental distress are not only blameless but also helpless in terms of being unable to control their own behaviour.

Corrigan and Watson (2004) argue that calling mental illness a brain disease is a moral imperative (because in their opinion, the weight of evidence supports this). They further argue, somewhat contrary to their own logic (and contrary to the evidence), that somehow this will also reduce the stigma, despite acknowledging that research suggests otherwise. Their argument is rebuffed by Luchins (2004) who points out firstly that the evidence that schizophrenia is a brain disease is far from convincing, thus challenging the notion that there is a 'moral imperative' to inform the public of this 'fact'. He also makes a valuable contribution to the debate around stigmatisation by noting that stigma may not be entirely attributable to understandings of the causes of mental illness. He reminds us that images of mental illness are shaped by a range of factors including, in the Western world at least, the poverty and isolation of those who are mentally ill. He argues that factors such as these contribute to the negative stereotypes held of mental illness and suggests that tackling issues such as poverty would be one way of tackling stigma.

Angermeyer and Matschinger (2005) report on a recent large-scale interview study in Germany and suggest that biologically-orientated destigmatisation programmes may be having some impact, though perhaps not of the kind intended. They found that the views of the general public have changed over recent years, veering more towards a biological perspective (and more in concordance with dominant professional paradigms) and that this is associated with increased desire for social distance and increased fear of those who are mentally ill. They note that while families continue to attribute the causes of mental illness to psychosocial factors there is also a greater tendency to see biological factors (such as brain disease and hereditary factors) as causally implicated, and this tends to be associated with increased stigmatisation of those who have mental health problems.

Haslam (2005) outlines a conceptual framework for understanding lay models of psychological abnormality, 'the folk psychiatry model', that posits that lay judgments about behaviour are influenced by considerations of how rare, deviant, unexpected, and hard to comprehend the behaviour is viewed to be and that these factors are associated with stigma. Haslam and Ernst (2002) suggest that information which suggests that mental health problems are biologically based encourages 'essentialist beliefs', which are beliefs that a particular category (such as a diagnosis) is fixed, immutable and homogenous. Further, they suggest that such essentialist thinking is associated with stereotyping and prejudice towards those so categorised.

We can see then that general public understandings of psychosis are an important factor in how those with mental health problems will be treated and that destigmatisation programmes which promote only biological understandings of psychosis may contribute to increased stigmatisation. Much of the research considered so far relates to understandings of mental health problems in general, and psychosis in particular, as found in the Western world. However, understandings of those experiences considered indicative of psychoses are not confined to Western cultures. When we look to other cultures, we find a vast array of perspectives on those experiences that within the Western medical framework may be construed as signs of psychosis.

5.6. Cross-cultural perspectives on psychosis

Much of the cross-cultural research into perspectives on mental health has been undertaken within an anthropological framework with writers such as Fabrega (1989) and Kleinman, Eisenberg and Good (1978) outlining the important contributions that an anthropological approach can make to the study of conditions such as schizophrenia. Kleinman (1987) argues that research and clinical endeavours can be enhanced by greater appreciation of the various ways in which mental health is considered cross-culturally. For example, the already mentioned, but poorly understood finding of better outcomes in developing countries for those diagnosed schizophrenic is a *prima facie* case for the importance of exploring how these experiences are considered and treated in different cultures (Sartorius et al., 1986; Word Health Organisation, 1979). This finding is consistent with the argument that cultural notions of illness not only shape understandings of the experience, but also influence the course of the condition and the kinds of symptoms experienced (Scheff, 1984; Townsend, 1975). Kirmayer (1994) goes further, arguing that it is not only the course of a condition that is modified by understanding, but that the very concept 'mental' is culturally relative, fitting as it does within a Cartesian notion of mind. He argues that the notion of 'mental disorder' is peculiar to Western cultures, where there is a tendency to distinguish the physical from the mental: a distinction not found universally. Kirmayer (1989) discusses research which suggests that schizophrenia presents in more somatic forms in non-Western countries, and goes on to argue that the individualistic psychological theories of the West may serve to divert attention from social, economic and political influences on health.

An anthropological perspective can also be of some importance on the clinical level. Mental health services are frequently faced with clients of diverse cultural backgrounds who bring with them their various ways of understanding the experiences they may be troubled by. Working successfully with such clients may require that clinicians have some appreciation of cross-cultural differences in how psychosis is understood and experienced. At the very least, an anthropological perspective may help the clinician realise that his or her perspective is but one among many ways of making sense of psychosis, and that this may not correspond to how the client sees his or her experience. For example, Ward (1989) points out that possession states are accepted by 90% of the world's population, though they may not be recognised within current medical diagnostic manuals. Thus, clinicians, if they want to develop good working relationships with their clients, need to be sensitive to how the client understands the experience, and culture will be an important component of this.

I will now explore some of the literature relating to how psychosis is understood within different cultural frameworks. Reflecting the unique position occupied by the indigenous people of New Zealand, I will begin this discussion by looking at Māori understandings of health, mental health and psychosis. Following this, and reflecting the cultural composition of the client population of the service within which this research was carried out I will discuss Pacific Island understandings of mental health. I will then briefly consider research which investigates understandings of psychosis in other cultures.

5.6.1. Māori understandings of health

The Treaty of Waitangi is New Zealand's founding document. Signed by Māori and the British Crown in 1840, the Treaty embodies the undertaking and the obligation that the Crown, the government and all its agencies (including health authorities) work in partnership with Māori, enable the participation of Māori, and protect the rights of Māori. This context must be taken into account when considering issues relating to Māori within healthcare. I have included Māori understandings of psychosis within lay understandings as, by and large, these indigenous conceptualisations have more in common with lay perspectives than with professional ones.

To understand Māori understandings of psychosis, it is necessary first to consider the general framework of health and well-being that these fit within. Durie (1994; 2001) provides a comprehensive overview of Māori conceptualisations of health, which I will endeavour to summarise here. Durie makes clear that Māori approaches to health and well-being differ considerably from their conventional Western (or 'Pakeha') counterparts. One notable difference between Māori and Western notions of ill-health is in the locus of health and ill-health: Western notions tend to locate this *within* the body of the individual, whereas Māori view both health and illness as located within broader social networks, such as the family or the tribe.

Durie (1994) explores Māori perspectives on health, noting that while many of the concepts he invokes are rooted in Māori tradition, these models relate to contemporary Māori conceptions of health, and hence continue to provide a general framework within which many contemporary Māori may conceptualise their health difficulties. Durie identifies factors which are considered essential to Māori general well-being and which clearly distinguish Māori from Pakeha conceptualisations of wellness. These include concepts such as 'mauri', a central principle in Māori views of health, which has no direct equivalent in English, but which Durie likens to a 'life force' or a 'life sustaining principle'. Durie also discusses what he identifies as the 'three institutions of health' for Māori: land, language, and family. Durie argues that access to these is crucial to Māori, and disturbance in one or more domain may be associated with poor health. In contrast to Pakeha notions of health and sickness, which are more individualistic in their orientations, Durie (1997) points out that notions of 'whanau' (family relationships) and 'whanaungatanga' (process by which whanau ties and responsibilities are strengthened) are central components of Māori health, such that ill-health may be viewed as caused by disturbances in these relationships.

Durie (1994, chapter 5) discusses different models of Māori health, and focuses on the 'whare tapa wha' (four-sided house) model, which, though not the only Māori framework for health, is, Durie notes, the most widely used currently. 'Whare tapa wha' is a model of health which posits that health is a 'house' supported by four related walls, each of which contributes to general well-being. These four walls, which represent different aspects of health as seen by Maori, are:

- Taha Wairua (relating to the spiritual side of being, and often seen as the most essential)
- Taha Hinengaro (pertaining to the mental side of being, including thoughts and feelings)
- Taha Tinana (physical being)
- Taha Whanua (the extended family and support system)

As with the walls of any house, the structure can be threatened if there is a weakness in any one of these aspects of health. These four 'walls of health' are each central to well-being and are considered to be part of an integrated whole, which includes not only the individual person, but also his or her family, community relationships and connection to tribal lands, each of which is fundamental to a sense of well-being.

When considering the causes of ill-health, Māori perspectives look beyond the individual concerned and consider broader social factors as important. Durie (1994; p.16) observes that for Maori:

> 'Theories of causation relate disease and illness to wider social, spiritual, and environmental events and did not confine them to explanations based only on the behaviour of the affected individual.'

So, explanations of ill-health for Māori include the possibility that the causes of ill-health are not located entirely within the individual, but may be viewed as reflecting upon, and located within, the individual's whanau.

Durie (1977; 1994, chapter 5) notes that in general terms Māori view sickness as being related to some infringement of 'tapu' (or sacred laws) by the individual or family and distinguish between illness which has no obvious physical cause ('mate atau') and illness caused by accidents, or injuries from battle ('mate tangata'), where the physical cause is more obvious. Durie argues that for 'mate atua' (which will include most cases of mental health problems as well as a wide range of physical problems) the cause of illness will be viewed as being an infringement of some law of tapu and this will often be an unspoken fear held by the client and whanau, should the clinician not allow this to be expressed.

5.6.2. Māori understandings of mental health

Durie (1999) notes that the greatest threat to Māori health is now mental health, though he points out that this has not always been the case. The past 50 years or so have witnessed significant increases in the numbers of Māori presenting to mental health services. Sachdev (1989) studied historical data relating to psychiatric presentations and concludes that on most measures (such as outcomes, suicide rates, symptom severity), Māori have fareed generally worse since the 1950s. Durie (2001) notes that Māori have gone from being under to over-represented in mental hospitals, having higher than average rates of schizophrenia. Durie (1999) notes that compared to figures for Pakeha, Māori fare worse on admission and readmission rates to hospital (particularly for psychoses), and on drug and alcohol use, with Māori men between 20 and 29 years old being at greatest risk of mental illness. A number of factors have been identified as being associated with these increased risks of mental illness for Maori. These factors include not being closely associated with family and Māori culture, supporting Durie's contention that family, language and land are pre-requisites for health among Māori. Consistent with this, Marsden (1986) argues that for Maori, mental health difficulties reflect a loss of connection with Māori traditions and in particular with Māori spirituality and that recovery will be made through a rediscovery of what has been lost.

In addition to the general framework for mental health which I have outlined, Māori also have specific concepts which relate to experiences that in Western culture might be considered signs of psychosis.

- "mate Māori" and "makutu"

Durie (2001, chapter 1), discussing culture-bound syndromes, considers the notions of 'mate Māori' and 'makutu', both of which are seen by Māori as causes of ill-health or uncharacteristic behaviour. In 'mate Māori' ill-health is seen as stemming from the infringement of a tapu (tribal law), whereas a 'makutu' is a disturbed state believed to have been caused by an indirect punishment (such as a curse) from a malicious outsider. Both mate Māori and makutu are explanatory frameworks for the kinds of disturbed behaviour that from a Western medical perspective may be construed as signs of psychosis. As Durie points out, when the individual and/or whanau construe uncharacteristic behaviour as either mate Māori or makutu, they will, in all likelihood, resist medical intervention. Given that the experience is construed as being spiritually caused, spiritual remedies are more likely to be pursued. Durie (2001; p.22) suggests:

> 'Significant numbers of Māori patients, many with overt psychotic features, will be managed away from doctors as long as the disorder is seen as mate Maori.'

He also points out that from a Māori perspective such a conceptualisation makes more sense than biological explanations (Durie, 2001; p.25):

> 'Within modern Māori society, and to many people, mate Māori sounds more convincing than explanations that hinge on a biochemical imbalance or defect in cerebral neuro-transmission.'

- 'Whakamaa'

Another culture bound syndrome discussed by Durie (2001) and others is the notion of 'whakamaa': an explanation for unusual behaviour that sees the cause as residing in the interpersonal, rather than the spiritual, realm. Whakamaa relates to feelings of shame or embarrassment brought on by a sense of disadvantage or loss of standing vis-à-vis others (Williams, 1975), or from feeling dishonoured as a result of failing to meet obligations or the demands of a situation, and a feeling of social inferiority (Sachdev, 1990). Whakamaa may manifest in the individual through slowness of movements; a lack of response to questions; avoiding engaging with the questioner; blocking of normal activity and cognitive processes; withdrawal; flight; and even suicide. In extreme causes whakaama may resemble what in the Western medical framework would be considered catatonia.

Though the Māori notions discussed so far do not correspond exactly to Western notions of mental health, what both have in common is that the behaviours discussed are, in some way, considered problematic, even if the cause and the sources of these problems are quite different in the Māori and medical frameworks. However, there are other experiences, including those that may sometimes be considered signs of psychosis from the medical perspective, which are seen quite differently by Māori. Durie (2001) notes that for Maori, hearing of ancestors or seeing dead relatives (which might be considered auditory or visual hallucinations in the medical framework) are not considered unusual, nor in themselves problematic. Fenton and Te Koutua (2000) point out:

> 'The mental health system has mistakenly diagnosed experiences such as hearing voices or having visions. Our old people believe these experiences were *te au wairua* which connected us to past present and future'.

Durie (2001; p.91) also points out that in Māori culture, metaphorical and indirect ways of communicating are highly regarded in certain situations as ways of conveying subtle nuances of meaning, but these could easily by mistaken for 'thought disorder' if seen through a strictly Western diagnostic perspective. Here then we have examples of experiences, or ways of communicating, which to Māori may be viewed in a generally positive way, but these very same experiences may, if one is not sensitive to the role of culture in determining the meaning and significance of experience, be viewed from a Western medical framework as pathological indicators of a serious mental health problem such as psychosis. Again, we see the importance of the explanatory framework that one uses to make sense of experience and the quite different implications that derive from different frameworks. Healing methods associated with Māori views of mental health problems are outlined in Durie (1994) but will not be discussed here as our primary concern at this point is with ways of understanding psychosis rather than ways of healing.

5.6.3. Pacific Island understandings of psychosis

Another cultural perspective which merits special attention in this thesis is that of Pacific Islanders. This is so for two reasons: firstly, because of the large presence of Pacific Islanders in New Zealand, and secondly, because some research has suggested this group have a greater likelihood than other groups in New Zealand of being diagnosed with psychotic disorders (Pulotu-Endemann, Annandale & Instone, 2004), a statistic reflected in the clinical service within which this research was carried out, with 30% or more of the clients of the service being Pacific Islanders (in an area where Pacific Islanders are approximately 12% of the population).

As Bathgate and Pulotu-Endemann (1997) point out, there is a diversity of peoples covered by the term ‘Pacific Islander’. This diversity includes people whose geographical and cultural origins vary, covering a number of different Pacific Islands (Samoa, Cook Islands, Tonga, Niue, Tokelau, and Fiji). There is also diversity in terms of the range of experiences that those identified as ‘Pacific Islanders’ have, given that this term is used to cover both New Zealand-born people of Pacific Island ethnicity and those who have moved more recently to New Zealand. Despite this diversity, Bathgate and Pulotu-Endemann (1997) note there is also considerable commonality among Pacific Island people’s beliefs regarding mental illness, and as such, it is possible to comment on ‘Pacific Island’ understandings of mental illness, while acknowledging that there is, inevitably, some variation.

The most widely used general framework for conceptualising Pacific Island perspectives on mental health is the fonefale (*fone*: meeting of significance; *fale*: house) model as developed by Poluto-Endemann, Crawey and Stanley-Findley (1995) and Poluto-Endemann et al. (2004). This model has much in common with the “whare tapa wha” model discussed above and, like that model, it is commonly depicted graphically using the model of the Samoan meeting house (see Peach, Ehau, de Souza & Nonu-Reid, 1997 for an illustration). Though the model is developed from Samoan culture, Poluto-Endemann et al. (1995) propose that it can be applied more broadly to encompass the perspectives of other Pacific Islanders. Like the Māori model, the fonefale model considers that spiritual, physical, and mental factors are all essential components of well-being, as are broader contextual considerations such as family, culture, environment and time. Poluto-Endemann et al. (2004) explain the metaphor of the model in the following way: the house (or *fale*) has as its foundation the family, with the floor of the house representing genealogical links, and the shelter being provided by cultural values and beliefs. The four posts upon which the roof rests represent the inter-connected aspects of spiritual, physical, and mental well- being, with the fourth post including ‘other’ important aspects of mental health (such as gender, age, sexuality, etc.).

Pacific Island perspectives on mental health tend to embrace physical and spiritual matters and to see familial and cultural factors as being important in understandings of the cause and location of illness (Bathgate & Pulotu-Endemann, 1997; Poluto-

Endemann et al., 1995). Mental illness is seen not as located or originating solely within the individual, but rather is considered a manifestation of spiritual forces, or of ancestral spirits, who have taken possession of the person, possibly because the family has broken a custom, or have offended spirits in another way, which may result in mental health difficulties for the individual and family. As such, it is common for traditional healing methods to involve the whole family, rather than just the troubled individual.

Examples of specific notions of mental illness which relate to psychosis include the Samoan concept of 'ma'I fasia', which explains hallucinations and other out-of-character behaviour as resulting from the person being occupied by a spirit which can cause hallucinations, and the Tongan concept of 'fakaselesele' (translated as 'totally insane') which is attributed to the effect of ancestral spirits on the individual/family (Bathgate & Pulotu-Endemann, 1997; Poluto-Endemann, et al., 1995). Tamasese, Peteru and Waldegrave (1997) used a qualitative methodology to look at Samoan understandings of 'mental unwellness' and report on differences between traditional Samoan understandings of 'mental unwellness' (as expressed by elders who had greater access to this information) and understandings of the causes of mental illness for Samoans living in New Zealand. Traditional understandings of mental illness attributed this to breaches of custom, with the focus being on the balance of social relations within and between families and villages. This may result in a curse ('malaaumatua') being placed on those who have breached the custom and the weight of this curse may carry through subsequent generations and manifest itself through mental illness. By contrast, Samoans who live in New Zealand view mental illness as caused by these traditional notions, but they also invoked a range of psychosocial stressors which were also considered to cause mental illness. These psychosocial factors included poverty, poor housing, cross-cultural marriage, loss of extended family support, racism in schools (for children) and isolation. This report nicely illustrates the point made above, that Pacific Islanders have varied experience which influences understandings of mental illness, although some commonality is also apparent.

Finally, Puloka (1999) discusses the Tongan notion of 'avanga', which is considered a mental illness of short duration, believed to be caused by 'a spook' (a spirit or ghost).

Symptoms of ‘avanga’ include inappropriate, erratic and agitated behaviour, talking to one’s self or to an imaginary companion, and feeling compelled to go to a quiet location (such as a burial place, the bush, or the beach). Puloka (1999) argues this is a culture-bound syndrome distinct from, though clearly showing some similarity to, Western notions of psychotic experiences. Looking at the experiences of Pacific Island users of mental health services in New Zealand, Malo (2000) reports that faith and spirituality were viewed as very important factors in understandings of mental health problems (‘aitu’), which may be seen as punishment for past sins committed by the client or by family.

5.6.4. Other cross-cultural perspectives

There is extensive anthropological and cross-cultural research into cross-cultural understandings of madness. A thorough overview of this literature is not possible here. Instead, I will briefly discuss some examples of research into how madness is understood in different parts of the world, in order to illustrate the range of understandings.

The tendency to see mental distress as being caused by spiritual factors is not restricted to Māori and Pacific Islanders. Aboriginal Australians share much with both these cultures in terms of understanding mental distress, expressing the belief that this may be caused by sorcery which effects the whole clan not only the individual. This reflects the belief that mental experiences are not private, but are experiences shared within the clan (Eastwell, 1976). Patel, Musara, Butau, Maramba and Fuyane (1995) report that the way of categorising madness in Zimbabwe resembles Western categorisations. However, when it comes to understanding causes of madness, explanations which involve spiritual causes, witchcraft and ancestral spirits are more prevalent in Zimbabwe. A similar tendency to attribute mental distress to supernatural causes has been noted among Malays, where 75% attribute psychosis to supernatural causes, a view associated with increased drop-out from services and poor medication compliance in patients (Razali, Khan & Hasanah, 1996). Phillips, Pearson, Li, Zu and Yang (2002) report that Chinese beliefs regarding aetiology of mental illness often intensify stigma. They found that Chinese, particularly in rural areas, commonly see schizophrenia as a form of punishment from ancestors for the family’s misbehaviour, a view which tends to pathologise the family. Similarly, in a report on the mental health of Asians in New Zealand, the authors note that many Asians view schizophrenia as a supernatural punishment for wrong-doing, which causes intense shame for the family (Ho, Au, Bedford & Cooper, 2002). A recent study by Das et al. (2006), notes that relatives of people with a diagnosis of schizophrenia invoke both traditional ‘supernatural’ beliefs and ‘naturalistic’ (i.e. medical) beliefs about the causes of schizophrenia. They note also that following ‘educational intervention’, which consisted of presenting a biomedical perspective, relatives’ beliefs changed, becoming more aligned with the biomedical framework. This study has been challenged by Taitimu and Read (2006) who suggest this fails to respect indigenous beliefs and overlooks the evidence suggesting that biomedical understandings are associated with more, not less, stigma.

Research such as the above illustrates significant differences found across different cultures in terms of the ways in which madness is understood. However, it would be a mistake to assume that this necessarily implies that we will find uniformity within a given culture, particularly when we consider the diversity found within ‘Western’ cultures. For example, Townsend (1975) compared lay understandings in Germany and USA and reported that Germans tended to view mental illness as inherited, biological, enduring, and not influenced by personal effort. By contrast, in USA, there was a greater tendency to think of mental illness as more transient and more likely to be associated with difficult personal circumstances. Also, Americans expressed a stronger belief that mental illness can be influenced by one’s personal effort. Within USA, different understandings have been reported for different ethnic groups. Comparing attitudes of black and white Americans, Tucker (1979) reported that blacks held more stereotyped biomedical views than did whites. Other cross-cultural research has reported agreement between different, even quite diverse cultures. Dietrich et al. (2003) compared attitudes to mental illness in Mongolia, Russia and Germany. In all three countries, the most common response was to see mental illness as being caused by acute stress brought on by life events, with biological causes (such as brain disease or heredity) coming second.

To conclude this section, the research discussed here illustrates the wide range of ways of understanding mental illness in general, and psychosis in particular, that we find among different people in different parts of the world. Further, different understandings have different implications for issues such as whether or not the experience will be construed as problematic, and if so what might be considered an appropriate response, attitudes that the individual and others may have towards recovery and also stigmatisation of the individual and/or the family by the wider community. Such research reminds us that the Western, biological understanding of psychosis is but one among many possible understandings.

6. The subjective experience of psychosis

The focus in this chapter will be on how people who have first-hand experience of psychosis make sense of and relate to this experience. I will begin by considering research into the subjective experience of psychosis, before discussing what I will refer to as 'first-person accounts': that is, accounts of psychosis that have been composed by those have had such experiences. I will end this chapter by discussing the recovery moment, which grew out of personal stories of recovery.

Psychotic experiences are, by definition, subjective experiences. Clinically, making a diagnosis that someone has some kind of psychotic disorder depends largely (though not entirely) on the individual's report of subjective experiences. Unlike in other areas of medicine, there are no biochemical tests that can be carried out to establish a diagnosis of psychosis (Andreasen, 1997; Newnes, 2002). While observed behaviour may inform the diagnostician (particularly in the cases of catatonia and thought disorder, where subjective reports of the purported underlying experience may not be forthcoming), ultimately it is the client's subjective experiences upon which the diagnosis rests, whether this subjective experience is accessed through client reports or through clinicians' deductions based on observations of the client's behaviour. This reliance on subjective experience is as pronounced in research as it is in the clinical domain. In short, the individual's reports of, or behavioural manifestations of, subjective experience are a *sine qua non* for investigations into the nature of psychotic experience. One might reasonably expect, therefore, that research into subjective experience would be the cornerstone of research into psychosis.

However, when we examine the research literature on psychosis, we find that research into subjective experience is a largely neglected field with commentators repeatedly lamenting the paucity of research in this area. Kaplan (1964; p.vii) in his introduction to a rare compendium of clients' accounts of the experience of mental illness, complains that in the search for 'objectivity':

> 'too often psychiatry has not listened carefully enough to its patients, choosing instead to take seriously only what it could observe and verify.'

A decade later, we find the situation remained much the same. Weinstein (1974; p.798) in his study into clients' perceptions of their mental health difficulties echoes Kaplan's position when he notes:

> 'Surprisingly, very few reports can be found that are concerned either entirely or in part, with patients' attitudes toward their illness.'

This neglect of the clients' perspective remains a pervasive aspect of the research and clinical literature on psychosis. Considering the experience of being hospitalised, Lally (1989; p254) comments:

> 'In general there has been a neglect of the patients' perspective, and there is very little information about how people with mental disorders cope with the challenges their hospitalization and symptoms present.'

Neglect of first-hand lived experience is even noted in research into the experience of discrimination and stigma, somewhat to the amazement of Wahl (1999; p468), a leading researcher in this field, who summarises the position thus:

> 'What is conspicuously absent from these explorations of mental illness stigma is the mental health consumer – the person with the mental disorder who is presumably the recipient of stigma.'

More recent overviews of this area reach the very same conclusion: research into subjective experience remains neglected. Jenkins and Barrett (2004; p7), in their introduction to a rare text exploring subjective experience in schizophrenia, reflect that:

> 'The subjective experience of schizophrenia has been a neglected area of research in the latter part of the twentieth century.'

This position is substantiated by Calton, Cheetham, D'Silva and Glazebrook (2005), who examined the past two decades of research into schizophrenia and noted that this has been dominated by the use of quantitative methods in research (although as we shall see below, some researchers have used such methods to investigate subjective experience) and that there has been a pronounced tendency of researchers to ignore subjective experience in schizophrenia. Hardly any wonder, they conclude, that schizophrenia remains such an enigma given this tendency to overlook the very essence of madness.

Despite this general trend of disregarding subjective experience, there have, nonetheless, been those who have argued that greater attention be given to subjectivity. Strauss (2000) warns against excluding subjectivity just because conventional research methods struggle with this aspect of human experience. Strauss (2000; p.23) puts forward a convincing case for extending research to cover subjective experience, arguing that neglect of this contributes to many of the difficulties now faced by psychiatry, both conceptually and clinically:

> 'The path to finding the answers, I believe, starts with listening and observing more effectively, by noting what people with mental disorders are trying to tell us that does not fit with our diagnostic and conceptual frames of reference.'

Strauss (2000; p.20) is clear that research methods suited to this task must be adopted if we are to make progress in this field, proposing that qualitative methods are best suited to capturing what has to date been largely missed:

> 'The narrative form, at least for the present, may be the only form available to describe the complexities, meaning and depth of human experience.'

Though research into subjective experience has been largely on the periphery of the psychiatric and psychological literature on psychosis, it has not been completely absent. Indeed, there appears to be increasing interest in research into subjectivity, as evidenced by books such as that by Jenkins and Barrett (2004). They argue that research into subjective experience is becoming increasingly important, as greater recognition is given to the primacy of lived experience, and they propose that such research may help in building bridges between the conscious experience of the individual and the social realities within which we live. Borrowing terms more commonly used within anthropology and sociology, research into subjectivity is 'experience-near' (as opposed to 'experience-far'). Such research aims to yield findings which may be expressed in 'experience-near' constructs which illuminate the area being investigated (Geertz, 1993, chapter3). The current research is undertaken in this spirit, focussing as it does, on the client's lived experience of psychosis.

Evidence supporting the twin claims that research into subjective experience of schizophrenia is on the periphery of the scientific literature, but that there are signs of growing interest in the area can be seen through searches using MEDLINE and PsycINFO data bases. Using the search terms 'schizophrenia' and 'subjective experience' (which yielded more hits than either 'first-person accounts' or 'subjectivity'), we find that through MEDLINE (covering the period 1966 until 20 October 2006), 0.17% of the total schizophrenia literature related to subjective experience. For PsycINFO (covering the period 1806 until week 3, October 2006), we find this figure is a little higher, at 0.27%. This increased figure in PsycINFO is probably attributable to the fact that the data base covers more social science, whereas MEDLINE has a more medical orientation. Clearly, both figures indicate that research into subjectivity occupies a very small proportion of the literature on schizophrenia, reflecting the marginal nature of this research. However, when we do the same search, 'schizophrenia' and 'subjective experience', and limit our results to specific time periods we can see that there has indeed been a growth of research in this area, in terms of absolute numbers, and as expressed as a % of the total schizophrenia research. Comparing the decades 1965 – 1975, 1975 – 1985, 1985 – 1995, and 1995 – 2005, we find a gradual growth using both data bases. Using MEDLINE, we find the proportion of schizophrenia research which includes subjective experience has more than doubled each decade, from 0.02% (2 articles) in 1965 – 1975, growing to 0.28% (78 articles) in 1995 – 2005. A similar pattern is found using PsycINFO, with the figures growing from 0.1% (6 articles) for the decade to 1975, to 0.45% (118 articles) in the decade ending 2005. There is a clear trend of increased interest in this area, though we should not lose sight of the fact that these figures are very small, in both % figures and in absolute terms.

6.1. Research into the subjective experience of psychosis

I will now discuss some of this research into the subjective experience of psychosis, beginning by some general considerations of this research before moving on to consider specific examples of research into subjectivity. Leudar and Thomas (2001) illustrate an important caveat in research into subjective experience: the risk of taking this experience out of context and so distorting the meaning of the experience. They illustrate this point by discussing examples such as that of Socrates' *daemon*, which included him hearing a voice, which has led some to argue that this demonstrates that Socrates was psychotic. Leudar and Thomas (2001) argue that this conclusion is unwarranted and derives from imposing our current views on such experiences, and so neglecting the view of the individual and the culture within which this experience occurred. They remark (p.175):

> ‘The sensible conclusion is that whatever our own ontology we also need to understand the conduct and experience of voice hearers in terms of their own categories.’

6.1.1. Client understandings of psychotic experiences

The aspect of the subjective experience of psychosis which has been given most attention in the research is that of the client’s ‘explanatory model’ (Kleinman, 1988). As already discussed (chapter 4) the client’s explanatory model has myriad clinical implications. In this section, I will consider research which has investigated how clients actually understand the experiences seen within the medical perspective as being symptoms of psychosis/schizophrenia.

Perhaps the first question one must ask regarding clients’ explanatory models for psychosis is whether or not individuals do in fact develop understandings, or models, of their experience. Research findings are consistent in this regard: the vast majority of clients of mental health services (whether new presenters or longer standing clients) do indeed have explanatory models (EMs) for their experiences. For example, Angermeyer and Klusmann (1988) carried out survey and interview research in Germany, asking approximately 200 patients with a diagnosis of schizophrenia if and how they made sense of their experience. They found that the majority of clients had some notion of likely causes of their experience: 74% of patients express this in interview, whereas 93% of their sample were able to identify their own particular understanding of their experience from a checklist of possible causes. Similarly, Bannister (1985) studied EMs of 60 patients newly admitted to a British psychiatric hospital and found that patients had already developed fairly sophisticated understandings of their experience within the first three days of admission, with only 18% saying it was a ‘total mystery’. Further, Dittmann and Schuttler (1990) report that among patients with a diagnosis of schizophrenia, when asked about causes of their experience, only 12% were unable to offer an explanation. It is clear then, that those who have psychotic experiences do indeed strive to make sense of these experiences and build EMs for their experience.

That individuals develop notions of causes of their experience does not imply that they see the experience in medical terms. McEvoy, Aland, Wilson, Guy and Hawkins

(1981) studied the EMs of hospitalised patients with psychotic experiences. Although their sample had a long involvement with mental health services (with a mean of 13 years since the first admission to hospital) only 13% of their sample saw themselves as having an illness. Findings such as these reinforce the argument that if we want to study clients' EMs of their experience then we must move beyond the narrow illness-based notion of 'insight' (see chapter 4) and consider what clients actually believe.

Two common findings from the research into how people with psychotic experiences construe their experiences are firstly, that multifactorial explanations are not unusual, and secondly that individuals commonly identify psychosocial factors as causal factors. Dittmann and Schuttler (1990) report that 38% of their sample gave multifactorial explanations for their psychotic experiences, identifying at least two factors from quite different domains (including personal, environmental and endogenous causes). They note that 30% of their sample viewed stressful experiences in childhood or later life as contributing to the cause of the condition, and 20% identified external reasons (for example, blaming people in their home town) which Dittman and Schuttler identify as 'mostly delusional'. In recognition of the complexity of clients' understandings, Larsen (2004) proposes using the concept of a 'system of explanation' (rather than EM) to draw attention to the dynamic nature of clients' understandings, as well as the plurality of understandings available to clients.

Angermeyer and Klusmann (1988) report that in their sample of 200 patients in Germany, 82% favour psychosocial factors of recent origin as likely explanations (such as unemployment, poverty, or loneliness), although 26% implicate their own personality and 16% see biological factors as causal. A fairly large proportion (59%) identified the parental home as causally implicated. Another large scale study was carried out in USA by Weinstein (1974), who asked more than 500 inpatients (two-thirds with a diagnosis of schizophrenia) in a psychiatric hospital about their understandings of the aetiology of their conditions. Weinstein used a 36-item questionnaire, listing potential etiological variables, and asked participants to identify which factors they believed to have causally contributed to their experience (this study is an example of how quantitative methods can be used in studying subjectivity). Weinstein (1974) reports that the most highly rated factors were parental neglect and adult rejection. Weinstein notes that participants in the study tended to see recent difficulties as causal and he suggests that this reflects a difference between clients who focus on precipitating factors (more proximal in time) and their psychiatrists who focus on predisposing factors (remote in time), such as genetic inheritance. Roe and Ben-Yashi (1999) note that clients and clinicians use different narrative forms to express the relationship between the individual and the disorder, with clients' narratives seemingly functioning to facilitate coping with the condition and acquiring a sense of agency.

Differences between how clinicians and patients view mental health difficulties were also noted in an early study by Manis, Houts and Blake (1963) who, following up on the seminal work by Nunnally (1961), compared attitudes of staff and patients in a mental hospital. Interestingly, and in contrast to more recent research, Manis et al. (1963) found that staff tended to reject biological explanations more so than did patients. However, they report that there was a tendency for patients' views to shift over the course of their admission, becoming more congruent with treating staff over time. Manis et al. (1963) note that an important contaminating factor in this research is that agreeing with staff understandings of the experience was associated with early discharge from hospital, providing a powerful motivation for patients to express such views. This research is a reminder of how power dynamics can play an important role in determining the kinds of explanations that individuals may offer for their experience.

In addition to these staff/patient differences, other variables which seem to have a bearing on how one understands mental health problems have also been identified. Limitation of space does not allow a full discussion of this research here, however two factors which are worth noting are the influence of gender and culture. Molvaer et al. (1992) used a questionnaire method to ask 88 psychotic clients how they made sense of their experience. Factor analysis yielded three factors, accounting for 48% of the variance: family and relationships (25%); personal inadequacy (13%) and 'chance' (10%). They note that there was a significant gender difference with women more likely than men to identify family relationships and personal inadequacies as causal factors, and men more likely to attribute the experience to chance. Research has also shown that culture is an important influence on how psychotic experiences are understood. For example, McCabe and Priebe (2004) studied clients from four different ethnic groups (White, Afro-Caribbean West African and Bangladeshi) in UK. They found that white clients differed from the other ethic groups in terms of their EM for psychosis, with white clients being more likely to consider biological causes and treatments as being implicated (albeit they did so less than the clinical staff), with the other three ethic groups being more likely to identify more social or supernatural causes and treatment.

6.1.2. Client understandings of hallucinations

Mirroring the focus on individual symptoms discussed earlier (2.2.3), some researchers have eschewed diagnostic terms such as ‘psychosis’, or more generally ‘mental illness’, in favour of investigations of specific experiences, such as hallucinations. For example, Miller, O’Connor and DiPasquale (1993) used a semi-structured interview schedule to study how voice-hearers (n = 50) related to their experience. While they found that almost all (98%) of voice-hearers reported some negative impacts of hearing voices (such as financial problems associated with finding work, emotional distress, feeling scared and loneliness), they also found that some 52% of their sample reported some positive effects of the voices (such as being relaxing, providing companionship and being protective). Further, they found that 32% did not want their voices to stop completely. Findings such as these are of crucial importance clinically and draw our attention to the implicit and clearly fallacious assumption that hearing voices is necessarily or wholly distressing and that voice-hearers universally want the experience to stop. Miller, O’Connor and DiPasquale (1993) note that pre-treatment attitudes to voices influenced response to treatment, with those who had a more favourable attitude to the voices being less likely to respond to treatment.

The classic research by Romme and Escher (1989; 1993, chapter 2) showed that people who hear voices adopt many and varied perspectives for making sense of this experience, including metaphysical, mystical, medical, parapsychological and psychodynamic understandings. They report that whether, and to what extent, an individual feels distressed by the voices is at least partly determined by the framework of understanding the individual adopts. Romme and Escher (1993) also note that in practice clinicians adopt a broader range of perspectives than one might assume from reading the professional literature alone. Similar findings regarding voice-hearing are reported by Jones, Guy, and Ormrod (2003), who carried out a small scale q-methodology investigation of twenty voice-hearers' understandings of their experience. They report three broad frameworks that individuals adopt to make sense of the experience: biological, psychological, and spiritual. They note that those who saw their voices in spiritual terms tended to be less distressed by them, whereas those who were clients of mental health services tended to see their voices more negatively and that these different positions have different associations with attitude to treatment. They conclude that their study highlights the breadth and complexity of beliefs held by voice-hearers and they also consider some of the treatment implications derived from this finding. They challenge the notion that there could, or should, be a standard treatment offered to all who hear voices, but rather they propose (Jones, Guy & Ormrod, 2003; p.191) that:

> 'understanding the range of beliefs that voice hearers hold about their voices should therefore be of great importance to researchers and clinicians and treatment options need to reflect these differences'.

Spiritual aspects of voice-hearing, as understood by those who have these experiences, are also reported by Heery (1993). Conducting an analysis of in-depth interviews of nine voice-hearers, Heery reports that seeing the experience as indicating 'fragmented parts of self', which are somehow beyond the self and in the spiritual realm, was a common framework adopted by people in this study.

It is worth remarking that through my literature search, I was unable to locate any studies which investigated research into the explanatory models held by clients who experience delusions. This may reflect the fact that delusions are defined in terms of the client holding a particular belief to be true and the assumption that their explanatory model therefore is identical to the delusional belief. Clearly, this is an assumption that warrants further investigation as it may be the case that such clients' explanatory models differ in important ways from their delusional beliefs.

6.1.3. Client understandings of negative symptoms

The concept of 'negative symptoms' is a core component of current notions of schizophrenia, forming part of the DSM IV-R (APA, 2000) diagnostic criteria. Poverty of affect (or 'blunted affect') is a prime example of a negative symptom, considered a central feature of schizophrenia and, as the term implies, denotes a general lack of emotional responsiveness and emotional experience in the individual. This has now become a central tenet within the psychiatric literature, with countless research projects incorporating this concept. My purpose here is not to provide an overview of this extensive research into negative symptoms, but to illustrate how research into subjective experience can contribute to our understandings of these experiences.

Research into the subjective experience of negative symptoms (Boker et al., 2000; Selton, van der Bosch & Sijben, 1998) shows that some patients report that they experience intense emotions (such as anxiety), despite appearing to others to be emotionally and cognitively dulled: that is, for some clients it may be that the paucity of emotion relates to expression but not to subjective experience. As discussed more fully by Kring and Germans (2004), research such as that by Seldon et al. (1998) shows that there can, at times, be a discrepancy between what observers may assume and what the individual is actually experiencing. This research draws our attention to an implicit, unstated assumption made within the psychiatric nosology, namely that expression of emotion (as noted by others) corresponds directly to the experience of emotion. This mistaken assumption reflects what Jenkins (2004) calls a 'failure of intersubjectivity': a failure to attend to the subjective experience of the other. There are clear clinical and research implications associated with this failure. Findings such as these point to the grave risks inherent in assuming that the internal state and experience of another can be gauged accurately and reliably by an outside observer without at least checking out these assumptions against the subjective reports of the individual. Here then, we have a *prima facie* case for the necessity of research into subjective experience if we hope to develop an adequate understanding of schizophrenia/madness, as well as helpful clinical services for those who has such experiences. In passing, it is worth noting that some (such as Healy, 2002) have questioned whether or not the difficulties commonly considered to be negative symptoms of schizophrenia, may in fact be attributable to side-effects of neuroleptic medications, being part of a 'neuroleptic-induced deficiency syndrome'.

6.1.4. The experience of psychosis

The research into negative symptoms moves beyond looking only at the individual's understanding, or explanatory model, for the phenomena in question, to considering in more general terms, the nature of the subjective experience, including, but not limited to, the individual's understanding. This research is more truly in the tradition of phenomenological research, and has much in common with the current research. There is a developing literature which focuses on how the client conveys the nature of the experience of being psychotic.

Vellenga and Christenson (1994), in a study similar in nature to the present study, interviewed fifteen 'severely mentally ill' outpatients, who were long term clients of mental health services in the USA. They used a phenomenological methodology, and continued with their interviews until they had identified common themes in participants' accounts of the experience. They identify four such themes which they see as characterising the experience for the individual: a sense of stigmatisation and alienation; a feeling of pervasive distress; reaching a form of personal acceptance of the experience; and the desire for this acceptance to be shared by others (family and friends).

Jenkins (1997) carried out a larger scale study in USA, involving interviews with 80 patients of Latino and European origins, with diagnoses of schizophrenia or depression. Jenkins notes that in discussing their mental health difficulties very few participants (16%) invoked the notion of 'mental illness' explicitly and without prompting, with even the more general notion of 'illness' of any sort being used by fewer than half of those in the study. Jenkins notes a cultural difference here, with those of European descent and with a diagnosis of schizophrenia being more likely to consider their experience in terms of some form of illness (physical, mental, or 'nerves'). Jenkins notes a common theme which conveys the subjective experience of psychosis, which he identifies as being out of step with the 'rhythm of life'. Jenkins makes a convincing case that narrative, or story, is the best way to bridge the gap between subjective and objective descriptions of mental health difficulties.

Locally in New Zealand, Walton's (1995) study focussed on subjective experience, using a qualitative methodology involving in-depth interviews with ten long-term clients of mental health services with a diagnosis of schizophrenia. She concludes that in terms of subjective experience, schizophrenia can best be characterised as constituting a quite distinct 'way of being in the world' (in the Heideggerian sense).

Walton explains that this consists of a quite different way of dwelling in the world, with mind-body experience being altered, which she suggests relates to the nature of 'being with self', 'being with others', and more generally 'being in the world'. She concludes that the subjective experience of schizophrenia, rather than consisting of discrete symptoms, effects one's 'whole being in the world'.

Ridgeway (2001) analysed four published narratives of women who had suffered and recovered from serious mental illness. Ridgeway notes that while there is great variety in such narratives of recovery, she was nonetheless able to identify common themes, including finding hope, understanding and accepting one's condition, becoming actively engaged in life, and moving from having a sense of alienation to having meaning and purpose in life.

Knight and Bradfield (2003) focussed more specifically on the subjective experience of being diagnosed by a health professional as having a 'mental illness'. Though a small-scale study (with only three participants), this study, by paying such close attention to the participants' own accounts of the experience, nonetheless manages to shed light on this experience in ways that quantitative research approaches rarely do. They note that this experience of being diagnosed is overwhelmingly negative for the individual concerned who reports feeling that a part of the self is 'colonised' by the diagnosis. Also there are social implications, with the individual diagnosed reporting a fear of being rejected by others, and a growing sense of alienation and isolation, combined with a sense that there is now a lack of 'validation' from others. This study is a good example of how an in-depth, qualitative investigation can illuminate the area being investigated, even with a small sample size.

In a study looking at the development of narratives of schizophrenia in those with this diagnosis and in family members, Barker, Lavender and Morant (2001), using semi-structured interviews of 8 clients and 8 relatives, report that this narrative develops over time from the first diagnosis. They found that the first episode tends to be characterised, by both clients and family members, as consisting of disruption to one's life and difficulty in making sense of the experience. They report that clients complained of finding professional explanations unhelpful and of feeling unheard by professionals.

Larsen (2004) investigated the experience of fifteen clients of a Danish first episode psychosis service, through three research interviews over a two year period. He reports that finding personal meaning in the experience was of central importance to clients, who demonstrated flexibility/malleability in their ways of understanding the experience. Larson emphasises that meaning-making is an active process and the individual draws on a range of sources available to him or her, including spiritual factors.

Jacobson (2001), using a symbolic interactionism method, studied 30 first-person accounts of recovery from mental illness and identified four central dimensions found in recovery narratives: recognising the problem (naming and framing); transforming the self (to fit with the new circumstances); reconciling the system (making most use of mental health services to aid self transformation and recognising the problem); and reaching out to others for support (making connections).

Related to studies of the experience of psychosis, Carrick, Mitchell, Powell and Lloyd (2004) looked at the subjective experience of taking anti-psychotic medications, based on a sample size of nine participants. They report note that a central feature in participants' accounts of this experience revolved around the notion of 'well being' (which included functioning, feeling and appearance) and that clients' perspectives on taking anti-psychotic medication did not differentiate between 'symptoms' and 'side-effects' (now more commonly referred to as 'adverse effects'), but considered each only in so far as they impacted on this general sense of 'well-being'. This may contrast with the view of clinicians who commonly distinguish between these (and may believe that symptoms are more of a concern than side-effects). Carrick et al. (2004) note that this difference between clinicians' and clients' perspectives could be of some clinical significance and tackling this may involve making clinician and client goals explicit as these may not be identical, as clinicians may focus on symptom control, which may be less of a priority for clients than a more general sense of 'well-being'. They note that 'subjective feelings cannot be ignored when making treatment decisions'.

The New Zealand Mental Health Commission has produced a number of excellent reports which focus on the subjective experiences of mental health service users. These include a series of pamphlets on subjective aspects of mental health difficulties as experienced by Pakeha clients and their families (O'Hagan, 2000a), forensic service users and their families (0'Hagan, 2000b) and also from Maori (Fenton & Te Koutua, 2000) and Pacific Island (Malo, 2000) perspectives. Common threads which run through this series include a general discontent with mental health services and the narrow medicalisation of the individual's experience to the exclusion of other ways of construing the experience, particularly cultural and spiritual frameworks. An impressive larger-scale study into the subjective experience of mental health problems produced by the NZ Mental Health Commission is the *"Kia Mauri Tau!"* report (Lapsley, Nicora & Black, 2002) which summarises the findings from interviews with forty participants, representing different groups (male, female, Maori, non-Māori) who had recovered from mental health difficulties. This report considers many aspects of the subjective experience of mental health problems, with a focus on recovery. They note that participants commonly located the origins of their mental health difficulties in experiences such as childhood abuse, feelings of loss and abandonment, and the sense of having been 'different from others' as a child. In terms of the process of recovery, Lapsley et al. (2002) identified the core components of the recovery journey as consisting of hope, self-esteem and agency, being in relationship and having connection with others, and transitions in sense of identity such that the individual was able to develop a new, positive personal identity moving away from seeing oneself primarily in terms of 'mental illness'. A recent report by the Mental Health Commission (Barnett & Lapsley, 2006) reports similar findings in investigating young adults' experiences of mental health difficulties, with the issues of trauma and adversity being dominant in participants' understandings of their experience.

6.2. First-person accounts

6.2.1. The position of first-person accounts

The research discussed above gives some indication of the ways in which subjective experience can be the focus of formal research investigations, and demonstrates that these studies can yield important insights about the experience of madness. Research of this sort aims to 'bridge the gap' between the type of scientific research characterised by remote objective methods and first hand-lived experience. Another important though much less formalised source of information about the nature of subjective experience in schizophrenia is found in the 'first-person' literature: that is, personal accounts of the experience of psychosis. These accounts come in a variety of forms, and can be found in a range of sources, as will be discussed below. However, as has already been noted, it is exceptionally rare for these first-hand accounts to be incorporated (or even acknowledged) within the professional literature on schizophrenia. A massive gulf exists between the professional, 'objective' accounts of what madness is and the first-hand accounts that have been offered by those who have had these experiences. Before giving further consideration to this first-person literature, it is worth briefly touching on some arguments that have been made regarding the contribution to our understandings of experience that first-hand accounts can provide.

From a philosophical position, writers such as William James and George Santayana have argued that knowledge of an experience from the inside is different from external knowledge. While James' (1902) concern was the nature of religious experience, Santayana (1948) argued that, in relation to madness, certain aspects of the experience are available only to the person who has the experience:

> 'The physician knows madness in one way: he collects the symptoms of it, the causes and the cure; but the madman in his way knows it far better. The terror and the glory of the illusion, which, after all, are the madness itself, are open only to the madman or to some sympathetic spirit as prone to madness as he is.'

As already noted, greater attention to subjective experience can help correct mistaken assumptions which an over-reliance on 'objective' ways of knowing may entail. Ridgway (2001) extends this argument beyond specific difficulties, such as negative symptoms, to the dominant discourse of the times (such as the notion that schizophrenia is an 'incurable deficit' syndrome), which may be called into question by first-person accounts which contradict aspects of this discourse (in particular, the notion that there is no hope of recovery):

> 'First-person narratives are important source materials that can help us refocus our thinking beyond the myopic and outdated deficit perspective.'

One example of a first-person account which forces us to question our assumptions regarding the treatment of schizophrenia is provided by Tomecek (1990), who firstly attacks the notion that schizophrenia should be viewed as a brain disease then goes further in suggesting that for him schizophrenia is a way of being in the world that involves an element of choice. Tomecek (1990) acknowledges that this way of being can be problematic, but, for him, it is also associated with artistic expression and 'being gifted' and is, in certain respects, preferable to being 'normal'. He expresses anger at the idea that schizophrenia should necessarily be treated with a view to eliminating the condition. Accounts such as this force us to recognise and question the often implicit assumption that madness ought to be 'treated'.

May (2003), who occupies the rare, though not unique, position of being both a clinician and having personal experience of madness, argues that exposure to other people's accounts of the experience of and recovery from madness can have important therapeutic value through helping engender hope in those who may be struggling with their own experience of psychosis:

> 'Meaningful accounts of psychosis that allow us to connect with others and make choices about our lives are essential to any recovery process.'

Attention to subjective experience, either through research which focuses on subjectivity, or through consideration of first-person accounts of madness is an essential requirement in the dual quest to understand the nature of the experience and, where appropriate, to offer hope and assistance to those who may find such experiences troublesome. This is not to deny the importance of 'objective' research into madness, but rather to argue that such research, on its own, is inadequate. Writing in the early 1960s, in his introduction to a collection of first-person accounts of madness, Kaplan (1964; p. ix) looks to the future and considers the contribution that such accounts may make to psychiatry:

> 'One is led to speculate that patient psychiatry might make a meaningful contribution to our understanding of mental illness.'

While Kaplan's speculation has taken considerable time to start to bear the fruit promised, as discussed above there are now signs of a subtle shift within the literature on madness such that subjective experience is coming to be given more attention and the gulf between 'objective' approaches to madness and the subjective experience may be lessening somewhat as research which endeavours to bridge this gap becomes more prevalent, thus creating greater opportunities for syntheses of the various ways of understanding madness available to us.

6.2.2. First-person literature

First-person accounts of madness are of direct relevance to the current research. There is now a vast literature in this area, where individuals have, in their various ways, documented their own personal experiences of madness and made these available to the public. These are often moving, sometimes painful, sometimes humorous, always informative, deeply individual expressions of the human aspects to the experience of being mad. It is worth noting that there is also a growing literature on the experience of psychosis, written by carers and family members (e.g., Lachenmeyer, 2000; Olson, 1994). This carer and family member literature will not be discussed here.

Given the vast quantity of first-person accounts that are available, it is impossible to provide an in-depth analysis of the content of this literature here. Instead, here I will endeavour to provide an overview that will, hopefully, convey something of the extent and diversity of this literature. This diversity is apparent not only in the content of first-person accounts of madness, but also in the format. While written narratives are by far the most common format, these are by no means the only medium in which expressions of the experience of madness can be found. For example, Gilman (1988) discusses the 19th century British artist, Richard Dadd, who had profound experiences of madness (which appear to have been implicated in Dadd murdering his own father). Dadd, spent much of his life incarcerated against his will in mental hospitals, but continued to portray madness in his paintings. Gilman (1988) comments also on van Gogh's images of madness and notes that both Dadd and van Gogh portray madness in a way which conveys the humanity and the passion of the individuals, as well as the mundane daily existence of the inmates of mental hospitals. Gilman (1988) notes that these portrayals differ markedly from the images of madness by their 'sane' contemporaries, a difference which Gilman attributes to both Dadd and van Gogh having had personal experience of madness.

Other media that have been used to capture and express the essence of the first-hand experience of madness include cinema, such as the self-directed, award-winning documentary about the experience of madness, "People Say I'm Crazy" by John Cadigan (2004), as well as poetry, such as that of Sylvia Plath (1965) and others, examples of which can be found in Estroff, (2004). Another format in which first-person accounts of madness are presented is through oral presentation, such as at conferences. For example, at the 2005 International Society for the Psychotherapies of the Schizophrenias (ISPS), Making Sense of Psychosis conference in Auckland, five presenters related aspects of their own personal experience of psychosis.

However, by far the most extensive record of first-person accounts of madness is in the written narrative form. Here we find a vast and ever-growing collection of diverse stories of the experience of madness. Historically, first-person accounts of madness written in English can be traced as far back to the 15th century (Hornstein, 2002), with sustained interest developing in mid 19th century England, when the son of a former prime minister of Britain published, at his own expense, a booklet outlining his experience of madness and documenting his concerns about the psychiatric treatment he had received against his will (Percival, 1840). Percival's account is damning of the treatment he received and makes a heartfelt plea that efforts to understand rather than simply control people who have such experiences would be a more appropriate and helpful response. From the 1960s we see a burgeoning growth in the number of publicly available written accounts of the experience of madness. Greenberg's (1964) tale of the experience of madness has been credited as stimulating interest in the area of first-person accounts. This development coincided with the growth of the consumer movement within mental health. See Chamberlin (2004) and O'Hagan (1994) for overviews of this movement.

6.2.2.1. First-person accounts: journals

A number of journals regularly publish first-person accounts of the experience of madness. Not surprisingly, consumer-orientated journals, such as the Journal of the California Alliance for the Mentally Ill, and Asylum regularly feature articles about the experience of madness written by those who have had such experiences. Though mainstream scientific journals rarely publish such accounts, there are exceptions to this rule, notably both Schizophrenia Bulletin, (which from the mid 1980s onward published regular first-person accounts) and Psychiatric Services (which did the same on a regular basis from 1994 on). Generally, these are short pieces which focus on particular aspects of the experience of schizophrenia.

6.2.2.2. First-person accounts: anthologies

There have been a number of collections of first-person accounts of mental distress (including, but not limited to, the experience of psychosis) which have been published, including many local publications. The New Zealand Mental Health Commission has been active in this area, having commissioned four booklets which contain the stories of the experience of mental illness from different perspectives (Fenton & Te Koutua, 200; Malo, 2000; O'Hagan, 2000a, 2000b) as well as one book, "A Gift of Stories", a collection of first-person accounts of mental illness (Leibrich, 1999). Similarly, the New Zealand branch of the Schizophrenia Fellowship (1999) published a collection of stories of survival and optimism in the face of mental illness. Outside New Zealand there has, of course, also been a number of publications which have collected stories of the experience of madness. Among these, collections by Kaplan (1964) and Romme and Escher (1993) are worthy of particular note. Kaplan's book is of interest both because of the early date of publication as well as its focus on the inner experience. Romme and Escher's (1993) collection is of interest because it focuses specifically on the experience of hearing voices and because it contains contributions from those who have been patients of mental health services as well as, unusually, some from voice-hearers who have had no contact with mental health services.

6.2.2.3. First-person accounts: books

Full-length books which explore the experience of madness, by virtue of the fact that they are of greater length than either journal articles or contributions to collected accounts, allow for more consideration of the experience and the context within which this experience takes place. They allow the author to explore in greater depth the subjective nature of the experience and his or her thoughts about the causes and meaning of these experiences as well as closer examination of factors such as the responses of others, social stigma, and the role of mental health services. These books are now voluminous in number and many are readily available, having been popularised, in part at least, through celebrated and successful movies such as 'Girl, Interrupted' and 'An Angel at my Table', which are based on first-person accounts of madness by Kaysen (1993) and Frame (1984) respectively.

Despite the vastness of first-person literature and the richness of these accounts, the gulf between these and the scientific literature is great. There have been valiant attempts to try to remedy this, most notably by Sommer and his colleagues in USA, who, over a period spanning some forty years attempted to draw attention to this rich source of data about the experience of mental ill-health. Sommer and colleagues have been champions of the importance of first-person accounts of the experience of serious mental health problems, arguing that these can provide important insights into a variety of factors including phenomenology, changes within diagnostic practises and the kinds of treatments offered, as well as the ways in which the public respond to people with mental health problems. Sommer and Osmond (1960; 1961; 1983) compiled bibliographies of first-person accounts (limited to those who had spent some time in hospital) and this was developed further by Sommer, Clifford and Norcross (1998), who updated this list and proposed a method of classification of such literature, using variables such as demographic factors, diagnosis, treatments and the attitude of the writer to his or her experience of mental ill-health. More recently, a more comprehensive bibliography has been developed by Hornstein (2005), listing more than 300 first-person accounts of madness written in English, dating from the 15th century. Hornstein (2002) suggests that we should view first-person accounts of madness as a form of 'protest literature' analogous to slave narratives and is very critical of the way in which the medical profession responds to patient narratives, arguing that 'psychiatrists have not simply ignored patients' voices, they have gone to considerable lengths to silence them.' She goes on to point out that given the lack of certain knowledge in our understandings of serious mental illness, 'ignoring accounts by patients seems perverse'.

6.2.2.4. First-person accounts: internet

The sudden growth in published accounts of madness since the 1960s has been overtaken and overshadowed by the development of the internet, which has made it relatively easy and affordable for ordinary individuals to make available their accounts of the experience of madness. This contrasts with the situation in 19th century England when only those with considerable financial resources, such as

Percival (1840), were in a position to make their stories available to the public. The number of web pages which are either totally or largely dedicated to the individual's account of the experience of madness is impressive. For example, the NAMI South Caroline branch website alone lists over 100 links to personal accounts (www.namiscc.org/Experiences/index.htm). There are also innumerable individuals who have documented in some detail various aspects of their experience of schizophrenia (for example, Ian Chovil: www.chovil.com). Each of these sites lists links to other organisations and individuals who have documented their personal experience of psychosis on the internet. Given the nature of the internet, establishing accurately the number of such accounts available may be impossible. However some indication of the extent of this literature is provided through the following results using the Google search engine (September 2006): 'personal account' and 'schizophrenia' yields 19,900 hits, 'personal account' and 'psychosis' yields 902, and 'personal account' and 'madness' gives 61,100 hits. Of course, these figures do not necessarily reflect the number of unique web pages, but they do, nonetheless, convey the extent of this growing body of literature.

We can see that despite the fact that subjective experience occupies a peripheral position in the mainstream literature on schizophrenia, there is a growing body of literature which does attend to the subjective experience of madness. This includes research, such as the present study, which focuses specifically on first-hand experience as well as a vast and growing body of first-person accounts available in various formats, with the development of the internet having contributed significantly to this. The existence of this literature draws our attention to an important challenge facing clinicians and researchers: how to investigate the nature of psychosis in a way that is both true to the subjective aspects of the experience as well as having some form of scientific validity and clinical utility. As documented above, there are examples of research which do manage to successfully traverse the subjective-objective divide and provide insights into the nature of the experience which can help illuminate our understandings and make more sensitive our clinical interventions. By and large, research of this sort utilises qualitative methods. The current research is such a qualitative investigation into the subjective experience of psychosis.

6.3. The recovery movement

Closely aligned with the growth in the interest in first-person accounts of mental health difficulties, is the ‘recovery movement’. This is a consumer-driven movement which grew out of the consumer and civil rights movements in USA in the 1970s (Davidson, 2003). Roberts and Woolfson (2004) note that first-person accounts have become the founding story of the recovery movement. This movement was also inspired by outcome studies which demonstrated that recovery from ‘severe mental illness’ is possible even for the most ‘chronic’ cases, in contrast to the pessimism of traditional conceptualisations of schizophrenia (Harding, Brooks, Ashikaga, Strauss & Brier, 1987). Some have suggested that the recovery movement shows interesting parallels with the ‘interpretative turn’ discussed earlier (1.1) in that it aims to deconstruct notions of ‘mental illness’ and encourage agency within the individual to interpret their own experience (Walker, 2006).

Davidson (2003) provides an overview of the recovery movement (which has variously been referred to as a paradigm, a model, a philosophy, a process and a movement: I will use the latter term here). He identifies key components of this perspective, which include assuming a sense of agency and responsibility for dealing with one’s difficulties, and of hope regarding a positive outcome. Roberts and Woolfson (2004) report that the recovery movement assumes that those with mental health difficulties ‘can recover without the help of doctors, and sometimes even despite them’. They go on to argue that this does not necessarily imply that the movement is anti-psychiatry, but instead consumers reclaiming agency and developing hope for a positive outcome represents a ‘potentially unifying goal of recovery’, which will allow clinicians and clients to work together towards this common goal, albeit with the need for their roles within this process to be redefined.

Deegan (1988), one of the foremost advocates of the recovery movement, defines recovery as ‘a process, a way of life, an attitude, and a way of approaching the day’s challenges’. She stresses that recovery is a deeply personal process and that the definition of ‘recovery’ is also personal, with the individual being best able to identify his or her own recovery goals, which may or may not include control of symptoms. Deegan (1996) comments:

> ‘The goal of recovery is not to become normal. The goal is to embrace the human vocation of becoming more deeply, more fully human.’

Roberts and Woolfson (2004) note that the process of recovery is often inspired by a ‘pivotal moment’, which may include, for example, finding personal meaning in the experience of psychosis.

The recovery movement has had a significant impact on many aspects of mental health care in many parts of the world. This movement has had a major impact in New Zealand, with public mental health services adopting a recovery-based philosophy since 1998 (O’Hagan, 2001). The mental health service (ADHB) within which the present research was conducted has embraced ‘recovery’ as a core philosophy. Manifestations of the influence of the recovery movement in clinical practice within ADHB include consumer representation within all services and clinical practices such as consumer-driven aspects of the service (Burdett, 2001; Burdett & Geekie, 2003). The recovery movement, both internationally and more locally within New Zealand, is an important aspect of the context within which the present research took place.

Having now provided an overview of various aspects of literature relating to the present study, I will now move on to consider the kind of methods, qualitative in nature, which are commonly adopted for investigating subjective experiences.

7. Methodology

In this chapter my focus will be on qualitative methodologies which have been used to investigate a wide range of topics, such as the meanings that individuals ascribe to experiences of the sort discussed in the previous chapter. I will begin this chapter by revisiting some of the epistemological issues mentioned in chapter 1 of this thesis. I will consider aspects of the divide between quantitative and qualitative methodologies, before looking more closely at some of the general principles which characterise qualitative approaches to research, then look at some examples of qualitative methodologies. I will end the chapter by discussing in some detail the method chosen for the current research: grounded theory.

7.1 The qualitative/quantitative debate

Historically, the development and application of qualitative methodologies within the social sciences can be traced to the work of Dilthey (1977, originally published in 1894), who is often described as 'the father of the hermeneutic enterprise in the human sciences' (Tappan, 2001). Dilthey argued that there are crucial differences between the human world and the natural world, such that quite different methods of investigation are required for study of these two different domains. He suggested that human sciences must focus on '*verstehen*' (meaning or understanding) and that such studies must be rooted in 'lived experience' and interpretations of the meanings that people ascribe to their behaviour and experience. This approach to the human sciences began to gain legitimacy in the 1920s and 1930s in sociology through the work of the 'Chicago School' (through the works of scholars such as Margaret Mead, Gregory Bateson, and Evans-Pritchard). However, compared to social sciences such as sociology and anthropology, it is only relatively recently that qualitative methods have come to acquire some acceptance within psychology (Woolgar, 1997).

Dilthey is not alone in arguing that quite different methods are required to study human experience. Within psychiatry, Jaspers (1963; p.302) warned against the risks of trying to quantify 'psychic events, which by their very nature have to remain qualitative' and he proposed that quantification is impossible 'without losing the actual object of the enquiry' (although, Jaspers also argued that there was no meaning to be found in many psychotic experiences). Similarly, and more recently within the health sciences, Kleinman (1988; p.28) proposes that quantitative methods are not suited to in-depth explorations of the experience of ill-health and suffering:

> 'Ethnography, biography, history, psychotherapy – these are the appropriate research methods to create knowledge about the personal world of suffering. These methods enable us to grasp, behind the simple sounds of bodily pain and psychiatric symptoms, the complex inner language of hurt, desperation, and moral pain (and also triumph) of living with an illness.'

Though the difference between quantitative and qualitative methods may, superficially at least, be a purely pragmatic consideration about which method best suits which research projects, many argue that the difference between the two is, in fact, at a more fundamental level than this. The debate between quantitative and qualitative methods has, at times, been quite vitriolic, with researchers from the opposing camps providing damning critiques of the other, and political and epistemological differences receiving far greater attention than mere technical differences between the two approaches. For example, Woolgar (1997) points out that qualitative methods question some of the basic assumptions of the 'received view' of science, which adopts a positivistic epistemological position and sees quantification as the only route to genuine knowledge. Woolgar (1997) notes that many of the dearly held principles of positivistic approaches are questioned, such as the assumption that the object of observation is entirely independent of the observer, that it is possible to acquire objective and unchanging knowledge, and that it is possible for science, and scientists, to occupy a position of neutrality in the quest for knowledge. Many researchers, particularly those within the qualitative camp, argue that the two different approaches to knowledge rest on quite divergent paradigms, which contain fundamentally different assumptions about what it is to be human, and how one can go about studying human experience. Guba and Lincoln (1982) adopt this position and argue that qualitative research is founded upon phenomenology and '*verstehen'*, that it uses naturalistic research settings, and that within the qualitative framework any understanding of the social world must be grounded in people's experience of that world.

A number of writers have explored this debate in some detail, considering both the philosophical and the practical aspects of the differences between quantitative and qualitative methods. A helpful overview of the debate is provided by Bryman (1988, chapter 5), who suggests we should distinguish between what he calls ‘minimal’ and ‘maximal’ aspects of the quality-quantity debate. He argues that the ‘minimal’ debate relates only to technical and pragmatic matters, such as the choice of methods to be used, whereas the ‘maximal’ debate revolves more around the underlying philosophical positions. Byrnam points out that how one views this debate (in the ‘minimal’ or ‘maximal’ sense) will determine how far apart one considers these methods to be, and whether one believes that integration of methods within a single study is possible.

Pidgeon and Henwood (1997) also discuss the different epistemological positions underpinning different methodologies. They contrast the largely positivistic assumptions of quantification with the largely constructivist assumptions of qualitative research. They also point out an important practical difference between quantitative and qualitative methods, namely that quantification generally involves operationalising pre-existing concepts, whereas qualitative methods are more suited to developing new theory and concepts. A word of warning on this debate is sounded by Rabinowitz and Weseen (2001). They focus on how this debate plays out within psychology, which has a tradition of strongly favouring quantitative methods in its endeavour to achieve ‘scientific’ status. Rabinowitz and Weseen (200; p.23) note that debates about methods are often highly abstract and often polarising in practice:

> ‘Our concern is that the relentless disembodied philosophical critique of both qualitative and quantitative methods in psychology will deepen the divide between those at the poles and have a paralyzing effect on those in the middle.’

While acknowledging that there are important philosophical differences between quantitative and qualitative approaches, and that there are significant power and status differentials in terms of the extent to which these approaches are deemed of value to science and knowledge, my concern here is more of a pragmatic nature: considering which method is best suited to the aims of the present study. As such, I find the position adopted by Leventhal and Nerenz (1985) pertinent. They point out that the method one chooses will relate to the state of knowledge at the time for the area being investigated. The less is known about the topic, the more the chosen methods should be oriented to discovery and exploration. The more that is known, the more one's methods should allow for verification and refinement of specific hypotheses. Qualitative methods are more suited to studies which are exploring new areas of investigation and aiming to develop new concepts (such as the present study), whereas quantitative methods have greater utility when one is examining established concepts in detail. Morse and Field (1996) point out that qualitative research is about uncovering meaning, not measuring the distribution of a quality in the population, for which quantitative methods are far better equipped. A similar point is made by Sciarra, (1999), who notes that qualitative methods are about hypothesis generation, whereas quantitative are about hypothesis testing.

Finally, I agree with the position of Ponterotto and Grieger (1999), who, after reviewing the important differences between quantitative and qualitative research, conclude that these methods should be viewed as 'complimentary, rather than as competing camps' (p.54) and suggest that researchers will be more enlightened if they have a good understanding of both approaches. However, they do advise against combining both in single research project: not because of any profound epistemological differences but simply because it will be 'too much'. I will now focus on some of the principles of qualitative research, as they have a clear bearing on the research reported in this thesis.

7.2 Principles of qualitative research

There are some general characteristics of qualitative research, in terms of strategies and aims, which are common to the different qualitative methods. Morse (1992) identifies three characteristics common to qualitative research: the effort to elicit meaning from the participant's perspective; being holistic and integrative, and aiming to identify underlying values and the place of context; being inductive and interactive. The essential component of qualitative methods is that they place emphasis on meaning over measurement. They aim to provide a deeper understanding of the experience being studied and to do so from the perspective of participants.

7.2.1 Epistemology

As already noted, epistemological matters are often made explicit and given some prominence in discussions of qualitative research. A common (though not universal, as we shall see when discussing Grounded Theory) principle underlying qualitative methods is the notion that knowledge is constructed, rather than ‘found’ or simply uncovered. That is, much qualitative research operates within a constructivist paradigm, which assumes that the researcher is not an innocent, objective bystander who simply observes ‘facts’, but rather the researcher is deeply involved in the process and the outcome of research, and through his or her research activities, the researcher constructs a particular version of the world (Henwood, 1997). Qualitative methods, in contrast to positivistic science, tend to operate on the assumption that social reality is not single and unitary, but rather there are many social and experiential realities which are constructed, not ‘found’, and the researcher is an integral part of this process of constructing reality.

7.2.2 Reflexivity and the role of the researcher

One of the clear implications that emerges from this epistemological position is how we consider the role of the researcher and in particular the relationship between the researcher, the people being investigated and the analysis of the findings. In simple terms, in qualitative research there is much less ‘distance’ between researcher and the people being studied. This is commonly reflected in the choice of language of researchers: quantitative researchers may talk about the ‘subjects’ of their research, whereas qualitative researchers are more likely to use terms such as ‘participants’ or ‘informants’, stressing the active role played by those who are the focus of the research and the more intimate relationship between the researchers and the research ‘participants’. As noted by Sciarra (1999) this puts the qualitative researcher in a particular relationship vis-à-vis research participants, which is considerably different to the relationship between a quantitative researcher and his or her ‘subjects’. The qualitative researcher is an actor, inevitably involved in the action, rather than an onlooker, and is more in the position of learner, rather than expert. The qualitative researcher is, inevitably, involved in, rather than detached from, the area of investigation. While quantitative research allows the researcher to at least strive towards designing a research project which endeavours to minimise the role of the researcher, this is not a position open to qualitative researchers, for whom involvement is a requirement. This can confront the researcher with particular challenges, one of which is to balance the twin roles of participant and observer. As noted by Patton (1990; p.128):

> ‘The challenge is to combine participation and observation so as to become capable of understanding the program (setting, participants) as an insider while describing the program for outsiders.’

Occupying these twin roles may cause considerable uncertainty, particularly for the novice researcher. Karp and Kendall (1982; p.250), considering the oft-noted difficulties faced by anthropologists in the field in coming to terms with the multiple roles of observer, participant and interpreter/analyst of the cultural experience, comment:

> ‘The uncertainty that lies at the heart of field work experience is not a disease, but one of the conditions of existence of anthropological research.’

Thus, the researcher must not only acknowledge this multiplicity, but embrace it as a *sine qua non* for qualitative research. Of course, embracing this position does not mean that one has thereby tackled the potential difficulties that this position brings with it, only that one has accepted that these are part and parcel of qualitative research methods.

This positioning of the researcher as an active participant brings with it a demand that exactly how the researcher is involved in the research must be made explicit in order to ensure that others may have some awareness of this factor. This calls for the researcher to reflect upon and explicate the ways in which he or she is involved in the investigation. This process is commonly referred to as ‘reflexivity’ (Mead, 1934), and requires that the researcher attends to his or her social position vis-à-vis the participants, the nature of the relationship they develop and other factors such as prior knowledge of the area under study, and how the researcher responds emotionally to the process of carrying out the research (Gilligan, Spencer, Weinberg and Bertsch, 2003). More simply, Grbich (1999; p.65) notes that reflexivity involves:

> ‘a process of self awareness that should clarify how one’s beliefs have been socially constructed and how these values are impacting on interaction and interpretation in research settings.’

This necessitates that the researcher focuses not only on the area of investigation, but also on him or her self, to examine how who the researcher happens to be may have influenced what the researcher happens to see. As King (1997; p.175) points out, ‘an understanding of the experiences not only of our participants but also of ourselves as researchers constitutes a fundamental part of the research process’. Further, the researcher's active involvement in the research can have a dynamic impact on how the project develops over time. Henwood and Pidgeon (1992) note that qualitative researchers much acknowledge the ways in which the research activity inevitably shapes the object of inquiry, which, they argue, should be highlighted and revealed in the study.

The role of prior knowledge of the area to be investigated is an issue which receives considerable attention in the qualitative research literature, with opinion varying from the view that prior knowledge is an obstacle likely to contaminate the researcher, to the notion that prior knowledge is a requirement that will help guide the researcher into the area of study, and to the kinds of questions to explore in the project, as well as making the researcher aware of what studies have already been carried out in the area, thus avoiding unnecessary replication (Limb, 2004). Despite these sometimes polarising positions, there is recognition that some degree of prior knowledge of the area to be studied is both inevitable and desirable. Strauss and Corbin (1990) consider prior knowledge helps with 'theoretical sensitivity' (that is, it sensitises the researcher to area to be investigated). They suggest that it is important for researchers to make explicit the prior knowledge they have of the area (whether acquired through personal experience, professional experience, and/or from knowledge of the literature) to allow others to consider how this may have impacted on the research project. One suggestion is that researchers should try to 'bracket' this knowledge, by (as far as possible) setting aside their own assumptions during the research project.

Another aspect of the relationship between researcher and participants to acknowledge is that of the power differential. Tappan (2001) discusses this issue and advises that qualitative researchers must recognise that, at least in terms of the research project, they have the power to articulate the experience of the research participants and this bring with it considerable power and responsibility. Tappan (2001) comments that qualitative researchers much 'be constantly aware of our power, and thus try not to violate, unwittingly, the humanity of those whose lives we hope to understand'.

7.2.3 Sampling

Another issue where qualitative and quantitative research methods are markedly different is in the area of 'sampling': that is, in decisions regarding how participants are selected, and how many are considered adequate for the research project (Maykut & Morehouse, 1994). Grbich (1999) notes that the essence of this difference revolves around quantitative methods being based on probability techniques whereas qualitative methods employ non-probability techniques. This gives rise to quite distinct concerns regarding the questions of who and how many participants are required for a study. Quantitative methods aim to be representative of the group being studied, and the number required is determined by factors such as the need for statistical power. Qualitative studies aim for a more in-depth illumination of the area being investigated and make no claims about 'representative-ness' of the sample, though will hope that the results are nonetheless generalisable. For qualitative researchers, the main priority is to select participants who are 'information-rich' (Grbich, 1999) in that they are able to contribute significantly to the research project. Patton (1990) discusses the various ways in which this sampling can be achieved in qualitative research, including theoretical sampling, where sampling reflects the theoretical needs of the study as it develops (hence this cannot be determined in advance, but evolves with the study) and snowball sampling (where word of mouth and social networks are used to locate participants).

7.2.4 Trustworthiness

One of the most important questions that one can ask of any research project is how 'trustworthy' are the findings from the research. This is one of the most contentious aspects of the debate between quantity and quality, and one which requires considerable effort to fully grasp. Within the quantitative paradigm, there are well-established and generally well-accepted procedures for evaluating research in terms of its trustworthiness. Essentially, these involve the notions of reliability, validity, and generalisability, concepts which are often made explicit in quantitative research reports (McGrath & Johnson, 2003). These concepts are most commonly used in referring to qualities of the measures (such as questionnaires) used in quantitative research. Reliability relates to the 'repeatability' of the measure and is assessed using statistical techniques. Forms of reliability include 'test-retest reliability' (the consistency of the measure if used at different times), 'inter-rater reliability' (the degree to which different raters will obtain the same results using the measure) and 'parallel-forms reliability' (the extent to which different forms of the measure yield similar results). Validity relates to the 'truth value' of the measures. That is, the extent to which the measures used are bias-free measures of the quality being investigated (for example, to what extent does an IQ test accurately measure 'intelligence'?). As with reliability there are various forms of validity. These include 'face validity' (the perceived legitimacy of the measure to those who use it), 'criterion validity' (the extent to which the measure correlates with other measures of the same attribute), and 'predictive validity' (the extent to which the measure is able to predict other related behaviours or measures etc.). Generalisability relates to the scope of applicability of the findings from a research investigation, that is, the extent to which the findings can be generalised beyond the specifics of the particular study to a wider population and range of situations.

A repeated criticism of qualitative methods is that they do not readily submit themselves to scrutiny in terms of reliability and validity. However, qualitative researchers (e.g., Merrick, 1999) point out that the concepts of validity and reliability are part of a positivistic framework (which qualitative researchers largely eschew) and cannot simply be imported into qualitative analyses. Merrick (1999) argues that the underlying epistemological differences between quantity and quality mean notions which have value in one domain may have no utility in the other. She argues that the notions of 'reliability' and 'validity' rest upon the assumption that there is a single indisputable 'truth' (rather than multiple 'truths') and that this truth is 'found' (rather than 'constructed'): these are assumptions that are held within the quantitative framework but questioned within the qualitative one.

However, dismissing the notions of reliability and validity as inappropriate in evaluating qualitative research still leaves us with the question of how we can evaluate the quality and integrity qualitative research projects. This is, of course, a question which qualitative researchers have tackled, though unlike in the area of quantitative research, no generally accepted criteria have been established and accepted (perhaps reflecting the diversity of methods subsumed within the 'qualitative' framework). This question is usually framed in terms of how one can establish the trustworthiness of qualitative research, this being considered a more appropriate term than ‘validity’ and ‘reliability’. Though there is not single set of standardised procedures for evaluating trustworthiness there are a number of common factors suggested by contributors to this discussion and a consensus that the particular approaches adopted should reflect the specific requirements of the individual research project.

Merrick (1999) suggests that important components of trustworthiness include the researcher disclosing and making explicit his or her personal orientation towards the area being investigated (something which quantitative researchers rarely, if ever. disclose), as well as discussing the findings with others, including participants in the research, and incorporating their responses into the final analysis. Respondent validation, where the researcher checks out his or her interpretations with those who participate in the research is also advocated by Stiles (1993). Lincoln and Guba (1985) identify four processes that contribute to the trustworthiness of research, including respondent validation, utilising multiple methods of collecting data, making a clear and explicit “audit trail” (where the researcher documents the process of analysis and theory generation), and working as part of a research team. The process of using multiple methods and perspectives is commonly referred to as ‘trianglulation’ and Bryman (1988, chapter 6) also argues that this increases the confidence one can have in the data and analysis.

In addition to the processes discussed above, which aim to establish trustworthiness through clarifying and expanding the processes of data collection and analysis, other writers focus more on the impact of qualitative research as an important component of trustworthiness. This reflects the focus of qualitative research on ‘understanding by participants and readers’ rather than ‘uncovering the truth’ (Mishler, 1990). The meaning of the research, as evidenced by the researcher’s analyses, is considered of importance in evaluating the research itself. As Henwood (1997; p.27) notes:

> ‘Qualitative research lays down its claim to acceptance by arguing for the importance of understanding the meaning of experience.’

This focus on meaning implies that factors such as the utility, the coherence and the creditability of the analysis are critical aspects of our evaluation of the research (Chamberlain, Stephens & Lyons 1997; Stiles 1993). Ridgway (2001; p.341) argues that one of the tests of the trustworthiness of qualitative research is the contribution it makes to our understanding of the slice of life under examination:

> 'The test of qualitative research is whether an inquiry identifies patterns and concepts that advance collective thinking.'

This sentiment is similar to that expressed by Mischel (1990), who goes further to suggest that that ultimate test in evaluating qualitative data is whether we believe findings strongly enough to act on them.

Clearly, none of the criteria listed above are on their own sufficient to establish the trustworthiness of any particular study. Simply because the results of a study inspire people to act on them would not, in itself, be sufficient to establish that this study is, therefore, trustworthy from a scientific point of view. Nor, on its own, would the agreement of the participants with the conclusions of the researcher be adequate to demonstrate the trustworthiness of the research. The point is that in comparison to quantitative research, evaluation in qualitative research is a complex process that involves a number of possible criteria, not all of which will be appropriate for every research project. Evaluation of a project might include consideration of how explicit the researcher is in identifying his or her own contribution to the analysis, how clear is the 'audit trail' in identifying the steps the researcher took in reaching his or her final conclusions, the feedback sought from other interested parties (including research participants), as well as other factors such as the impact on understanding and practice in the area investigated.

A good example of a research project which illustrates the utility of many of the above principles is Davidson, Sayner, Lambert, Smith and Sledge's (2001) evaluation of a programme designed to reduce re-admission rates into a psychiatric unit. They found, somewhat to their surprise and disappointment, that clinical programmes designed to reduce re-admission rates (which included identifying early warning signs, and other standard 'relapse prevention' techniques) seemed to be singularly unsuccessful in this endeavour. Reflecting on this failure, they noted that the programmes had failed to incorporate clients' perspectives within the project. Using a qualitative approach, they set about exploring the perspective of the re-admitted patients, and established that avoiding re-admission was not a high priority for patients, who often found the hospital environment preferable to their community placement. Taking this into account, they radically altered their programme to reduce readmissions, shifting the focus to making the community environment more attractive to discharged patients. This revised programme proved more successful in reducing readmission rates. In terms of the present discussion this research project illustrates how the trustworthiness of the findings of a qualitative research project can come through the implementation (and evaluation) of the findings from the project.

7.3 Qualitative methods

I will now discuss specific examples of methods used in the qualitative paradigm. As noted by Denzin and Lincoln (2000) in their introduction to their mammoth handbook of qualitative methods, these methods are diverse in approach and vast in number, with researchers commonly taking the stance of a '*bricoleur*' ('jack-of-all-trades', or 'maker of quilts'), blending aspects of different methods in carrying out their research. As such it is impossible to provide a comprehensive overview of qualitative methods, and, in practice, somewhat artificial to consider these methods as distinct entities. Baring in mind these considerations, I will now provide brief descriptions of commonly adopted qualitative research methods.

7.3.1 Ethnography

One of the earliest formalised qualitative methods, used particularly in sociology and anthropology, is ethnography. This is an approach to research commonly used in field-work research, which excels in investigations into how communities are created and sustained by human interactions, making this an ideal method for trying to understand a particular sub-cultural group in a specific setting (Potter, 1998). Van Mannen (1988) defined ethnography as the 'search for culture', or more specifically the study of the knowledge that members of particular group share. The principle method in ethnography is field work (Potter, 1996, chapter 4), and may involve the researcher working closely and intensively with a small number of research participants. The main focus of the research tends to be on meanings of the language and actions of the participants. Examples of this approach include Goffman's (1961) classic study of asylums (1961), looking at how the asylum came to define the identity of patients, and Rosenhan's (1973) study of hospital admissions, looking at how 'pseudo-patients' were treated within a psychiatric hospital. Data collection methods usually involve a mix of different methods, such as interviews and participant observation. Potter (1998) notes that these methods tend not to be clearly defined.

7.3.2 Content analysis

Qualitative research may study ‘texts’, such as movies, speeches, and other such media. A commonly used method for such studies is ‘content analysis’, defined by Krippendorf (1980) as an approach to the ‘study of communicative and symbolic media’ (movies, cartoons, speeches, etc.) which aims to develop the investigation beyond a merely descriptive approach to provide a more analytic conceptualisation which uncovers the latent and manifest meanings of the content. This may involve coding the particular media being studied, with a view to establishing trends or themes which permeate the data. An example of this approach is Cowan and O’Brien’s (1990) study of ‘slasher’ films, aimed at identifying characteristics of victims in such movies. Content analysis approaches generally specify strategies and procedures for analysing the data (as well as measuring ‘reliability’) through operational definitions of the categories identified.

7.3.3 Narrative analysis

The storytelling or narrative approach to psychology (see chapter 1) is concerned with the structure, content and function of stories in our lives (Murray, 2003). Narrative analysis is an approach to research derived from this narrative approach. Within this type of analysis, data (which is commonly interview material) is analysed for narrative structure and function based on narrative theories. As such, the researcher may try to identify the narrative processes in people’s stories, such as ‘plot line’, sequencing of story, rhetorical devices, etc. An example of such research is Langer’s (1991) study of the holocaust survivor testimonies. Langer (1991) argues that these accounts commonly lack ‘narrative coherence’, which reflects the trauma of the experience as well as the difficulty of fitting such accounts into ‘standard narrative forms’ (socially acceptable narratives). Narrative approaches give emphasis to the notion that language is fundamental to experience and identity. Various methods of data analysis may be used in this approach (Murray, 2003).

7.3.4 Discourse analysis

Though most approaches to qualitative research recognise the possibility of a plurality of meanings and interpretations in any given situation, discourse analysis is explicit in making this plurality the focus of the research. Heavily influenced by the work of Foucault (1971), discourse analyses commonly consider the relationship between language use, discourse, the creation of knowledge, and power dynamics (Grbich, 1999, chapter 6; Potter, 2003). Discourse analysis consists of analyses of the details of 'texts' (which may include speech, non-verbal behaviour, the written word, and cultural practices) and examination of how these contribute towards the existing power relations. Discourse analysis has some similarity with narrative approaches, with an important difference being that within discourse analysis there is an explicit focus on variation and contradiction within the text, with more consideration given to how the text positions the person, and more focus on social power structures and how texts construct and maintain these. Examples of discourse analytic research include Wicks' (1992) study of how, in interviews, doctors and nurses spoke differently about the process of patient healing. Nurses 'discourse' tended to challenge the medical view of healing and gave emphasis to aspects of healing that nurses felt more within their control (such as wound care, and pain relief).

7.3.5 Grounded Theory

Grounded theory was developed by Glaser and Strauss (1967) as an approach to carrying out their own research looking at how hospital staff deal with dying people. Glaser and Strauss are the main proponents of grounded theory and the associated methods, and have articulated this in various stages of its development (Glaser & Strauss, 1967; Strauss, 1987; Strauss, 2000; Strauss & Corbin, 1990). A number of other researchers have also contributed to the development and elaboration of this evolving theory.

Although grounded theory specifies procedures for analysing data (which will be discussed further below) it does so in a flexible manner. As noted by Strauss (1987; p.5):

> 'Grounded theory is not really a specific method or technique. Rather, it is a style of doing qualitative analysis that includes a number of distinct features, such as theoretical sampling, and certain methodological guidelines, such as

> making constant comparisons and the use of a coding paradigm, to ensure conceptual development and density.'

That is, grounded theory is a set of flexible procedures that helps render qualitative data meaningful (Pidgeon & Henwood, 1997). Grounded theory was developed specifically with a view to developing methods which allow the researcher to investigate research participants' views of the experience being investigated. As noted by Pidgeon (1997; p.76):

> 'Grounded theory places great emphasis on attention to participants' own accounts of social and psychological events and of their associated local phenomenal and social worlds.'

The primary aim of grounded theory is, as the name suggests, to develop theory which is 'grounded' in the data (remembering that 'data' in grounded theory is participants' accounts of their experience). Glaser and Strauss argue that qualitative research approaches must adopt methods which facilitate the development of an intimate relationship between the researcher and the data, and that it is out of this relationship that new theoretical insights can develop. They specify procedures which constitute a framework which will help the researcher generate theory: these will be discussed below.

Pidgeon and Henwood (1997) propose that grounded theory is particularly useful in taxonomy development, especially in an area where taxonomy may be lacking. Pidgeon and Henwood (1997; p.260) note that grounded theory can help stimulate conceptual development in the area investigated through identifying themes which permeate the interview material:

> 'Grounded theory is most typically well suited to the analysis of the broad "themes" and content of participants' accounts.'

Potter (1998) reaches a similar conclusion, stating that grounded theory is best suited to studying people's understandings of the world in context and that this helps with the development of typologies (or taxonomies) of the relevant phenomena.

7.3.5.1 Grounded theory: epistemology

An aspect of grounded theory which merits consideration is its epistemological basis, an area about which there has been considerable debate. The initial formulation of this theory by Glaser and Strauss was framed within a positivist epistemology, with the notion being that theory is ‘discovered’ through the application of grounded theory procedures. This position is evident in the title of the first major grounded theory text (‘The Discovery of Grounded Theory’; Glaser and Strauss, 1967) and reiterated in subsequent expositions of the theory. Strauss and Corbin (1990; p. 23) expound this positivist perspective when they state:

> ‘Grounded theory is inductively derived from the study of the phenomenon it represents. That is, discovered, developed, and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon.’

The positivist leanings of grounded theory have been called into question, most notably with a constructivist revision of the theory being proposed by Charmaz (1990; 2000). Charmaz argues that grounded theorists do not ‘discover’ theory from within the data, but rather, through an intimate relationship with the data, researchers may construct new ways of looking at and understanding the data, and that this is what constitutes the development of new theory. Pidgeon (1997) provides a theoretical overview of grounded theory and a discussion of these epistemological tensions, concurring with Charmaz’s constructivist revision of grounded theory, where theory is ‘not discovered, but constructed’. This constructivist revision makes grounded theory more congruent with the general philosophical position of qualitative methods, as well as fitting more comfortably with the orientation of the current research. The only substantive change to research methods that Charmaz (1990) proposes is that, in accordance with the constructivist position, grounded theory research must recognise the importance of the ‘researcher perspective’, as this will have an impact on the researcher’s analysis of the data. Glaser (2002) discusses (and largely rejects) this constructivist revision of grounded theory, restating the positivistic position that grounded theory involves the ‘discovery of latent patterns’ found within the data. However, he also concedes that Charmaz’s constructivist revision may be appropriate for selected grounded theory projects which involve in-depth, lengthy interviews conducted over longer periods of time (as employed in the present research). A more thorough critique of epistemological issues relating to grounded theory is provided by Thomas and James (in press).

7.3.5.2 Data collection and analysis

Grounded theory specifies procedures for the collection and analysis of data. An important point to note is that unlike in conventional research, data collection and data analysis may occur simultaneously, rather than sequentially, with the researcher 'flip-flopping' between collection and analysis. The process of data collection is not predetermined at the outset of the research, but rather the ongoing analyses of the data influence the process of data collection, a process which Glaser and Strauss (1967) refer to as 'emergent design'. Through the process of analysing data (usually interview material) the researcher may become more aware of the main themes and issues within the data. This developing knowledge can guide and shape the researcher's choices regarding further data collection.

The process of analysing data is an important aspect of grounded theory. Essentially, this involves the researcher 'coding' the interview material, looking for common threads or themes within the material. This is a slow, gradual process which involves the researcher becoming intimately bound up with the data. This process evolves over time and consists of different stages of analysis. Through these different stages, the coding of data moves from being descriptive to being more analytic and theoretical. An overview of the process of coding data is provided by Pidgeon and Henwood (1997).

Initial stages of coding data involve the researcher reading and re-reading participants' accounts in order to identify commonalties in the content and themes of these accounts. This is referred to as 'open coding' and is a largely descriptive exercise, whereby the researcher identifies 'categories' in the data. As the analysis develops, the researcher will begin to define, or label, these low-level descriptive categories. Writing definitions of categories is part of the analytic process and will help clarify certain categories as well as help the researcher begin to notice relationships between different categories.

This process of continually sifting and comparing of categories and their contents ('elements') is a crucial component of grounded theory analysis, referred to as the 'method of constant comparison'. This requires that the researcher becomes fully immersed in the data, as relationships between categories are developed and elaborated, and the level of analysis moves from being largely descriptive to becoming more abstract and analytic. The researcher moves from grouping data initially in terms of 'look or feel alike', to analysing and grouping the data in more propositional terms (Lincoln & Guba, 1985).

Three levels of coding have been identified by researchers (Limb; 2004; Strauss & Corbin, 1990): open or descriptive coding (where basic categories are identified); 'axial' coding (where categories are refined, developed and related); and finally 'selective' coding (where the 'core category', or categories are developed). Core categories are those of greatest theoretical significance in the research. These are abstract categories that are central to and account for much of the data, relate to or subsume other categories, and help identify relationships within the lower-level categories. It is the core categories which have greatest implications for the development of theory (Strauss, 1987). It is important to point out that the categories do not simply emerge from the data, but rather that judgement on the part of the researcher is always involved in the coding process at every level of abstraction. This is a point made even in the earliest versions of grounded theory, perhaps indicating the tension between positivistic and constructivist versions of grounded theory noted above. Even within Glaser and Strauss' (1967; p.251) original exposition of the theory, we find comments such as the following, which seems to run counter to the more positivistic notion that the theory is 'discovered' within the data, 'emerging' through the application of grounded theory procedures:

> 'The root source of all significant theorizing is the sensitive insights of the observer himself.'

Thomas and James (in press) provide an excellent discussion of some of the epistemological tensions within grounded theory (for example, the positivistic versus constructivist revisions of the theory) and suggest that some of these tensions relate to the status of qualitative research at the time the theory was first articulated. They suggest that the need for qualitative research to establish legitimacy meant that positivistic positions were mimicked. For the purposes of the present research, the constructivist revision is embraced.

7.3.5.3 Theoretical sampling

Grounded theory specifies factors to take into account when considering the issue of 'sampling' (which participants and how many). As already noted, the emerging theoretical analysis is important in determining choices regarding sampling in grounded theory. The grounded theorist can, and should where possible, select new 'samples' (research participants) which reflect and further the developing analysis. 'Cases' may be selected for inclusion in the research according to the potential for expanding or refining concepts already developed by the researcher. Similarly, to develop and elaborate the theoretical framework the researcher may select for inclusion in the research 'samples' which do not appear to 'fit' this developing conceptual system (this process is referred to as 'negative case analysis'). Another consideration regarding sampling relates to when the research may conclude that an adequate sample has been collected. Again, this is largely driven by theoretical concerns. The central notion here is that of 'saturation'. Saturation point is reached when further sampling ceases to add anything new to the theoretical concepts (the core categories) developed by the researcher.

7.3.5.4 "Good grounded theory"

As already noted, evaluating the quality of qualitative research has been a contentious area which involves quite different criteria from those used in quantitative research. Strauss and Corbin (1990) propose criteria which should be used for evaluating grounded theory research. They suggest that 'good grounded theory' should:

- Be a good fit for the phenomenon investigated
- Be comprehensible and it should further understanding of the area studied
- Apply in a range of contexts: the theory should not be so narrowly defined as to have very limited applicability
- Have practical application, by indicating some form of basis for action in this area (for example, in terms of the current research, it may provide pointers for therapeutic interventions)

Other criteria which may be considered when evaluating grounded theory are discussed by Pidgeon and Henwood (1997). These include 'respondent validation' (that is, asking for feedback from members of the group or sub-culture investigated). Other considerations include how well documented was the process of analysis and how concepts/categories are linked and whether or not this is done in justified ways, and whether or not the role of reflexivity was adequately addressed by the researcher.

7.3.5.5 Examples of grounded theory research

Grounded theory has been used extensively in a wide range of research settings, and seems particularly popular in research in the area of health and disability. Some of the studies mentioned earlier in the previous chapter (section 6.1.4) used grounded theory methodology. These include Barker et al.'s (2001) investigation of client and family members narratives of schizophrenia, which identified four 'core categories': a sense of disability; impact on self development; coping and services; relationships (with friends, family and services). Knight and Bradfield's (2003) investigation of the experience of being diagnosed was also a grounded theory study, as was Ridgway's (2001) analysis of women's recovery narratives. Carrick et al.'s (2004) study of the subjective experience of taking anti-psychotic medications also used grounded theory, with the core construct which emerged being that of 'well being'. Lorencz (1992) used grounded theory to investigate the experience of being discharged from psychiatric hospital. Lorenz interview four patients on leaving hospital and reports that 'becoming ordinary' was the core category here, which captured much of the experience of returning home after a stay in hospital. Other areas of health care which have been researched using grounded theory include nurses' perception of the use of seclusion (Muir-Cochrane, 1996) and patients' perceptions of medication in primary care (Dowell and Hudson, 1997). Grounded theory has also been used in a wide range of organisational and business settings (Martin and Turner, 1986)

7.3.5.6 Why Grounded Theory chosen for this research

As I hope will be clear from the above discussion, grounded theory is particularly appropriate for an investigation into the client's experience of, and understanding of, 'psychosis'. As already noted, grounded theory was developed specifically with a view to investigating participants' own perceptions and understandings of the phenomena investigated, making it well-suited to the aims of the current research. Further, grounded theory has a good pedigree in health research, having been used extensively in this area.

As I have noted elsewhere (6.1), there is a paucity of research into clients' understandings of mental health problems, and consequently a dearth of concepts and terms to refer to the client's experience. As such, this makes this area ripe for investigations into how the so-called disease entity is conceptualised in the first place (Sass & Parnas, 2003). As we have seen, grounded theory is particularly suited to developing new conceptualisations and new taxonomies, again making it appropriate for the present study. Further, Rennie, Phillips and Quartaro (1988), in discussing the role of grounded theory in psychological research, comment that it is particularly suited to developing theory in areas that are difficult to access using traditional methods, as it has the advantage of being more systematic than other qualitative approaches. Clients' perceptions and understandings of their experience of psychosis are indeed difficult to access using traditional research methods. This may, in part at least, account for the lack of research in this area.

Thus, grounded theory seems exceptionally well-suited to the aims and subject matter of the current research. It allows for systemic analysis of complex interview data; it facilitates the development of new taxonomy and new conceptualisations of an area of study that traditional (quantitative) methods struggle to access. And, crucially, it is a research methodology designed specifically to investigate and illuminate participants' own accounts of their experience. These factors mean that grounded theory is a more appropriate research method for the current research than any of the other qualitative methods, such as those discussed above. In particular, grounded theory suits the present research because of its explicit focus on the development of theoretical constructs (or 'core categories') which help in the elaboration of a new taxonomy in an area where this is undeveloped. Other qualitative approaches, such as content analysis and narrative analysis do focus on the investigation of participants' own stories, but with less emphasis on the development of new taxonomies. Discourse analysis, with its emphasis on exploring power dynamics, would also not lend itself particularly well to the present study. While power dynamics are clearly important in mental health care (as discussed in chapter 1) they are not the focus of the present research. Secondly, given that the researcher is also the clinician in the present research, analysis of the power dynamics would prove difficult, if not impossible, given the fact that the researcher (in his role as clinician) embodies these dynamics and therefore would not be well-placed to analyse these. Choice of appropriate method for the present research was, therefore, fairly straightforward given the match between the aims of this research and the principles and practice of grounded theory.

8 Method

8.1 The consultation process: cultural, clinical and consumer input

The initial consultation process involved a number of discussions with a range of different clinicians and consumers in the field of mental health care in general, and early intervention for psychosis in particular. These discussions took the form of the author explaining the general aims of the project (to investigate clients' understandings of and experience of psychosis as expressed in psychotherapy sessions with the author and analysed using qualitative methodology) and soliciting feedback from the relevant individuals or groups.

Those consulted included clinicians (clinical psychologists, psychiatrists, psychiatric nurses, occupational therapists, family workers, social workers and researchers) working in mainstream mental health services, and in early intervention for psychosis services. The format of these consultations ranged from informal 1:1 discussions about the proposed research project to more formal discussions with presentations to relevant groups where the research was conducted: Regional Auckland Psychosis Group, New Zealand National Steering Group for Early Intervention, and staff of the community mental health centre (CMHC). Further, outlines of this research project were presented at the New Zealand National Training Forum for Early Intervention services (Geekie, 1998a) and at the THEMHS conference in Tasmania (Geekie, 1998b). Both presentations were received enthusiastically with encouragement for the research project, with those present commenting that they found the opportunity to explore in depth the meaning of psychosis as construed by the client an exciting prospect.

In addition to clinical guidance, advice was sought from culturally specific clinical services as well as from consumer organisations. Cultural consultation was sought from Auckland District Health Board (ADHB) Māori Mental Health Services (Manawanui) and from ADHB Pacific Island Mental Health Services (Lotofale), and from the CMHC Cultural Committee. Consumer consultation was obtained from Mind and Body Consultants Limited and from the consumer representative from the CMHC. Each of these expressed enthusiastic support for the project, stating that it was congruent with their own particular aims and understandings of mental health difficulties, including one consumer consultant expressing regret that she had not been given the opportunity to discuss her understandings of her experience of psychosis when she was a consumer of mental health services.

Feedback from Māori and Pacific Island mental health services, as well as individual Māori and Pacific Island clinicians, while generally supportive of the research project and aims, included an important caveat: namely, that they felt it impossible and culturally inappropriate for a Pakeha researcher to conduct research into Māori or Pacific Island culturally specific understandings of mental health difficulties. This led to fairly lengthy and productive discussions about whether or not Māori and Pacific Island clients should be included or excluded from the study. The advice received on this issue was that these clients should be included in the study, but that an in-depth exploration of cultural themes should not be subsumed within the remit of the research (this was, anyway, very unlikely to be the case, as clients who were eager to explore cultural understandings and aspects of their experience as part of their clinical care tended to do so with culturally appropriate clinicians and support workers from the aforementioned clinical services).

This consultation process led to the development of a formal proposal for this research project being developed, taking into account suggestions and feedback (such as including Māori and Pacific Island clients) provided by the various people consulted. This proposal was endorsed by the ADHB research committee and was given ethics approval by the Auckland Area Health Board Ethics Committee. Issues of clinical safety and potential coercion were, understandably, concerns for the Ethics Committee. Safety issues were addressed through the fact that the client was already under the care of the mental health service, with the researcher working as a clinician in this service. As this research was conducted within routine clinical care for the client, with clinical concerns taking priority over the research, safety concerns were paramount and were addressed through the routine clinical practices of the clinical team, including the researcher in his role as clinician. Matters relating to potential coercion were dealt with by excluding clients under the Mental Health Act and by ensuring clients invited to participate that their response to this invitation would have no impact on their clinical care (discussed further in section 8.3).

8.2 The context

8.2.1 The First Episode Psychosis Service

This research was conducted in the context of an out-patient First Episode Psychosis (FEP) service in the Auckland area, located within a Community Mental Health Service (CMHC) as part of government-funded health care within New Zealand. The researcher was, at the time the research was conducted, employed full-time as a clinical psychologist within the FEP team.

The CMHC within which the research was conducted provides general mental health care to clients who meet criteria for entry to the service: presenting to mental health services for the first time with psychotic experiences, between the ages 18 and 35 (with some flexibility), and residing within the geographical area covered by this service. The FEP service is a specialist team within the CMHC which offers intensive, multi-disciplinary support to clients. To provide an intensive service, the FEP team limits its caseload at any one time to a maximum of 35 clients. At the time of carrying out this research, staff on the FEP team consisted of a psychiatrist, family worker, nurse/family worker, occupational therapist and clinical psychologist (the author/researcher). The FEP team offers clients a range of services including regular medical reviews, psychotherapy, occupational guidance, family support/therapy, and also a selection of groups for both clients and families. The FEP team works closely with a number of other services, including cultural services (particularly Māori and Pacific Island mental health services), community support workers, drug and alcohol counsellors, accommodation providers, and respite and in-patient services.

The FEP team was established in 1998. It adopts an explicit recovery-oriented philosophy, and endeavours to foster a sense of optimism and hope in clients and families, who are expected to play an active role in negotiating with the clinical team regarding how the team can best meet their clinical needs. The clinical support that the FEP team offers and provides to clients varies from client to client, depending on the needs and wishes of the particular client and family. The FEP team generally works with clients for a period of up to two years. On ending with the FEP team clients may be discharged from mental health service or are referred on to an appropriate mental health service, depending on the clinical need at the time of discharge from FEP. A recent evaluation of this service (Theuma, 2004) found this service was effective at helping reduce the symptoms of psychosis.

8.2.2 Seeing the psychologist

Clients are offered the opportunity to meet with the clinical psychologist as part of their routine involvement with the FEP team. An adequate grasp of the English language is generally considered a requirement for the client to benefit from psychological therapy with the author (clients whose English is not adequate have, where possible, been referred to therapists who speak their language). Clients are informed that the team psychologist is available to meet with them to offer psychological support and therapy, which may include talking in more depth about their psychotic experiences (or any other mental health difficulties) and looking at ways of understanding and/or dealing with these experiences. The exact manner in which this invitation is made varies from client to client: for example, if the psychologist is involved in the assessment process, the offer may be made at this point by the psychologist himself, if clinically appropriate. For other clients, the offer may come from other clinicians currently working with the client when it seems that psychological matters are a significant aspect of the client's presentation. Almost all clients of the FEP service will be offered psychological input at some point during their involvement with the service, though not all will accept this. Approximately 70% of FEP clients will meet with the psychologist at least once, and the vast majority of these (approximately 80%) will engage in therapy with the psychologist.

8.3 Participant characteristics and sampling

8.3.1 Recruitment process

Clients of the FEP team who were already engaged with the researcher in his role as team clinical psychologist, and who were discussing their understandings of their psychotic experiences as part of their psychological therapy were, at the end of a routine appointment, informed about the author's interest in understandings of psychosis and his wish to carry out research in this area. These clients were provided with a brief outline of the research project and what this would entail, and were given the opportunity to ask questions about the project. If clients did not immediately object to the possibility of participating (in fact, none of those informed about the research did so), they were provided with an information sheet (see Appendix 1) outlining the nature and intention of the research. Clients were encouraged to take away the information sheet and to give some thought to whether or not they would be willing to participate in the research. It was explained to clients that the only significant difference to the therapy meetings would be that clinical sessions would be recorded using a portable tape recorder placed on the table between the client and the author. It was made clear to clients that their decision to participate or not in the research would have no impact on their relationship with the author, on the nature or content of the psychological therapy, nor on any other aspect of their service from the FEP team. Clients were also informed that confidentiality would be maintained and that no identifying characteristics would be included in any research reports or presentations. At the following clinical meeting with the author, clients were asked about their decision regarding participating in the research or not. Those who agreed to participate in the research were asked to sign consent forms (Appendix 2) indicating their willingness to participate.

The small caseload of the FEP team, and the low number of clients involved in psychotherapy with the author at any one time meant that selective sampling was not possible. Over the period of data collection, every client engaged with the author in psychotherapy, who met inclusion and exclusion criteria for the research, was invited to participate in the research project.

8.3.2 Participants' demographics

Fifteen clients in total participated in this research. All were clients of the FEP team and engaged already in seeing the psychologist. These participants were eleven male and four female, with ages ranging from 20 to 37 years old, with the average age being 26.8 years old. In terms of cultural orientation and ethnicity, ten participants identified themselves as Pakeha, two as Māori, three as Pacific Islanders and two as Asian (some clients identified with more than one ethnicity). Primary diagnoses of participants, made by the psychiatrist working in the FEP team, were: schizophrenia (6), schizoaffective disorder (3), bipolar affective-disorder (2), brief psychotic disorder (3), and schizoid personality disorder (1). All clients had had psychotic experiences as part of their initial presentation to mental health services.

8.3.3 Exclusion criteria: Mental Health Act and engagement difficulties

To avoid the possibility of actual or perceived coercion, clients who were under the Mental Health Act were not invited to participate in the research whilst still under the Act. In practice, no clients were excluded based on this criterion as at the time of carrying out the research there were no suitable candidates for the research who were under the Mental Health Act.

In addition, clients for whom either the author or any member of the FEP team considered there were difficulties in engaging the client with the service were not invited to participate. This was done so as to reduce the risk of an invitation to participate jeopardising the client's engagement with the team. An over-riding principle of this research project was that clinical needs would always take precedence over the needs of the research.

8.3.4 Clients who declined to participate

In total, 17 clients were invited to participate, with 15 accepting and 2 (one male, one female) declining. Clients who declined were not expected, nor asked, to provide an explanation for declining. This was so as to ensure that the client's clinical needs were not compromised to meet the needs of the research as it was feared that asking those who declined to provide an explanation may have been construed by the clients as either coercion or punitive. Thus, for the two clients who declined to participate, no explanation was solicited and therapy continued as per usual. As it happens, both clients who declined spontaneously offered an explanation for their reasons for declining: in both cases they explained that they would not feel comfortable with a tape recorder in the room as they felt this would make them self-conscious and thus less able to fully engage in psychotherapeutic discussions with the author.

8.4 The recordings

Recordings of 62 psychotherapy sessions were made. All recordings were made in the author's clinical office in the CMHC which was the usual venue for psychotherapy sessions. Most recordings were of approximately one hour's duration. Recordings were made on a portable tape recorder which was placed on a small table between the author and the client and was clearly visible to both. Prior to each recording, clients were asked if it was OK to record the session and were informed when the tape recorder was switched on. The number of recordings made of each client varied from 1 – 14, with the mean being 4.1 recordings per participant. This number reflected the number of meetings where the client's experience and understanding of psychosis were discussed during the time the data was collected.

All tapes were transcribed personally by the author. Clients were informed that this would be the case to help reduce any anxiety at the thought of an outsider listening to the recordings, which often contained quite personal information. Following transcribing, the original recordings were offered to participants for their own records. Seven participants requested the recordings of the sessions, with the other eight participants declining this offer (usually with the explanation that they didn't like listening to their own voice on recordings). Those recordings which participants did not wish to receive were retained and later destroyed by the author.

8.5 Data analysis

Transcriptions of the recordings of sessions were analysed using QSR NUD*IST 4 software. Each recording was examined by the author a minimum of five times (two for transcribing and three for data analysis). As already noted (chapter 7), grounded theory (Strauss & Corbin, 1990) was the methodological framework within with the analysis was made. Using the method of constant comparison, the interview data was analysed through being categorised according to common themes. This process involves moving from 'data-near' (open and axial) categorisation through to more theoretical categorisation and conceptualisation of the data (7.3.5). Results of these analyses will be discussed in the following two chapters. Here, I will describe in more detail the process of analysing the data. It is important to keep in mind that in accordance with the principles of grounded theory discussed in the previous chapter, recordings were not all analysed at the same time, but rather were transcribed and analysed shortly after they were made and, as such, they were analysed at various stages in the evolution of the data analysis described below.

In some ways, initial analysis of the data began in an informal way at the transcribing stage. This was a long, slow process and involved the author developing a close relationship with the contents of each recording simply through the process of transcribing. No formal analyses of data took place at this point, though inevitably the author began to recognise certain themes and commonalities among the recordings. Following the initial transcribing, to check accuracy, the author then listened to each recording while reading through the transcript. Following this, the formal analysis of data began. This consisted of the author reading through each transcript and focussing on those sections of the transcripts which related to the client's experience of psychosis. Inevitably, within each recording there were some sections which bore no relation to the research project.

The initial stage of formal analysis consisted of identifying comments from the transcripts that related to the experience of psychosis. The NUD*IST program allows these comments to be easily extracted and collated together. The main theme or themes of the comments were used to subsume these comments under open categories (or 'free nodes' in terms of the NUD*IST program). These are categories that are, at this stage, unconnected to other categories. This initial categorisation was based purely on the manifest content of the comments and generally used the client's words for this initial process. For example, the comment 'I feel sometimes that it may be a case of having too many thoughts' was categorised under 'too many thoughts'. This initial stage of analysis yielded a large number (164 at one point) of open categories.

The next stage of analysis consisted of the author focussing more on the content of these various open categories and looking for commonalities and relationships within these. Through this process, overlaps and commonalities between various categories were identified and subsumed within single categories. Generally this was a straight-forward process of identifying comments which were clearly related (for example 'worry' and 'anxiety' were subsumed within a single category). Simultaneous to this process of merging overlapping and highly similar categories, the next stage of analysis also developed. This involved the author creating more abstract groupings, which developed as the author recognised commonalities among a number of the open categories. One of the first such higher-order categorisations to emerge was that of 'causality' where a range of factors that were identified by the clients as causing their psychotic experience were grouped together. Seven such higher-order categories emerged, and these will be discussed in detail in the following chapter. Within each of these higher-order categories (or 'axial codes' in grounded theory terms) further sub-categorisation was possible, such that, for example, notions of causality were broken down into those that invoked psychological, developmental, biological, or spiritual factors. As we shall see in the next chapter, each of these contained further sub-categories identifying more specific elements. As new recordings were made and transcribed they were analysed within the context of this developing framework of analysis, and contributed to the modification and refinement of the framework.

The final stage of analysis consisted more of reflection on the framework so developed, and ‘flip-flopping’ between the framework and the original transcripts of recordings. This required that the author became more ‘immersed’ in the data and the developing analysis, and it is through this process that grounded theory predicts that theoretical constructs will ‘emerge’ (Glaser & Strauss, 1967; Straus & Corbin, 1990). This stage of the data analysis is central to grounded theory, yet also hardest to operationalise. The ‘emergence’ of these theoretical constructs is a product of the researcher’s deep immersion in the data and the ongoing analyses, and familiarity with the area being investigated. Though it was with some doubt and reservation regarding this ‘emergence’ that I entered into this study, I was, in fact, surprised to note that, as predicted by grounded theory, this is exactly what happened. Three theoretical constructs (presented in chapter 10) did emerge from this analysis. Though these constructs were refined as the analysis developed, they nonetheless proved robust and enduring in terms of capturing the essence of the data, both that which had already been gathered prior to their ‘emergence’, and recordings which were analysed subsequent to this. That is, ‘saturation’ point was reached.

8.6 Reflexivity and the role of the researcher

Prior to presenting the analyses of data, it is important first to consider an important aspect of qualitative research already touched upon (see chapter 7): the role of the researcher. As noted, in qualitative research the relationship between the researcher and participant as well as between the researcher and the analyses of data is of considerable importance and requires special attention. As such, it is important for the researcher to be aware of the position he or she adopts vis-à-vis the research topic and also for this to be declared to allow others to consider how these personal qualities of the researcher may have contributed to the research project and data analysis (Patton, 1990). With these points in mind, I will now attempt to declare aspects of my own personal position which may be of some importance in the context of the present research.

Firstly, it’s important to reiterate that I occupied twin roles in this research: those of clinician and of researcher. As a clinician I held particular roles and responsibilities towards the clients who participated in this research. These revolved around the provision of clinical services, mostly relating to providing psychological therapy, but also including factors such as monitoring of mental state and safety issues, and co-ordination with other components of the FEP team (for example, medication issues, or involvement in groups) as well as with other services (for example, helping with accommodation or other social matters). These clinical responsibilities need not always coincide with the aims of the research project. For example, if a client veered from the topic of the experience of psychosis (as they often did), as a researcher I may have felt inclined to guide the topic back to the focus of the research, whereas as a clinician my responsibility may have been more to be guided by the client’s desire to discuss other, unrelated matters. I was clear at the outset of the research that clinical needs would always supersede research needs. It is my belief that I remained true to this principle throughout the research project. This is evidenced by the fact that on numerous occasions, as shown by transcripts of sessions, clients did indeed introduce important topics which were unrelated to the research project and which became the focus of the clinical session. While this position clearly holds some disadvantages from the perspective of the researcher, this is, I believe, offset by the fact that the recordings analysed were, as close as is possible, naturalistic psychotherapy sessions, with the richness and depth that such sessions can entail, thus allowing an in-depth analysis of the range of meanings and understandings of psychoses expressed in such sessions.

It is also important to acknowledge that I came to this research project not as a *tabula rasa* but rather as a clinician with over 10 years of experience working in the field of adult mental health, much of this in the area of psychosis. I brought with me a passionate interest in working clinically with clients who have psychotic experiences, and also considerable knowledge of the literature in this field. As noted earlier (chapter 7) qualitative researchers express some concerns about the role of prior knowledge and the influence this can have on research. In the present research, it would have been impossible to carry out this project without adequate prior knowledge of the area: being a clinician and researcher simultaneously is an essential component of the design of this research. Accessing the material explored in the next two chapters required that I had a level of knowledge and expertise in this area.

Having noted the above, it is also important to provide some information on my own personal approach to and understanding of psychotic experiences, in order to make transparent any contribution this has made to the research project. I should also point out that, for both clinical and research purposes, I do endeavour to 'bracket' my own personal assumptions and ideas about the nature of psychosis, in order to allow the client to more fully explore and articulate his or her own understanding of the experience. This approach is consistent with my approach to working therapeutically. At the outset of this project, my position and personal orientation toward psychosis was influenced by a range of different, largely psychological, perspectives, combining notions from constructivist, cognitive-behavioural and psychodynamic perspectives. While this position was neither fixed, nor fully and clearly articulated, I did nonetheless enter into this research project with some reasonably well-developed notions about the nature of psychotic experience. I viewed symptoms of psychosis as being reflections of particular ways of construing experience, and I found the framework of personal construct psychology, as outlined by Kelly (1955) and elaborated by the likes of Bannister (1965; 1968) most congruent with my own thinking. In addition, I considered that life experiences, particularly traumatic events, played a role in the development of how one construes experiences, and found a psychodynamic framework also helpful in understanding how these life experiences may have contributed to the development of psychosis. Further, I also had some sympathy with both the sociological critique of concepts such as 'mental illness' and 'schizophrenia' as well as with philosophical perspectives such as that of Sass (1992; 2003). In short, my personal understandings of psychosis were tentative rather then conclusive, flexible rather than rigid, and informed by a range of theories, mostly from the field of psychology.

Over the course of this research project I became aware that my personal position regarding psychosis was changing somewhat. My ideas shifted from those outlined above, to the notion that psychosis (or other terms, such as 'schizophrenia') is best thought of as an ‘essentially contested concept’ (as outlined in chapter 1). This position developed, at least in part, in response to my greater immersion in clients’ stories and in the literature surrounding psychosis, and seems in some ways to be a ‘meta-theory’ about the various theories of madness, both professional and personal, that I have been exposed to as a result of this research.

Having now outlined the positions I look *from* in approaching this research area, I will now move on to where I looked *to* (following Polanyi, 1958) in terms of the results of my data analyses.

9 Results, part I

In the following two chapters analyses of the recordings of psychotherapy sessions will be presented. These chapters are organised in terms of the level of analysis being presented. The current chapter contains the more descriptive, data-near analysis, consisting of (in grounded theory terms) 'open' and 'axial' coding. In the following chapter the analytic/theoretical analysis will be outlined.

To recap, the process of 'coding' data involves carefully reading and re-reading the material, with a view to identifying 'units of meaning' and collecting similar units of meaning together under a single code. Initial coding is descriptive. Basic categories of data are identified, based on commonality of theme/content, without effort to sort these categories in any particular way. The next stage of analysis, 'axial coding', is where categories are refined and sorted into groups that show relationships between the various open, or descriptive categories (Limb, 2004; Strauss & Corbin, 1990). This process consists of recognising overlaps between categories (which may result in two categories being merged if they are deemed to be sufficiently similar) as well as connections and hierarchical relationships being established, which helps impose more order and structure on the data. The latter stages of analysis involve the 'emergence' of theoretical categories which capture the essence of the data, though these categories are not, as such, contained within the data: this analysis will be presented in the next chapter. The present chapter relates to the 'axial' level of analysis, which consists of establishing commonalities and relationships between the various descriptive categories.

At this point it is necessary to clarify some of the terminology used in this thesis when referring to the results of the analysis. As noted, the process of data analysis in grounded theory involves gathering related comments. This process is referred to as 'coding', although hereafter in this thesis the term 'categorisation' will be used to refer to this process as this seems to more clearly express the activity involved. Similarly, these newly formed collections of comments are referred to as 'codes' within grounded theory. In this thesis the terms 'category' and 'construct' will be used. Further, there are different levels of categories, relating to the degree of abstraction (from the raw data) involved in the establishing the particular category concerned. These vary, from the lower-order ‘descriptive’ categories, to the higher-order ‘axial’ categories, and finally to the highest level of abstraction of ‘theoretical constructs’.

The initial analyses of the present data yielded 164 descriptive categories. Further analyses reduced this to the final number of 103 total categories. This reduction came about largely through the recognition that many of the initial descriptive categories could comfortably be merged within a single unifying category. For example, in the initial analysis, three separate categories relating to causes of psychosis were identified: ‘fear’, ‘worry’ and ‘anxiety’. It became clear that these related to essentially identical units of meaning, where anxiety was deemed to have caused psychosis. As such, these categories were subsumed within the single category of ‘anxiety’ as a cause of psychosis.

The analyses presented in this chapter has organised data according to the general aspect of psychotic experience being referred to by participants. Seven broad categories, each of which subsumes a number of sub-categories, were required to capture the richness and spread of the data. These categories are largely, though clearly not wholly, independent of one another. These broad higher-order axial categories are shown in figure 1. An overall ‘map’ of the ‘Experience of Psychosis’, including all categories and sub-categories is shown in Appendix 3.

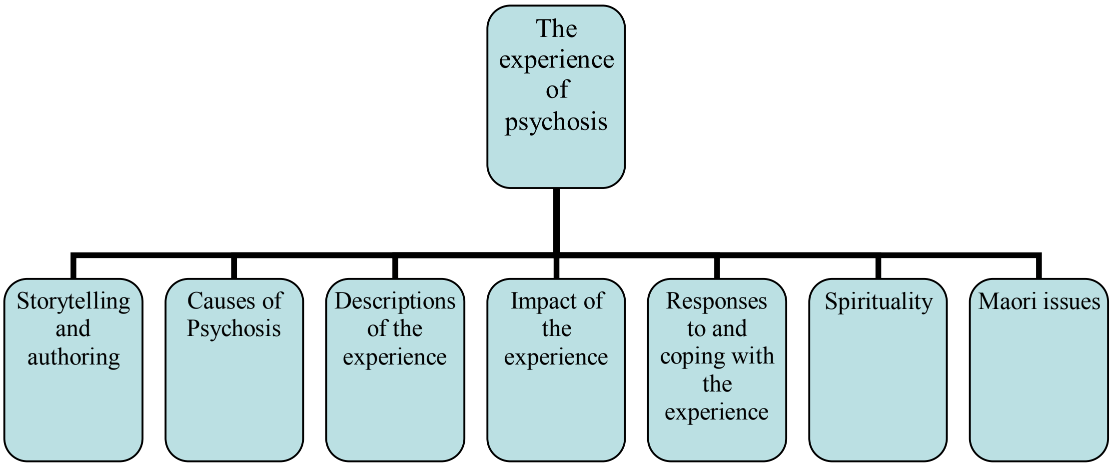


Figure 1: Major categories within the Experience of Psychosis

These seven axial categories will now be presented in turn. The order I have chosen to present these categories here is based partly on the order that issues commonly arise within therapy. This does, of course, vary from client to client. But, as a general pattern, clients' initial concerns often relate to what may have caused the experience, which develops into (and is informed by) a deeper discussion about what constitutes the experience, how it impacts on the person, and what the person is doing, or can do, to respond to and cope with the experience. Generally, it would be after these immediate concerns are addressed that more abstract issues relating to the nature of telling one's story and spiritual matters are more likely to emerge. I have, as far as is possible, presented the data in this chapter to reflect this pattern. The exception to this is that I begin this section by discussing the participants' comments on 'Storytelling and authoring'. I have put this first, not because it tended to be discussed early on in therapy, but because it provides a helpful context for much of what follows, in that it delineates participants' thoughts about the whole issue of telling one's story. Furthermore, this section represents, in its own right, one of this thesis' most important findings.

Each of the broad categories contains a number of lower-order, descriptive categories. Where these lower-order categories of meaning are presented, I will also include examples of comments from participants which will hopefully illustrate the meaning of the particular category of meaning. Names of all participants have been changed to protect confidentiality, as have names within quotes (where, for example, participants may name a friend within the quote). Similarly, any potentially identifying information within comments has been removed or altered to maintain participant anonymity. There are a few occasions where comments require some clarification to indicate the participant's meaning. Where this is necessary, I have added my clarifying comments within square [ ] brackets. For each category the numbers of participants (P) who made comments within this category and the total number of comments (C) contained within the category will be indicated in brackets after the name for the category. For example, section 9.2.1.1.1 below, 'low mood (P5; C21)' indicates that there were 21 comments from 5 different participants under this category. Within each higher-order category, subcategories are presented in an order which takes into account a number of factors, including frequency with which this factor was mentioned by participants, the relative importance of the matter (as judged not solely be the frequency of mentions, but by the context and the priority the participants gave to the issue) as well as by factors such as the logical flow of the discussion, which might mean that, for ease of reading, conceptually similar subcategories are presented in sequence. In short, the order in which these categories and subcategories are presented should not be taken to indicate the relative importance of each category.

9.1 Storytelling and Authoring (P13; C187)

Over the course of therapy, many participants reflected on the general matters relating to the issue of making sense of and narrating their own personal experience of psychosis. In this section, I have gathered participants' comments on this matter, which I refer to as 'storytelling', and the associated business of 'authoring' of one's story. Both of these were of central importance to participants in the research. Participants often spoke in a general, reflective sense about the business of making sense of the experience of psychosis. I refer to this as 'storytelling'. This incorporates matters such as what the experience meant to participants, how they viewed the process of telling their stories, and what impact this storytelling had on the individual and others. While much of this storytelling occurred within the psychotherapy sessions, this was not the only venue where storytelling occurred or where it was of importance to participants. Making sense of the experience of psychosis was a prominent concern for participants in the research, and an issue which held importance for many areas of their lives. Subcategories within this section are shown in figure 2.

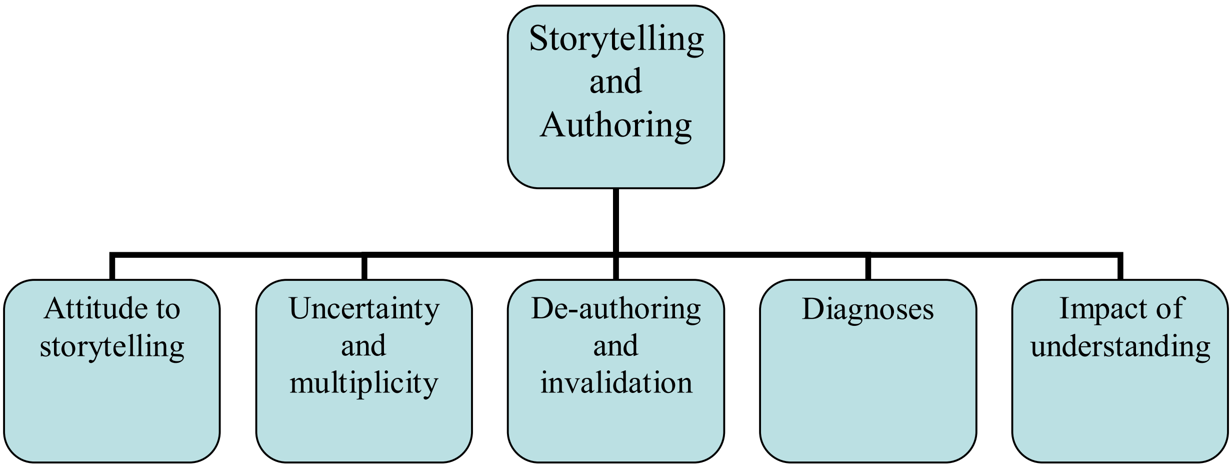


Figure 2: Storytelling and Authoring

9.1.1 Attitude to story telling (P12; C53)

- The importance of building a story

Participants often spoke about how they felt about making sense of the experience of psychosis, and putting this into some kind of narrative form. This was an issue about which many participants had very strong feelings, which they expressed clearly, stressing just how important to them making sense of the experience was. Isa:

> *'It is only through me understanding it that allows me to carry on living. Otherwise it would just be a void.'*

Others expressed a similar sentiment about the importance of making sense of their experience. John:

> *'I just hope I'll be able to make sense of the whole lot.'*

Tony:

> *'I don't understand much [about psychosis], but I'm rather curious about it though.'*

Participants emphasised the importance of telling their own story, which made *personal* sense to them, rather than simply accepting a 'ready-made' explanation of what their story meant to them. Sara explains:

> *'Um, just because I mean because I want to find out why it has happened and why it has happened to me.'*

Paul expressed a similar requirement, when, after reading a "What is psychosis?" information pamphlet, provided to him by the clinical team, politely reflected:

> *'Well, yes, that's very interesting. But I need to make my own sense of it.'*

While most participants narrated their story orally, some were keen to use other formats. Both Moana and Isa spontaneously decided to write down their stories. Moana, having decided to do this, tentatively asked at one session:

> *'You know, I was wondering if, but I don't know if you could take the time to do it. I was wondering if I could write my story down, and like ask you to take a look at it to put it in perspective.'*

Isa also wrote down his story:

> *'But for now the most important thing for me is to get my thoughts down on paper. It was good writing it down, to put it down on paper and then look at it and think, that's exactly how I feel.'*

One participant, Kevin, was particularly keen on having his sessions recorded when he was recounting his story of psychosis, as he thought this would be a wonderful record for him to keep:

> *'I've got to tell the story, got to summarise it on this tape here.'*

Kevin was not alone in valuing the recordings. As noted earlier, seven participants requested the recordings of sessions after they had been transcribed.

- The impact of telling

Generally participants were of the opinion that telling their story was a helpful exercise. Michael:

> *'Like, when I was talking to my friend one time. I just started talking to him about it [psychosis], and I was in a bad mood to start off, and all of a sudden I felt like I was...I felt really healthy right, and my head was working perfectly and...like, as it should be working like. But the only difference was I could explain myself and he understood it all.'*

The importance of having an opportunity to construct and tell one's story was conveyed by Sara. She had tried to discuss her experience with her family but felt they discouraged this, something she found both confusing and distressing:

> *'I mean with my family we haven't been sitting and discussing it, no, to figure it out. And each time I want to talk to my husband about it he says "Oh, don't think about the past". So, we haven't been discussing it to figure out what happened. Maybe they think that's going to hurt me if I talk about it, or, maybe that's why they don't talk about it.'*

In contrast, Michael and others noted that there were times when they found it unhelpful to discuss their experience:

> *'It's em, it's pretty helpful. But, if I'm not in a good state, it isn't very helpful at all.'*

Moana felt that she had to have sufficient distance from the experience before discussing it in depth:

> *'The thing is, I do want to look at it, take a look at everything that I imagined and really, really think about it, but I don't want to do it until I'm at a distance, because I feel like I'm too close to it.'*

Moana also commented on how, at times, she couldn't find meaning in her experience, and this was a struggle for her:

> *'I think for me though I'm finding it really hard to make it meaningful.'*

9.1.2 Uncertainty and multiplicity (P9; C55)

As well as stressing the importance of making sense of the experiences, some participants reported that they felt very uncertain about the sense they made. Part of this uncertainty related to having multiple ways of looking at the experience, rather than having a single, unchanging explanatory model. For many participants, having multiple understandings of the experience did not seem to be particularly problematic, even when these understandings seemed somewhat incompatible with one another.

- Uncertainty

Raj struggled to make sense of his experience. He was drawn partially to spiritual understandings, but also at times wondered if his experience was a sign of an illness. However, he saw flaws in both explanations and felt somewhat uncertain about how to make sense if his experience

> *'I just need to know what it is. I don't know what it is. What is it? Because it's so hard to believe.'*

Michael expressed similar doubts about his way of understanding his experience, though was less troubled by this:

> *'I'm sort of explaining them to myself in my head, but I'm not sure if I'm getting it right.'*

Others stated quite simply that they did not know what to make of their experience, as Janet's reply to a question about what she makes of her experience indicates:

> *'I don't know to be honest with you.'*

- Multiplicity

Many participants had a variety of ways of putting their experience together into a story. Generally, those who did were well aware of this, and not particularly troubled by it, as if playing around with different understandings of the experience was something that they enjoyed. Leon commented on this when discussing his understanding of his experience:

> *'Hmm. I'll probably think of different answers though at another time.'*

Michael was also aware of his propensity for looking at his experience in multiple ways:

> *'You know my understanding of everything, it's like I get all kinds of..I don't have one kind of understanding, I'm always coming up with just similar ones, sort of thing.'*

Moana was equally explicit about this:

> *'Yeah. I actually have variations, em, I've got a number of different ways of looking at it.'*

9.1.3 De-authoring and invalidation (P5; C25)

As part of the process of telling one's story, many reported that they struggled with the feeling of being discounted, defined, or 'invalidated' by others. Participants complained that they often felt that their storytelling capacity (in relation to psychosis, and more generally) was being undermined, as if they were being denied the right to author their own stories. Here, I refer to this process as 'de-authoring' and 'invalidation'.

For Margaret there were two aspects to this feeling of being invalidated. One part related to her experience of hearing voices. Initially, she had thought of these as being profound and divine voices. She struggled with the idea that these experiences were viewed by others in her religious group as psychotic in nature, or in her terms, 'my imagination':

> *'I'm so bloody confused. I'm finding it so hard to accept in myself that those 3 months it was not my imagination. Then I hear that there are other people in the group experiencing the same thing, but they're not being classified as psychotic. I am.'*

Margaret herself used the notion of validation. Her sense of being invalidated by others extended beyond her psychotic experience, to feeling that she herself was being written off by friends:

> *'Well, mine [experiences] aren't being validated as real. All my close friends..one close friend from Wellington almost has written me off, doesn't even bother with me now. Because it's almost like "Margaret is a lost cause to this. There's no way she's going to make it, she's cracked."'*

This was particularly painful for her, as she felt her mother had experienced something similar, many years before:

> *'Well, I feel like I've been written off as a bloody nutcase, like my mother was written off too.'*

Others struggled with the idea that their experience could be explained as 'psychosis'. This, they felt, invalidated their authorship, by denying them the right to determine the meaning of their own experience. This was a major issue for Isa:

> *'I feel down when I think other people are judging me or categorising me. I feel good when I feel validated.'*

Similarly, Raj found having his experience (aspects of which he felt very positive about) explained in terms of psychosis troubled him. While he did see parts of his experience in terms of psychosis, he felt convinced that other experiences he had (in particular, hearing the voice of a deceased loved one) were more spiritual in nature. He felt that the notion of psychosis undermined his belief that parts of his experience were spiritual in nature and this distressed him:

> *'Being told it's psychosis and then that makes my experience not real. And it's..that's what's made me more confused. Telling me I've gone through psychosis and all this. It's made me worse in the last two years. I haven't done anything. It's got me so down and out.'*

Interestingly, Margaret also felt invalidated by her own hallucinatory voices:

> *'The voices have also said I'm schizophrenic. I've also been told that by the voices.'*

Sara complained that she felt 'silenced' at home, where others quashed her attempts to discuss her experience, a process that she saw as undermining her capacity to author her experience:

> *'We spoke about it a couple of times, but he [husband] says don't think about it and try to get better as soon as possible.'*

9.1.4 Diagnoses (P9; C40)

As part of their clinical involvement with the service, participants would often come across diagnostic terms, and would often express a desire to be informed of which diagnosis was most relevant to their experience. Whilst other clinicians in the team discussed diagnoses with participants, the formal diagnosis was made by the team psychiatrist, who would share this diagnosis with the participant and explain this in some detail. As we have seen above, some participants struggled with the issue of diagnosis, feeling that this challenged their own understanding of their experience.

Others, however, reported that they found some solace in being diagnosed, as it conveyed to them that others had had this experience too. Leon:

> *'Oh, I suppose it just lets you know that it's psychosis, that it's not just you. You know, it's like, other people have had it.'*

Some adopted a more active role in relation to diagnoses, sometimes entering into negotiations with the doctor regarding this by pointing out what they saw as inaccuracies or inadequacies of the particular diagnosis made. Paul endeavoured to understand the diagnosis which had been applied to him (schizophrenia), but felt this missed an important aspect of his experience, namely mood:

> *'Well, I think that I read somewhere, and I believe that will relate to me, that I have been diagnosed, or sort of observed as having a psychosis, but with no mood disturbance. And now I would like to see if that is something that is..emm..what does it mean really? And whether I can sort of understand that view point, that diagnosis.'*

He later added:

> *'It definitely doesn't help you to get on with your life.'*

Kevin, who was also diagnosed as schizophrenic, was somewhat dismissive of this label. Though he readily admitted he had had difficulties, he tended to construe them differently:

> *'So, to say I am schizophrenic isn't quite true, I believe [laughs]. But, if it has to be given a name and if the symptoms of schizophrenia are blah blah blah then yeah, but then again..'*

Still others questioned not only how helpful it was to 'story' their experience in terms of diagnosis, but rather the broader 'meta-story' of construing their experience in terms of any form of illness. Sara had recently seen advertisements on television, and had also received some literature on psychosis, both of which put forward the notion that this was an 'illness, like any other'. Sara refuted this:

> *'I don't know because, I don't believe what they say. I mean what they say might be true and right, but I can't convince myself that it is. Saying you have a flu, or a type of flu. But, no. I don't know. It is really strange. I don't know if there is a name for it. I don't know if I can give it a name.'*

Isa:

> *'I constantly think that the notion of mental illness is a misconception. All it is, is failing to understand your own thoughts.'*

9.1.5 Impact of understanding (P6; C14)

The final subsection within this section looks at how participants spoke about the implications of different ways of understanding the experience. As noted above, participants often held more than one way of understanding the experience. We will see here that participants also considered that there were consequences for them which were directly attributable to how they viewed the experience. Paul lamented the loss of his ‘dream’, by which he meant his belief that he was telepathically connected with others (which he found appealing). Coming to understand this experience as ‘psychosis’ left him feeling empty:

> *‘It was a dream, like a dream, while it lasted, but then you had your dream taken away from you and then you have nothing.’*

Moana felt this was true of all people who had had a psychotic episode:

> *‘It kind of sucks cos they [people who experience psychosis] have to come out of the fantasy. Because I think some of us do enjoy it. I think for some of us it's really quite exciting and stuff.’*

Others felt that how they had come to understand their experience could in fact reduce their distress about it. Margaret had come to see her voices as a consequence of abuse and a manifestation of having a negative self concept. She found this understanding reassuring and felt it offered her hope:

> *‘I know now, that the voices are just not sort of..that I'm not going crazy, but it's something that I can change.’*

9.2 Causes of Psychosis (P15; C387)

All 15 participants were interested in considering the possible causes of their experience. They identified a wide range of causes. This was clearly an important aspect of the experience, as is illustrated by the range and number of factors identified as possible causes by participants. This was commonly the first issue participants wanted to address in therapy. In the following section, I will discuss participants' ‘descriptions’ of the experience. The essential difference between these is that within ‘causes of psychosis’, I have included comments which seem aimed at answering the question *why* the experience occurred, whereas under ‘explanations’ I have subsumed comments that seem more concerned with explaining *what it was like* to experience psychosis. While these do seem quite distinct areas of concern, there is considerable overlap. This is particularly the case when the process identified is both proximal and psychological in nature, sometimes making it unclear whether what is being offered is a causal explanation or a description (or both). I used the context within which the comment was made, as well as my broader knowledge of the individual concerned, to help make this distinction,

It is important to note at this point that each participant expressed a variety of ways of understanding causes of the experience, rather than adopting a single unchanging perspective. In addition, even within a single understanding of the experience, participants commonly held multi-factorial accounts of causality, rather than attributing psychosis to a single variable. Further, it's important to hold in mind that participants tended to offer causal explanations for particular experiences (such as 'hearing a voice', or 'feeling confused') rather than operating with a single diagnostic term which might encompass a number of experiences. That is, they largely operated within the 'individual symptoms' framework rather than a diagnostic, syndrome level framework (see section 2.2.3). Thus, they may have adopted, say, a psychological explanation for one symptom, a biological explanation for another, and a spiritual account for yet another. Participants were generally quite explicit in identifying factors they considered as possible causes of their experiences, and were often keen to discuss these in some depth, commonly in a way which conveyed that these notions were held flexibly, as possible explanations, rather than in a rigid fashion.

Through the process of data analysis it became apparent to me that notions of causality could be subsumed under broader categories which identified the kinds of causal factors participants saw as having brought on the experience of psychosis. Causal factors are subsumed under the headings in figure 3, each of which contains a further range of sub-headings which will be discussed in turn.

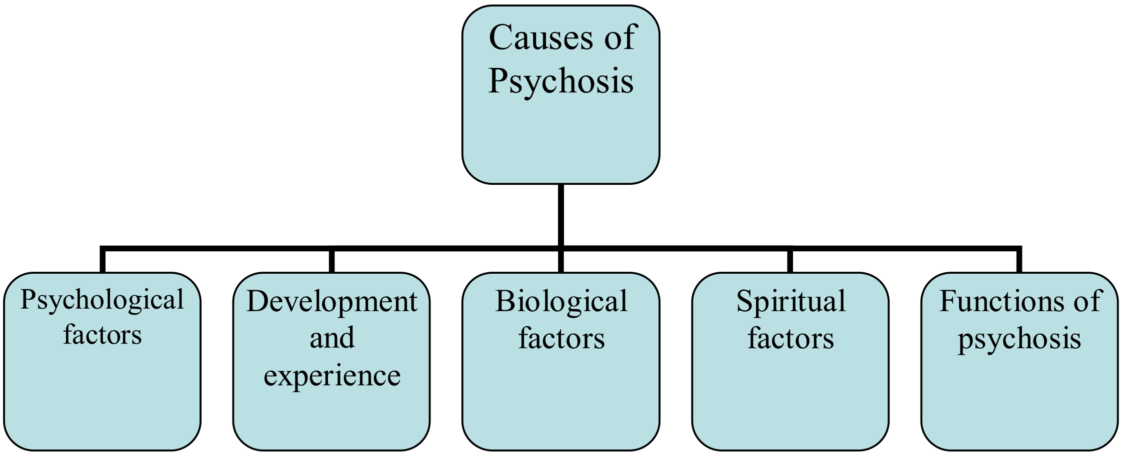


Figure 3: Subcategories within the Causes of Psychosis

9.2.1 Causes of Psychosis: Psychological factors (P15; C190)

Under psychological factors, I brought together comments that attributed the cause of psychotic experience to factors within the individual relating to his or her way of thinking or feeling, or other aspects of the self. Psychological causal factors are further subdivided into sub-categories as illustrated in figure 4. Each of these will now be discussed in turn. All 15 participants identified psychological factors implicated in causality. This may be as expected, given that the participants had elected to see a psychologist (the researcher) for input regarding their experience of psychosis.

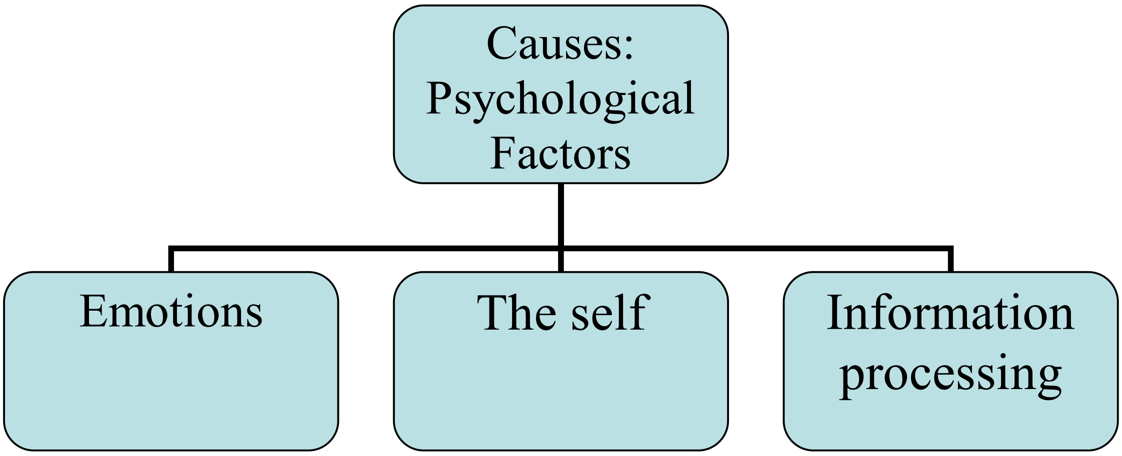


Figure 4: Psychological causes of psychosis

9.2.1.1 Causes of Psychosis; Psychological: Emotions (P12; C86)

Participants identified a number of feeling states and emotional experiences which were viewed as having a role in the cause of psychosis. Sometimes the experience of the emotional state was implicated whereas at other times it was the processing of (or failure to process) emotion which was seen as having given rise to psychotic experiences. Figure 5 illustrates the range of subcategories within emotional causes of psychosis as seen by participants.

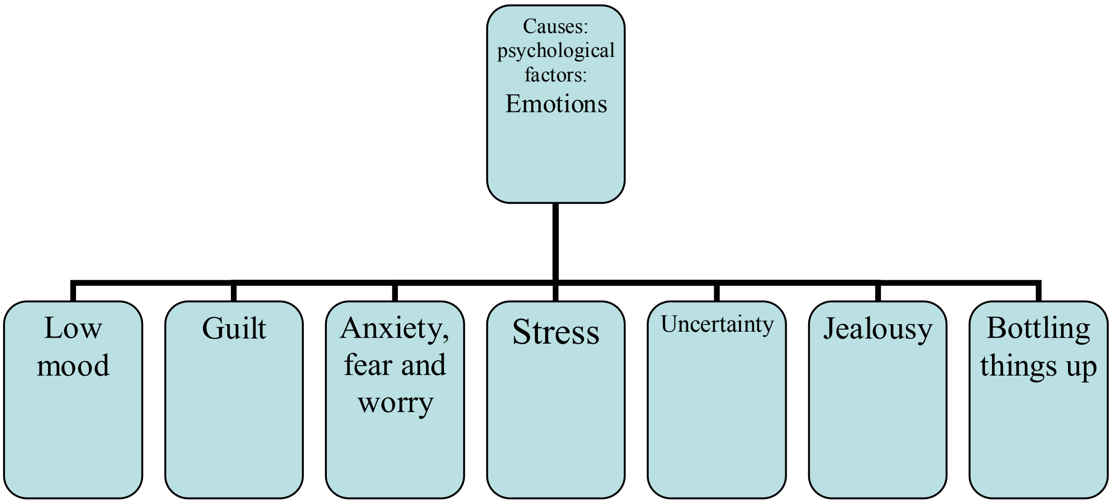


Figure 5: Psychological causes of psychosis: Emotions

9.2.1.1.1 Low mood (P5; C21)

A period of low mood often preceded or accompanied the experience of psychosis, and a number of participants viewed this as reflecting a causal relationship with the low mood seen as having brought on the psychosis. When discussing the onset of psychosis, Leon, a young man who had been troubled by a range of psychotic experiences including delusions and hallucinations explains his belief as to why he developed his delusional beliefs:

> *'I thought it was because before I was quite depressed and I wasn't laughing at all.'*

A similar association is suggested by Paul, who had experienced a period of pronounced thought disorder:

> *'I would think that apparent sort of jumbled thinking for me is a result of maybe being in a prolonged low mood.'*

9.2.1.1.2 Guilt (P3; C11)

Related in some ways to low mood, some participants identified guilt about past experiences as having fuelled the psychosis. This feeling of guilt related to real events from the person's distant or more recent past. Margaret, who had found herself quite incapacitated by invasive and confusing auditory hallucinations felt confident that her own guilt about unwanted sexual experiences as a child had a causal relationship to these voices. This is evident when she reflects on her understanding of the experience as well as her recently developed way of responding:

> *'I do feel a lot of guilt around it [the sexual abuse] still and I hear the thoughts and I say "OK, just let them go". I see them for what they are now. You know, and I just think, once you've cleared the guilt and everything round it, that stuff won't come up. It's the guilt that's bringing it up more than everything now.'*

John had had a car accident a few months prior to becoming psychotic, and felt that guilt relating to this had a role in him developing paranoid thinking:

> *'I think I was just getting paranoid about the accident. Maybe feeling like, quite a lot of like blame and things on me, from myself.'*

Spencer also saw guilt as implicated in his tendency to experience ideas of reference:

> *'It's more of a guilt trip, and I suppose I look for signs of the people around me knowing I'm not doing the right thing.'*

The common thread through each of these comments is identifying the experience of guilt as being causally implicated in psychosis.

9.2.1.1.3 Anxiety, fear and worry (P8; C20)

Some participants identified anxiety, fear or worry as having a strong part to play in producing psychotic experiences. Here, Tony, who in social situations found himself troubled by beliefs that his thoughts were being broadcast, describes this process clearly:

> *'It's like I get so nervous that I can't talk, or talk the way I'd naturally talk to a friend at home, yeah and that nervousness turns into fear, and it's like I just go backwards into psychosis.'*

In Sara's case the anxiety related to the fear of childbirth and becoming a mother (she had become psychotic around the time of the birth of her first child):

> *'I was scared, and I woke up suddenly and I was really scared of it. After that next day I gave birth and all that, but being scared happened then as well. So, I think being scared has to do with it.'*

9.2.1.1.4 Stress (P8; C16)

A feeling of being under stress and associated ‘pressure’ was seen by some as implicated as a cause of psychosis. Here, Leon expresses his thoughts about what brought on the psychosis:

> *‘Maybe just too much stress, too much to think about. Yeah.’*

Mark, who had had a period of profound, confusing and impulsive, behaviour which was sometimes quite bizarre, shared a similar view:

> *‘I didn't know what psychosis meant. I didn't know that it was something that happens and it can mend. Bit like a broken bone kind of thing. Just due to too many, in my case I think, due to too many pressures.’*

9.2.1.1.5 Uncertainty (P2; C13)

Two participants saw a sense of uncertainty about life in general, or about particular aspects of life, as having led them to becoming psychotic. John, when asked what he thought led to his ‘breakdown’ (his term) stated quite simply: ‘uncertainty’. Also, Paul, when reflecting on his experience, saw feelings of uncertainty that he had in relating to others as both causally important and a better explanatory framework for his experience than the psychiatric terminology (‘thought disorder’ or ‘jumbled thinking’):

> *‘It's just like you know in that situation, when you experience a little bit..is sort of uncertainty, “what is happening now?” And so, that's why I think that maybe that's why the jumbled thinking or that diagnosis maybe is not fair.’*

9.2.1.1.6 Jealousy (P1; C5)

Only one participant, Moana, clearly saw jealousy as being involved. However, she was very clear that jealousy played a causal role and this was a theme which permeated many of her discussions about both the cause and the content of her experience:

> *‘I had issues of jealousy and real, real, jealousy, the kind that really did make me sick. I mean I would like think about it all the time.’*

9.2.1.1.7 Bottling things up (P2; C8)

Two participants felt that it wasn’t the experience of emotion *per se* which had brought on the psychosis, but rather their way of dealing with this emotion by keeping it to themselves (or ‘bottling it up’) which had underpinned their psychosis. Paul:

> *'The manic phase of my experience was exactly what I would in my own term describe as bottling things up.'*

He went on to express his discomfort with the notion that his experience should be construed as 'psychosis' and his preference for his own terms:

> *'Now I am just trying to understand, was it really a psychosis, or was it really bottled up and mood disturbance, and maybe psychosis? Maybe we can put it [the term "psychosis"] away and use bottled up and mood disturbance.'*

9.2.1.2 Causes of Psychosis. Psychological; Self (P7;C57)

The next sub-category within the psychological causes of psychosis is that of 'self'. In this sub-category I have collated those notions of causality which attribute the experience to aspects of self and to the relationship with self. Generally these refer to relatively enduring aspects of the self (rather than fleeting emotional states) which the individual views as having rendered him or herself vulnerable to developing psychosis. The range of subcategories within this section is shown in figure 6.

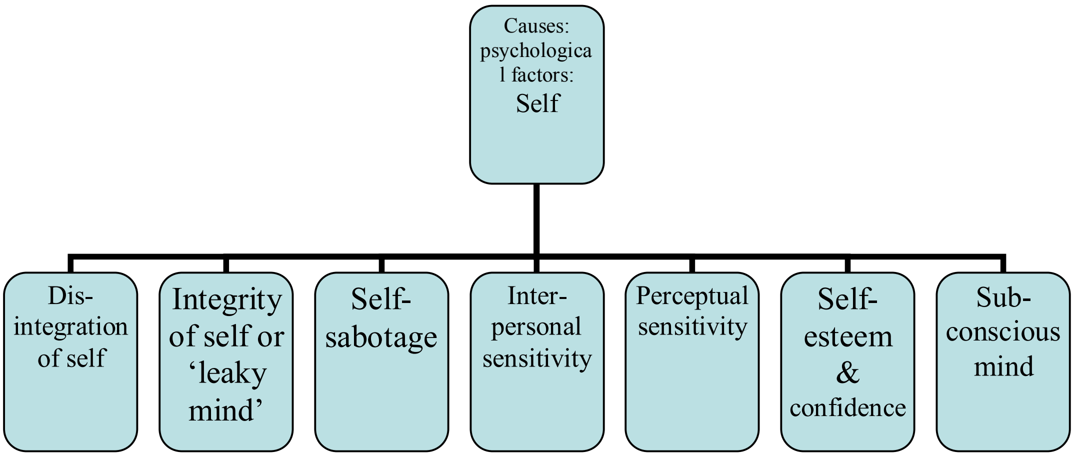


Figure 6: Psychological causes of psychosis: Self

9.2.1.2.1 Disintegration of self (P5; C34)

A theme which permeated the way in which many participants understood their psychotic experiences was that of 'disintegration' of self. By this, I mean a sense that the self is somehow experienced as not being as coherent or as fitting as it might be, with a sense of being 'out of balance' with one's self often being conveyed. This notion, that the sense is 'not together' or not integrated was seen as having contributed to the experience of psychosis. Michael expresses this view:

> *'I guess people have got more or less control over their moods, or they're in sync with their moods. I sort of know now that I'm way out of sync with everything.'*

That he is referring to more than simply his moods, but rather to his experience of himself, and that he sees this as differentiating him from other people is made clear in the following quote:

> *'Everyone's got a place, but I haven't got a personality or anything. I'm not in sync with my personality and my self or anything.'*

Moana, who often generalised from her own experience and understanding to articulate a more general explanation for people experiencing mental distress, expresses a similar notion of conflict within, or of disintegration of, the self as causing psychosis:

> *'Well, we're actually struggling with ourselves. If we're mentally ill, the characters that we make up in our sickness are just parts of ourselves.'*

Margaret also saw her derogatory auditory hallucinations as developing from her lack of balance in her self:

> *'Those comments came up because I was unstable, out of balance.'*

9.2.1.2.2 Integrity of self, or 'leaky mind' (P1; C2)

Closely related to the notion of disintegration is the idea that the integrity of the mind (maintaining the barrier between mind and world) has been compromised and that this causes psychosis, allowing thoughts to 'leak' out. Tony saw such a 'leak' as causing his 'thought broadcasting':

> *'I did feel that my mind was leaking. It felt like there was a great big speaker on my head actually making noise.'*

9.2.1.2.3 Self sabotage (P2; C6)

A couple of participants attributed their psychosis to their own tendency to self-criticism or self-sabotage. This was expressed most clearly by Margaret, who recognised that this tendency had been with her since childhood and she made it clear that she saw this as being the product of early life experiences where she felt put down by her parents:

> *'Well, it shows that I've got this sabotaging streak in me. I've had it right from birth, because that's just a reflection of what I grew up with, and it's still there, to destroy everything.'*

The context of this statement made it clear that Margaret saw her recent psychotic experiences as being another manifesting of this 'self-sabotaging streak'.

9.2.1.2.4 Interpersonal sensitivity (P2; C7)

Two participants put forward the idea that the aspect of themselves which may have brought on the psychotic experiences was their sensitivity to the influence of other people. This position was expressed most forcefully by Mark, who saw himself as being particularly susceptible to feeling pressured by others:

> *'So maybe, what I am thinking is that the personality trait about how you are that makes you vulnerable is your susceptibility to influence by other people.'*
>
> *'But I could feel the pressure. Maybe I am just oversensitive. Like I could really feel the pressure [from other people].'*

9.2.1.2.5 Perceptual sensitivity (P1; C3)

A seemingly related explanation for the cause of psychosis was the idea that psychosis resulted from perceptual sensitivity. Kevin saw this as central to his experience:

> *'I was quite sort of wise about my wisdom; I sort of believed that it was my senses that were killing me, you know, my senses of sight and hearing.'*

Going on to explain just how seriously he took this:

> *'I was just only considering going to a doctor and asking him to disable my hearing and reducing significantly my sight. Because I understood it was my senses that were stuffing me up.'*

9.2.1.2.6 Self esteem and confidence (P2; C4)

Two saw their psychosis as being related to self esteem or confidence (being either over or under-confident). Moana found that if she viewed the development of her psychosis as being the produce of low self-esteem, this helped her feel it had some meaning:

> *'I can make it meaningful in terms of if I look at it and say maybe I'm just someone who had low self esteem, and I was really depressed and I was sick mentally, is my way of dealing with it. If I define it like that it has meaning.'*

Spencer, a young Māori man who had had pronounced moods swings as part of his psychotic experiences, saw these as reflecting, and probably being caused by similar swings in his self-confidence, when asked what may have caused his psychosis, he replied:

> *'Probably just the changes that my confidence had been through, the extreme high and low.'*

9.2.1.2.7 Subconscious mind (P1; C3)

Isa, a Pacific Island man who, in terms of standard psychiatric nosology experienced particularly disabling hallucinations and delusional beliefs, nonetheless welcomed the opportunity to explore the meaning of these experiences (even whilst feeling troubled by them). Mostly, he considered that psychological and spiritual factors best helped him understanding his experience. Here he expresses his belief that the subconscious mind may cause his voices:

> *'The subconscious seems to confirm itself through the conscious mind. I believe my voices are my subconscious mind expressing itself.'*

He elaborated on this process specifying how he felt this happened:

> *'When I am in a situation where say I can't hear what people are saying, then my subconscious mind will fill in the blanks and I will hear what it wants me to hear.'*

9.2.1.3 Causes of Psychosis. Psychological: Information processing (P10; C97)

The final aspect of psychological causes of experience is that of 'information processing'. In this sub-category I have collated comments where participants indicate that how they process information is causally implicated in the origins of psychosis. Subcategories contained within this category are shown in figure 7:

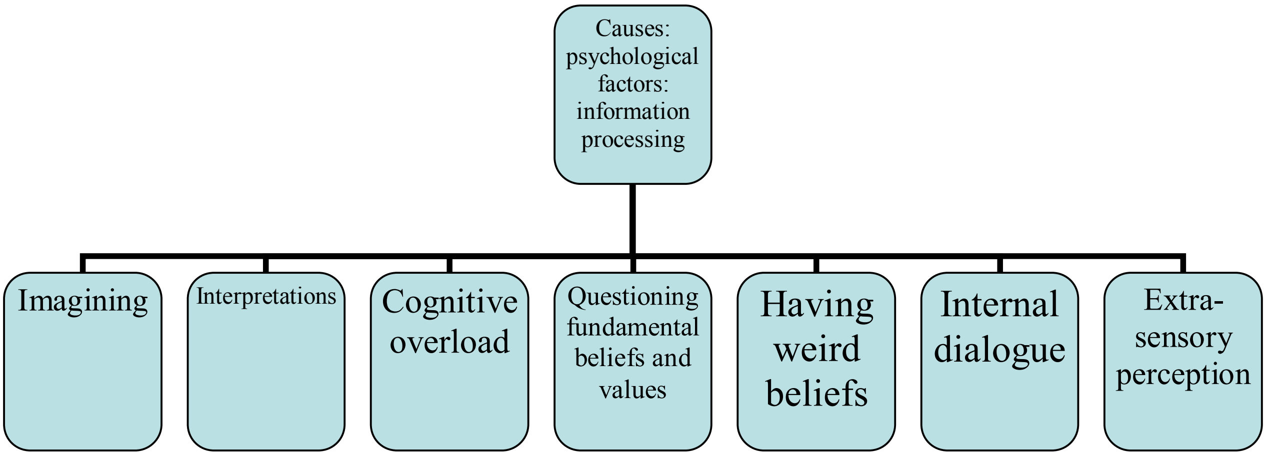


Figure 7: Psychological causes of psychosis: Information Processing

9.2.1.3.1 Imagining (P2; C25)

Two participants viewed their psychosis as having been caused by their imagination, through creating fantasies which then come to feel real to the individual. Moana often returned to this theme:

> *'Basically, most of the time, what I feel is that when I go to imagine something, I think it's really happening.'*

She went on to explain that she sometimes found it difficult to distinguish the real from the imaginary. Janet, who had experienced voices and other hallucinatory phenomenon on and off since her childhood, saw these as being the result of imagination:

> *'To me what I experience, like when I go into my little world is just imagination. I don't see it as part of the mental health.'*

9.2.1.3.2 Interpretations (P3; C17)

Another aspect of information processing that was cited as having a causal relationship to psychosis was habitual ways of interpreting experience. For example, Leon notes that his tendency to personalise information may have led to some psychotic experiences:

> *'Sometimes I take things personally I suppose. Just, dunno..read things into things too much.'*

Isa identifies that the expectations that he brings to a situation influence how he interprets what he sees (leading to interpreting the behaviour of others in a persecutory fashion):

> *'I guess that's what makes it bad. Then I expect it and just the slightest thing, I perceive it in a negative way.'*

Kevin also saw his focus on body language as well as his way of interpreting this as leading him to feel paranoid in certain situations:

> *'I had nothing to say, I took in the world non-verbally. So, you know, body language, that sort of thing. I'm trying to say that's all I had, and because it could be many things, it's not quite concrete. I'd interpret it in a certain way and this is how I'd interpret it.'*

9.2.1.3.3 Cognitive overload (P5; C15)

Another aspect of information processes implicated by some participants as contributing to the development of certain psychotic experiences was the notion of mental overload: the idea that having too many, or too intense thoughts can cause psychosis. When asked about how he thinks his disturbing psychotic thoughts develop, Tony replied:

> *'Hmm, I kinda feel sometimes that it may be a case of having em a lot…too many thoughts. Hmm, overload.'*

Michael expressed a similar position:

> *'Usually I'll be thinking too much about something and I won't be able to have a conversation with someone, because I'll be thinking about all those beliefs inside of me which just appear there.'*

9.2.1.3.4 Metacognition (P2; C12)

In some ways related to the notion that too many thoughts caused psychosis, was the view that thinking about one's own mental processes (or 'metacognition') causes psychosis. Isa:

> *'I constantly think that the notion of mental illness is a misconception. All it is, is failing to understand your own thoughts.'*

Michael held a similar opinion about how his delusional thinking developed:

> *'I'm sure that if I didn't notice it, I'd be fine because that's how I started getting into it. I started noticing things, and I started getting deeper and*

> *deeper in thought as I noticed more and more things, and I started getting disillusioned and getting delusional the more deeper I went.'*

9.2.1.3.5 Questioning fundamental beliefs and values (P2; C12)

Another cognitive process seen as causal in psychotic experience was questioning fundamental beliefs or values that one had previously held. Mark had undergone a number of changes in the months leading up to becoming psychotic, and he saw his rejection of previously firmly held beliefs as implicated in this process:

> *'And most of those values have taken as long as we have been alive, and when we just challenge them and tear them down, 'cos I think I did tear them down when I look back, and even without wanting to tear them down, I inadvertently tore them down. There was nothing holding the house up. It just hit the ground with a big crash, and I wondered why was there was a problem.'*

Paul:

> *'I'm starting to question everything I think and stuff. Like, why is this like this? Everything I experience, everything I live, is just my reality.'*

9.2.1.3.6 Having weird beliefs (P3; C3)

Related to questioning one's beliefs was the idea that holding unusual beliefs over a period of time causes psychosis. Leon:

> *'I think it might be something to do with having weird beliefs for so long, like just thinking bad things for so long that it just..you crack up or something.'*

Sara also implicated 'strange' beliefs in her experience (she uses the present tense but is, in fact, referring to past experience):

> *'I am thinking really strange and stupid things. And each time I just think, both times I think I wasn't belonging to anyone, I wasn't belonging to any family.'*

9.2.1.3.7 Internal dialogue (P4; C5)

A few participants explained some of their psychotic experiences as coming about as the result of having an internal dialogue in one's mind. Michael:

> *'I think it's got to do with me being like all inside of myself, not outside, like speaking out here, not speaking in here sort of thing when I'm talking to somebody.'*

Leon:

> *'I reckon you go crazy when you start having conversations with people in your head, which is what I used to do, sort of like, think about what I did that night or whatever. Just have conversations about what happened over and over in your head.'*

9.2.1.3.8 Extra sensory perception (P2; C6)

Two participants saw their experiences as related to accurate information processing, reflecting a particular skill (extra-sensory perception) which they felt they had, suggesting that they believed that other people either did not have this skill, or denied having it. Michael sometimes assumed that telepathy was a normal experience, but that unlike him, many people were unaware of even doing it:

> *'Like they're all interacting and doing all this telepathy stuff and they don't even realise it.'*

He wondered if people who did not have psychotic experience were somehow unaware of, or denying, the true nature of reality:

> *'This may be really deluded but, this is just one idea that I've got, a sort of philosophy. It's like, when I look at people who are healthy, I sort of..it's like they're in some big game or something.'*

Tony also at times held the position that extra-sensory perception could have caused his voices (although at other times he rejected this view):

> *'One of the problems is hearing a voice and thinking it's another person's em brainwave. That was when my paranoia would peak.'*

9.2.2 Causes of Psychosis: Development and Experience (P12; C107)

The second broad sub-category of participants' notions of causes of their experience is what I have called 'Development and Experience'. In this section, I have gathered comments which conveyed understandings of psychosis which attribute a causal role to aspects of the individual's life experiences and development. This section contains a number of sub-sections as seen in figure 8.

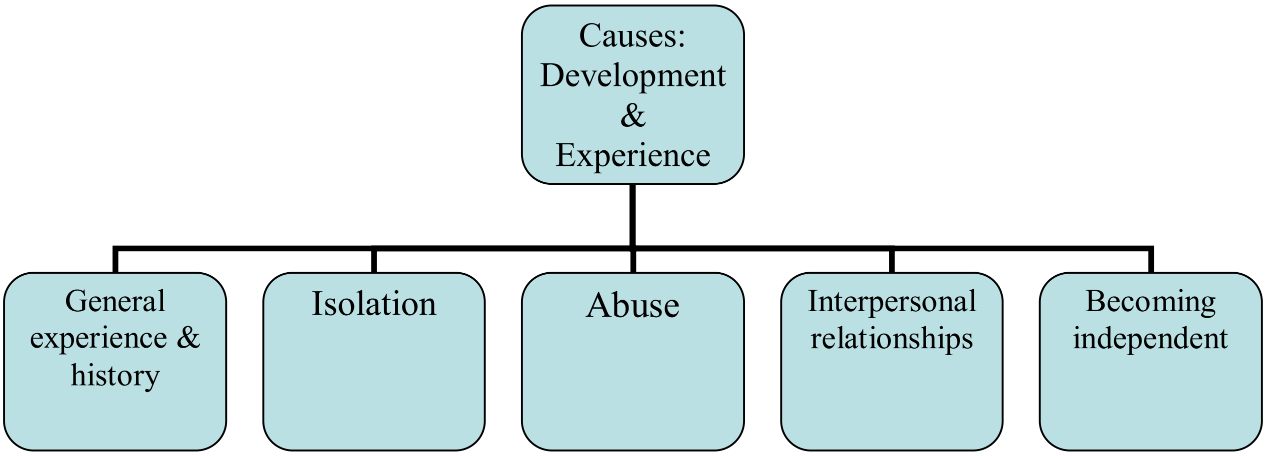


Figure 8: Causes of Psychosis: Development and Experience

9.2.2.1 General experience and history (P8; C24)

There were a number of comments that attributed psychosis to past experiences in a general sense (such as ‘my upbringing’) without specifying particulars (other than it being ‘difficult’). This category seems to reflect a preference on the part of the participant to attribute the experience, at times, to experience in a general sense. Typical of the comments in the ‘general experience and history’ category is the following from Moana, who sees ‘difficult times’ as a child making her prone to psychosis:

> *‘Yeah, a lot of really, really difficult times, so I'm would definitely be prone to a lot of things. But, I don't know, it's like, well, yeah, I know that, yeah I'm kind of quite open to that now, that I was probably set up early on to experience something like this.’*

Margaret states, on the topic of what caused her psychosis:

> *‘The past. Because I have had so much of it in my life that I perceive everybody as rejecting me when actually they're just being themselves in their own space.’*

9.2.2.2 Isolation (P9; C31)

An experience which was notable in participants’ stories was having spent prolonged periods of time feeling, and being, socially isolated. This was the case for Kevin, who was convinced that isolation was a factor in causing his psychosis, a theme echoed by many participants. The general notion here was that participants saw their loneliness as creating a vacuum which was filled by the psychosis. Comments in this section make clear that participants saw this isolation as causative of psychosis, not simply a consequence of becoming unwell, nor a way of coping with the distress. This position is articulated by Margaret who comments simply, yet poignantly:

> *'And through desperate loneliness I created all that.'*

Similarly, Leon:

> *'For me I think it was just like being left on my own too much.'*

The notion that isolation contributed to the psychosis and the mechanism by which it did so was a recurring theme in Moana's story:

> *'Yeah, because I'm spending time on my own and I'm at home, I feel that I'm getting out of touch with reality and everything, and then I start floating around in this, this bubble that's got God and the Devil, and I think it's just us in the whole universe. I think things like that.'*

9.2.2.3 Abuse (P3; C19)

Three participants saw their history of abusive experiences as being causally related to their experience of psychosis. Many of these comments relate to sexual abuse that the participant experienced, though within this sub-category I have include other experiences which could be considered abusive in a general sense (such as teasing and bullying at school).

Margaret, who had an extensive abuse history, was convinced that her experience of childhood sexual abuse was closely related to her hearing abusive auditory hallucinations later in life:

> *'When you saw the way my father used to behave around me and that. I think, well, no bloody wonder you've got a mind like that, Margaret. When your father bloody [whispers] exposes himself in front of you and things like that. Unintentionally, you've got to sit their and look at it. No wonder you've got this shit going on inside you. No wonder you feel dirty and unworthy.'*

She expressed an understanding of how this related to her abuse, seeing both the abuse and psychosis as transgressions of normal boundaries:

> *'I can see what's happening is the lack of boundaries was the cause of all this in the first place.'*

Kevin reported feeling terribly alone at school as a result of the teasing he received through much of his high school years and he saw this as rendering him vulnerable to psychosis and eventually providing much of the content for his delusional beliefs:

> *'The teasing got worse and worse and the staring and the being alone and even the teachers they sort of didn't want to see me. I noticed that they did move so they wouldn't see my insecure miserable face you know.'*

9.2.2.4 Interpersonal relationships (P5; C9)

Contrasting (though congruent) with the experience of isolation above, some participants saw difficult relationships as having a causal role in the genesis of psychosis. Sometimes the same individual could give a causal role to both isolation and to difficult relationships, illustrating the fact that participants had no difficulty in adopting models of causality that were multi-factorial. Here, Moana ponders the possibility that a failed past relationship rendered her unwell:

> *'I had really strong feelings for X. I mean he was someone I couldn't get over, which probably contributed to, you know, my sickness.'*

Mark, who had had a period of time prior to becoming psychotic when he had lived with extended family for a while, considered it likely that stressful interpersonal relationships contributed to his becoming unwell:

> *'I like freedom to be able to be myself, and that usually comes with the people you are with. If you are happy with the environment and your friends that come over into that, or you visit them. It's fine. You can be yourself and not be judged. But if I am living in somebody else's household and nothing I do will ever be good enough, and I shouldn't really be there in the first place because it's not going to be our building.'*

9.2.2.5 Becoming independent (P1; C2)

An interesting suggestion, from a developmental perspective, was proposed by Paul. Prior to becoming psychotic, he had felt he was at an age when he should move away from home and he found himself torn between living with family and moving into a shared flat, a situation which created a dilemma for him as he felt his parents had cultural reasons for wanting him to stay at home. He saw this tension and the stresses involved in becoming independent as having a significant role in generating his psychosis. He found this framework reassuring and saw his unusual experiences as a normal response to this:

> *'I am not worried too much about what is happening. I think it is just me trying to become...trying to sort um..yeah..to stand on my own two feet, to see if I can do things for myself.'*

9.2.3 Causes of Psychosis: Biological Factors (P11; C44)

In addition to the psychological and interpersonal factors listed above, many participants posited the notion that biological factors contributed to the development of psychosis. In this sub-category I have included those comments which identify a causal relationship between various aspects of biology and the psychotic experience. These are illustrated in figure 9.

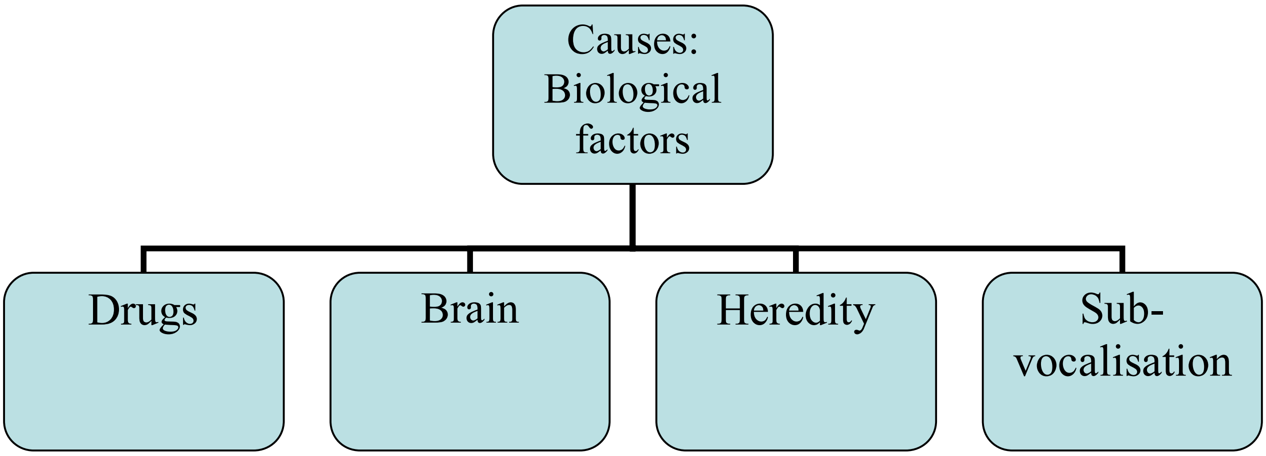


Figure 9: Causes of Psychosis: Biological Factors

9.2.3.1 Drugs (P7; C21)

Comments about drugs (mostly cannabis), as the wider context makes clear, generally refer to drugs as agents which had a biological effect on the brain. While many participants discussed drug use and psychosis, not all agreed on what kind of relationship, if any, existed here. In fact, a number of different relationships between drug use and psychosis were expressed, sometimes by the same individual. For example, in one session, Leon, reported having a smoke of 'weed', after having none for a year or so, and felt this caused paranoia:

> *'So, not very good. Cos I haven't had it for like more than a year. So, I did after that, got a bit paranoid.'*

Whereas later, he refutes this position:

> *'Nah, never. It's definitely not brought on by drugs, my psychosis.'*

This refutation cannot be explained as a misunderstanding of terms: Leon saw his 'paranoia' and 'psychosis' as largely synonymous. Rather, it reflects, I think, ambivalence about the relationship between psychosis and cannabis use. Not all participants felt so ambivalent. Some were clearer that drug use had contributed to their psychosis, and did not waver from this position. Spencer:

> *'It was actually because I had some LSD, and the chemical reacted pretty largely.'*

Others expressed a more positive attitude to drug use. For example, Tim (who was in disagreement with his mother about this issue):

> *'I think em it [psychosis] just happens. My mum reckons it was cos of all the LSD and things I took. Probably to tell you the truth even before I took those drugs I had sort of signs of it. Just getting depressed quite easily, but probably the LSD and the marijuana was kind of a bit of medicine for a while.'*

Others, such as Isa, also expressed more positive thoughts about cannabis use, suggesting that it was either unrelated to psychosis, or that it helped open up new ways of thinking (including, as Isa said on other occasions, about the psychosis itself):

> *'I just find that for some strange reason it [cannabis] effects…I don't know…maybe the chemistry in my brain, on a level that I can't reach when I'm not using, but in a positive way.'*

9.2.3.2 Brain (P3; C12)

Some biological accounts of psychosis attributed the experience to 'the brain'. Under this heading we find comments which see the brain, generally without further specification, as being implicated. The context of these comments makes clear that these participants were referring to the brain in organic terms as the causal agent, rather than using the term to refer to psychological processes within the brain. Here, Janet expresses this position clearly:

> *'I always believed that it was to do with my brain.'*

Similarly, Moana:

> *'I think I have to come to terms with the fact that, at some level, I must have done something. I must have done something to my head.'*

9.2.3.3 Heredity (P2; C6)

A couple of participants identified hereditary factors as being implicated in the genesis of psychosis. Janet, who had recently been made aware that a close family member had also experienced psychosis:

> *'I thought just that I'd been born with something not right.'*

9.2.3.4 Subvocalisation (P1; C5)

Another biological theory for explaining psychotic experience (in this case auditory hallucinations and associated delusional beliefs) was developed by Tony. He reported that he had noticed that when he heard voices, he also felt an unusual sensation in his voice box:

> *'I often wonder if I am mumbling under my breath to myself.'*

Later in the same session he elaborated:

> *'Just been wondering if my like, if this chatter's turning into something in my voice box and I'm speaking under my breath unconsciously.'*

Initially, he considered that this belief that he felt sensations in his voice box was delusional in nature:

> *'It's a feeling I have had for a while, that is in my throat and it's kind of like a delusional feeling that there's something going on there.'*

He was reassured to hear about the theory of subvocalisation as a contributory factor in auditory hallucinations.

9.2.4 Causes of Psychosis: Spiritual Factors (P3; C35)

Many participants expressed some thoughts about possible spiritual aspects of their experience, although not all saw this as a causal factor. More general issues relating to the position of spirituality in the participant's experience of psychosis are presented in section 9.6. In this section, I present only those comments which attributed a causal role to spiritual factors. These causal spiritual factors could be subsumed by two sub-categories of spiritual experience: 'other beings' and general spiritual matters.

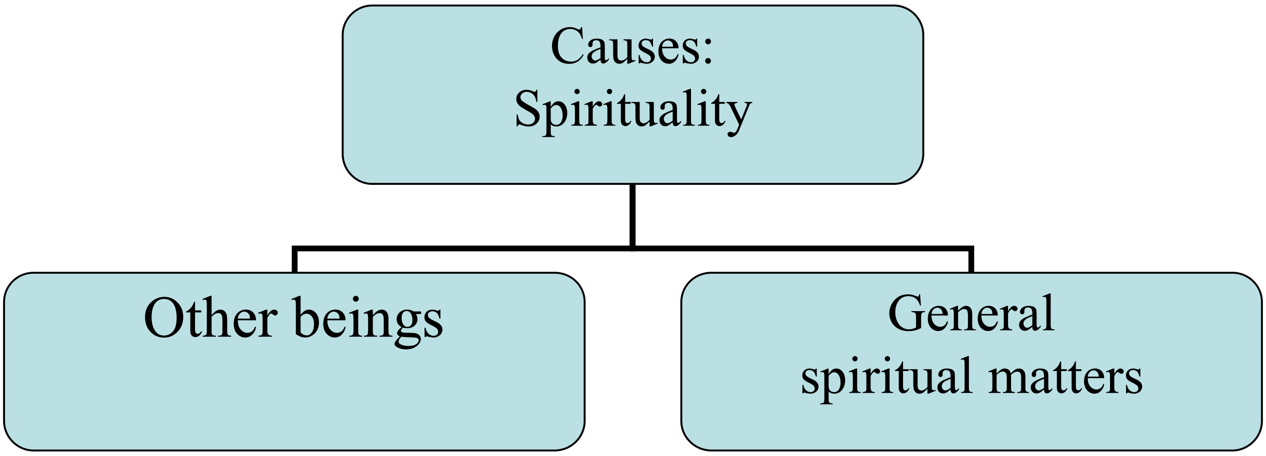


Figure 10: Causes of Psychosis: Spiritual Factors

9.2.4.1 Other beings (P2; C26)

Two participants felt that some of their psychotic experiences may have been produced by other beings, spiritual or human, using non-physical methods of conveying this experience to the individual. Also included within this sub-category is the notion of 'being possessed' by a spiritual being. Generally these theories were associated with some distress for the individual as they felt themselves subject to some form of attack by a being, or person, out of their control. Michael considers this as one plausible explanation for his experience:

> *'Yeah, but it's either coming from these beings, whatever they are, or it's coming from my head, from me.'*

At other times he seemed more convinced that other beings were implicated:

> *'I explain it that there are these alien things that are screwing with my head.'*
>
> *'I just said "psychotic" because when I look at myself I don't say that I'm a psychotic. I say that I'm..that this thing, you know, all about my belief of those things floating around and controlling me. I say it's because of them.'*

Moana felt this was a view commonly held by those who experience psychosis:

> *'I think a lot of us think that there are spirits that play around with us and that there is actually something out there that's shooting things into our head.'*

9.2.4.2 General spiritual matters (P2: C9)

Some expressed the view that spiritual matters of a fairly general nature had somehow contributed to the cause of their psychosis, often involving notions of 'good' and 'evil'. Moana:

> *'I spent probably the last 8 months thinking about the Devil and thinking that He's after me and thinking "far out, what is this about, who's after me?". You know, someone out there's got a problem with me, and like, em, yeah, I think it's probably caught up on me now.'*

Leon also often mentioned spiritual themes when he spoke about how he felt his psychosis had come about:

> *'Yeah, spiritual, like all your things that you've done bad, and you've done good, and it makes you laugh and it makes you depressed to the extremes, makes you like wear emotions to the extremes. It seems like something pre-planned but not really.'*

9.2.5 Causes of Psychosis: Functions of Psychosis (P7; P33)

The final sub-category within participants' understandings of the causes of psychosis is somewhat different from the others in that here we find the idea that psychotic experiences perform a particular function for the individual, and this functionality is seen by the participant as explaining why the psychosis occurred. These functional explanations tended to be psychological in nature. That is, the psychotic experiences were seen to have been caused by the need for the individual to address emotional or cognitive matters. There is considerable overlap between functions of psychosis and other notions of causality noted above. Some of the ideas expressed in this section could also have been subsumed within other notions of causality (for example, some of Moana's comments below relating to isolation could have been categorised under section 9.2.2.2 above). The essential difference here is that participants seem to be implying that it is the *function* which the psychosis serves (e.g., overcoming isolation) which causes the experience, rather than the difficult feeling (e.g., isolation) itself. Subcategories within functions of psychosis are shown in figure 11.

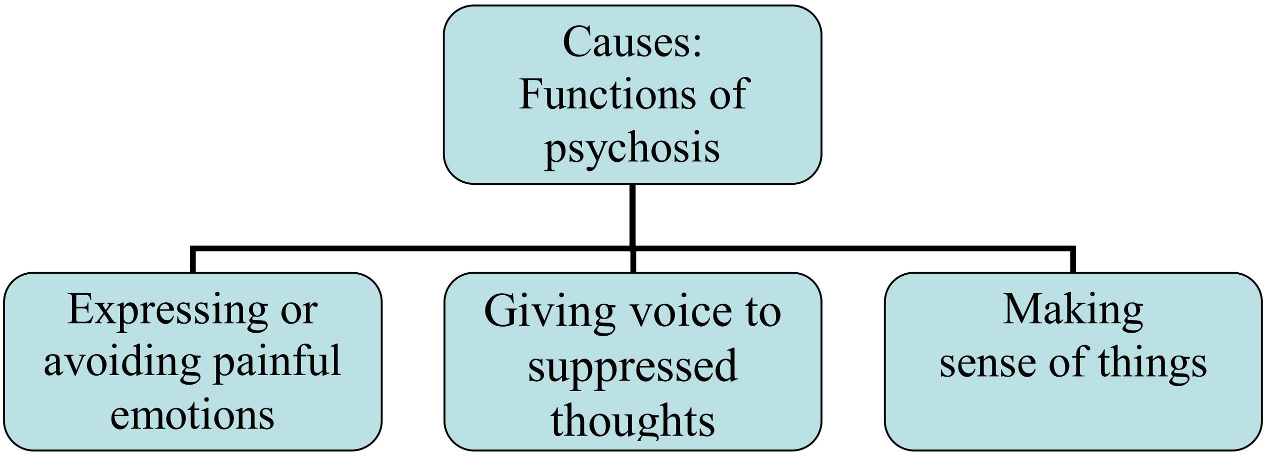


Figure 11: Causes of Psychosis: Functions of Psychosis

9.2.5.1 Expressing or avoiding painful emotions (P4; C27)

Some viewed their psychosis as reflecting, and having been caused by, their own way of expressing or avoiding painful emotions. These emotions included feelings of inferiority, which Tim saw as fuelling his manic episode:

> *'I suppose maybe that was my attempt to crush my inferior feelings. Maybe I just thought if I push myself to be just overly confident then I wouldn't get those em..cos I was thinking that when I was in the manic state that I was about how I used to be, and I would laugh it off and think, I'll never be like that again.'*

Moana also felt her psychotic experiences served functions which helped explain their cause. Here, she comments on her 'imaginary friends' (who came to feel real to her) and how they functioned to help her deal with the pain of loneliness:

> *'I think I was feeling lonely and stuff and then all of a sudden here I had some friends, some friends that were going to sit here and listen to me.'*

More generally, Moana commented that psychosis had helped cure her from depression, a theme which she expanded on to suggest that the psychosis had in fact saved her from suicide:

> *'It was like a miracle cure for my depression or something, but I haven't experienced it since. Like, it's almost like I feel like I've been walking my whole life quite depressed and suffering from something, and all of a sudden it's cured.'*

Margaret also expounded the position that psychosis had functioned to help her resolve a painful issue (being rejected) and that her need for resolution in this area had contributed to the cause of the psychosis:

> *'All I think was happening was it was giving me an opportunity to clear that rejection and start seeing things that clear the reality, and see things as they are now, not 15, 20, 30 years ago when you were back there as a child.'*

A couple of participants (Moana and Paul) suggested that their psychotic experiences functioned to help them avoid addressing difficult emotional issues, by distracting them from the matter. The context of these comments indicates that both saw this as having a causal component to it. Paul notes that whilst in the midst of his psychotic experiences he was able to feel good about himself, as it allowed him to ignore major changes in his life which threatened his sense of well-being:

> *'See I was feeling good about myself and about life and about everything. So that I, for me to accept that, that something has changed, would be like everything around crashed on me. So this way, I felt so alive, I felt so good about everything.'*

Moana also notes that were she not engrossed (as she was) by her vivid delusional world, she would have to face some rather unpleasant feelings about herself:

> *'I think that I'd be quite down and stuff and I'd be like, you know, I'd be like quite depressed, and I'd be like, you know, life sucks. And I'd be thinking about all the rat shit stuff that's happened.'*

9.2.5.2 Giving voice to suppressed thoughts (P2; C4)

Janet and Tony both felt that hearing voices was sometimes their way of giving voice to suppressed thoughts, which they felt unable to express, even to themselves, using more conventional means. Janet felt that her voices helped her express her true wishes:

> *'Em, part of me is thinking that it's like instead of being voices there in my thoughts, maybe that's what I'm wanting to do.'*

Whereas Tony felt that his voices expressed what he did not want to express:

> *'Yeah, it's like, kinda like..what do I want to say, like can't really find it, so what I don't want to say starts coming up.'*

9.2.5.3 Making sense of things (P2; C2)

Moana and Isa both expressed the view that their psychosis served a purpose of helping them understand aspects of the world or themselves (which may have been confusing otherwise) in a better, clearer way. Moana:

> *'Only because of the way this sickness developed. It was so logical, it just all came together in such a logical way, and it just explained everything and everything.'*

Isa also considers the possibility that the function, and possible cause of psychosis, was for him to 'learn something' (about the human mind):

> *'I guess with this, since being sick..I don't know why, but I think it was even meant to be, in order for me to learn something.'*

9.3 Descriptions of Psychotic Experiences (P12; C107)

The next broad category of participants' accounts of their experience of psychosis relates to descriptions of the experience. Whereas the previous section examined how participants viewed *why* the experience occurred, the present section looks at how participants explained *what it was like* to experience psychosis. That is, the present section relates to participants' efforts at conveying what they felt was happening when they had psychotic experiences, rather than attempting to identify the origins or causes of the experience. Again, this category consists of a number of sub-categories where particular descriptions of psychosis are invoked, as illustrated in figure 12.

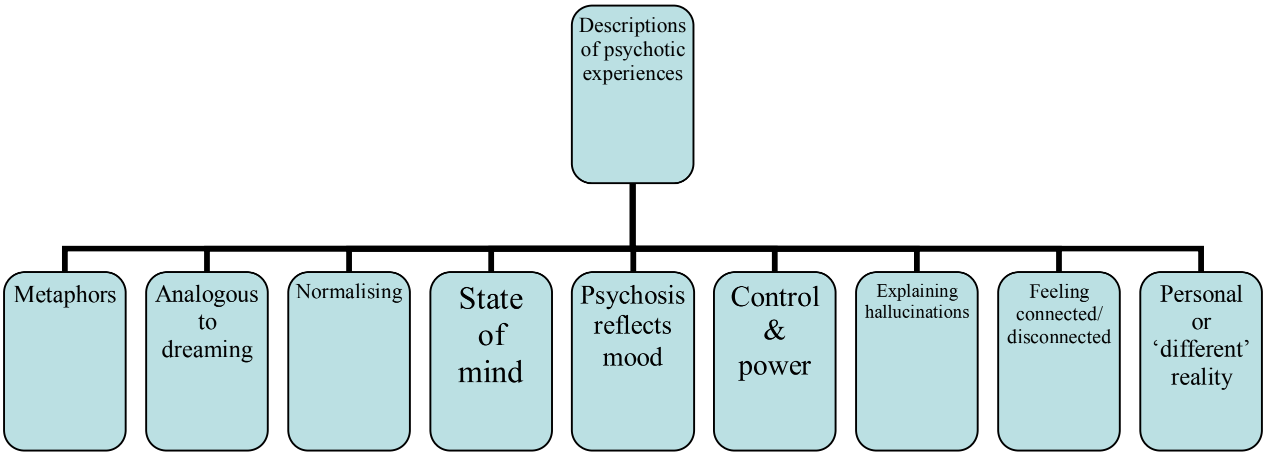


Figure 12: Descriptions of Psychotic Experiences

9.3.1 Metaphors (P6; C23)

When we look at how participants described their psychotic experiences we find that metaphors were often invoked to convey a sense of what it felt like to be psychotic.

These are rich and imaginative ways of conveying a subjective experience which often does not submit easily to description. These metaphors sometimes vividly capture important aspects of the experience, and illustrate clearly that many of the participants in this research maintained a capacity for abstract thought. (These metaphors helped convey to me a greater sense of the experience and also opened up new ways of thinking about the experience and new avenues to be pursued in terms of therapy.)

To convey the richness of these metaphors, I will provide several examples here. Describing her distorted visual experiences (which were at least partly hallucinatory) and the associated sense of alienation, Janet compared her experience to watching a sped-up movie:

> *'And it feels like things are happening so fast like you see on some programmes how people just stand there and the world goes by. That's what it feels like. That I'm standing there and the world's rushing by and I'm just sort of standing there.'*

She also used a metaphor from visual media to express how it felt to be harangued by a voice (auditory hallucination):

> *'Feels like you know how you see in cartoons you've got a little person on your shoulder. That's what it feels like.'*

A similar visual image is used by Tony, also to convey the experience of hearing voices:

> *'It felt like there was a great big speaker on my head actually making noise.'*

Further visual metaphors included Tony's account of his rich visual (and imaginary) world, which often interfered with his ability to interact in social situations:

> *'Yeah, without me even trying. It's like most people have to sit down with a pen and draw a picture, to create what I see accidentally.'*

Paul expressed the sense of losing one's bearings (as he felt when psychotic) as being similar to losing the capacity to see:

> *'Psychosis is like having your eyes closed. Nothing you see is making you grounded.'*

Leon used a metaphor from the world of computing (defragmenting of a hard drive) to describe his sense of falling apart when psychotic. This metaphor provided him with a framework which not only described the experience, but also indicated steps to remedy this situation:

> *'It's like defragmenting, you know, in a computer, and all the bits go back into the right places, or you've got to put them back, and that's what the medication helps do.'*

The struggle to contain the feelings of pressure associated with the voices in his head is captured by Tony's image:

> *'Em, [laughs], it's kind of like trying to hold a balloon under water. When I am feeling bad, the balloon keeps getting bigger and bigger and harder to hold under the water.'*

Moana:

> *'I'd get all these memories from the past, and just this whole story all of a sudden it would just be like a tapestry of you know, woven, well, you know what I mean.'*

Some used metaphors involving journeys. Tony likened his tangential thoughts to:

> *'Different trains going different places. [laughs]. Just short journeys here and there, and idly wasting time.'*

Isa:

> *'Now I see my voice as being like a spiritual journey.'*

Michael:

> *'I'd be healthy and then it would start up, and then I'd be sick, and then I'd come out of it like it was some kind of journey or something. I've thought about it that way right from the start.'*

9.3.2 Analogous to dreaming (P4; C10)

One specific analogy that featured in a number of accounts was that of likening the experience of psychosis to the experience of dreaming. Moana:

> *'I thought it was similar to dreaming, because I couldn't figure out, I just could not figure out.'*

Paul:

> *'Maybe it was sub-conscious. Or maybe it was something that was stronger than me, like in a dream or something.'*

9.3.3 Normalising (P5; C16)

In describing the experience of psychosis, many used a normalising framework, commenting that the psychotic experience was essentially similar to normal processes. The psychotic experience was described as a process which most people experienced (possibly taken out of context as a result of increased scrutiny) or a normal response to a difficult situation. The common thread here is that psychotic experiences are considered a normal aspect of human experience, rather than a qualitatively different experience. This position is summarised by Mark, who neatly captured the essence of a stress-vulnerability perspective:

> *'I suppose we must all have a breaking point.'*

Tony also saw aspects of his experience as an inevitable and normal response to having too much free time:

> *'Em, got a lot of time on my hands to think about things. Except even when I was working it still happens. Em, I don't know. I don't see myself as much different from other people.'*

Paul argued that description of his experience as 'thought disorder' failed to take into account his context:

> *'Maybe it's temporary, but in my opinion, it's not maybe fair and judging the circumstances under which I've been and if I was in the same circumstances as maybe my psychiatrist. Maybe on a day-to-day basis, he has something to talk about. He's not very low and he's not very pessimistic, then maybe I would make more sense.'*

Kevin:

> *'I valued and value highly the opinion of other people of me, and because they did that, I did check to see if they were staring at me. I did check to see if they were laughing at me. That's it and that's reasonable, and that's not different. That's normal.'*

9.3.4 State of mind (P5; C11)

Some participants described their psychotic experiences as reflecting a particular way of viewing the world, or a particular 'state of mind', generally different from what is considered to be the 'normal', or even the particular individual's usual, state of mind. Michael:

> *'Just things like that which I wouldn't believe in at one moment, and then the next moment it would be like it's really happening, like as soon as I go. I just click into it. I can actually sense when I click into it.'*

Paul:

> *'Just like different, from a different perspective, maybe a dark perspective or something, you know, from somewhere on the edge of the world or something, and I was looking at the world from a different perspective, you know.'*

9.3.5 Psychosis reflects mood (P4; C5)

Four participants referred to their moods when trying to describe their psychotic experiences, and commented that they felt that the psychosis was an expression or reflection of their underlying mood (though they did not imply, in these comments, that there was a causal relationship between mood and psychosis). Kevin notes that when he listens to his voices:

> *'It sounds like it's mirroring the way I am inside. I mean I notice the negative stuff in other people.'*

9.3.6 Control & power (P5; C15)

The issue of control over experience was something that some participants discussed. Some described their psychotic experiences as consisting of a sense of losing control of one's thinking or feeling. Janet reported that when she experienced a hallucination:

> *'It almost like feels like you're losing control of your mind.'*

Mark:

> *'And the feeling that overtakes you when it does, that you have very little or no control. And I think I am fighting against loss of control.'*

Moana:

> *'Where it's not relaxing and settling, because sometimes I'll be sitting there and I know my head's gone off to do something. And, I'll just let it go off and do it.'*

Michael:

> *'It's like, this is me right, and I'm back here, I'm not up the front controlling me, like feeling like I'm controlling me. I'm back here feeling like I'm out of control.'*

9.3.7 Explaining hallucinations (P5; C16)

Participants who experienced auditory hallucinations were generally asked, as part of therapy, how they discriminate the experience of a 'voice' from that of a 'thought'. This line of questioning led participants to describe in some detail the experience of hearing a voice, and to identify the properties of the experience of hallucinations that distinguish them from thoughts. The general notion within conventional psychiatric literature is that voices are distinguishable from ordinary thoughts because they have an auditory quality that thoughts do not. That is, the difference between thoughts and voices is seen as being phenomenological and perceptual in nature. This is how Tony described his auditory hallucinations, saying it was like:

> *'Having an audio thought without producing it myself.'*

However, others who heard voices described them quite differently, and differentiated them from thoughts on quite different grounds. Michael identifies voices as being different from thoughts based on voices being experiences which he has no notion of having produced intentionally:

> *'Yeah. It doesn't feel right, because like something will just pop out of my mouth and I'll be completely, like I wasn't even there when I said it sort of thing.'*

Janet differentiated thoughts from voices based on the content:

> *'But if it speaks about you, if it says 'you should' or something like that then that feels like a voice.'*

Another criterion used by participants to identify an experience as a voice was that of 'unfamiliarity'. That is, if the grammar or vocabulary of the experience felt unfamiliar, then it was deemed to be a voice. This is explained by Tony (who had also described some of his voices as being auditory in nature):

> *'It's like, emm, it just doesn't feel like it's something I've thought of. Or the actual sentence would be a sentence I wouldn't usually use in my dialogue.'*

These various descriptions of the experience of hearing a voice suggest that there may be different processes involved in how participants (even the same participant) come to construe experiences as voices. This issue will be considered further in the discussion.

9.3.8 Feeling connected/disconnected (P3;C9)

The sense of being connected or disconnected from the world and from other people was an issue of considerable importance for three participants. Those for whom this was an issue tended to see it as being fairly central to the experience. There was some suggestion that the early stages of psychosis are more characterised by feeling ‘connected’, whereas in the latter stages a sense of ‘disconnection’ is more evident. This was apparent in Paul’s story. He reported that at the earliest stages of his experience:

> *‘I was so connected to everything, to the air, to like throughout the distance, like clouds and stuff, and to music.’*
>
> *‘Everything was connected to me, was that..like my I don't know, spirit or something, was here, or was there as well. I was spaced out in a way.’*

However, he characterised his experience later on as consisting of more of a feeling of disconnection:

> *‘I would feel like I was put in some box, you know. And like I would just look in through this here, but I'm in a dark box and I'm looking somewhere outside.’*
>
> *‘The way it feels is like my mind has gone blank.’*

John also reported that being psychotic felt like being disconnected from himself and from his past:

> *‘I felt disconnected, more disconnected, when I couldn't work out what I was doing in the past.’*

Janet described her experience as having more a sense of social disconnection. When in social situations she felt out of place, which was unusual for her:

> *‘Like I don't know. Like I don't know if I belong here, or what.’*

9.3.9 Personal or 'different' reality (P3; C5)

The final sub-category within descriptions of psychosis is that of personal or different reality. This relates to the description provided by some participants that the experience of psychosis felt like inhabiting a quite different reality: different from the ‘normal’ consensual reality of others and from the reality previously known to the individual. Generally, this was expressed in tones of discomfort, as if one was confronted with the loneliness of a solipsistic universe, where other people were distant, and outside the individual's private universe. Paul expresses this position as well as the sense of distrust of his own thinking that this brings about for him:

> *'I'm starting to question everything I think and stuff. Like, why is this like this? Everything I experience, everything I live, is just my reality.'*

Michael also conveys a sense of isolation associated with psychosis:

> *'That's what's brought me away from life. And now I'm seeing life in new perspectives. From somewhere else, I'm locked in a room somewhere.'*

9.4 Impact of Experience (P11; C207)

In addition to talking about the possible causes of psychosis and describing the subjective experience, participants also spoke at some length about how the experience of psychosis had affected them: the impact of the experience. The psychotic experience was felt by participants to be both quite pronounced and profound in terms of its impact. Isa:

> *'I feel that my experience was powerful. It, em, it could only have done one of two things my experience: killed me or made me stronger. And it's made me stronger.'*

In this section I will discuss the myriad ways in which participants reported this impact (note however, that I have included 'spiritual implications' of the experience in the 'spirituality' section below). In the current section, I have sub-divided the impacts of psychosis on the person's life into sub-categories, each containing further sub-categorisation. The main sub-categories of impact are shown in figure 13.

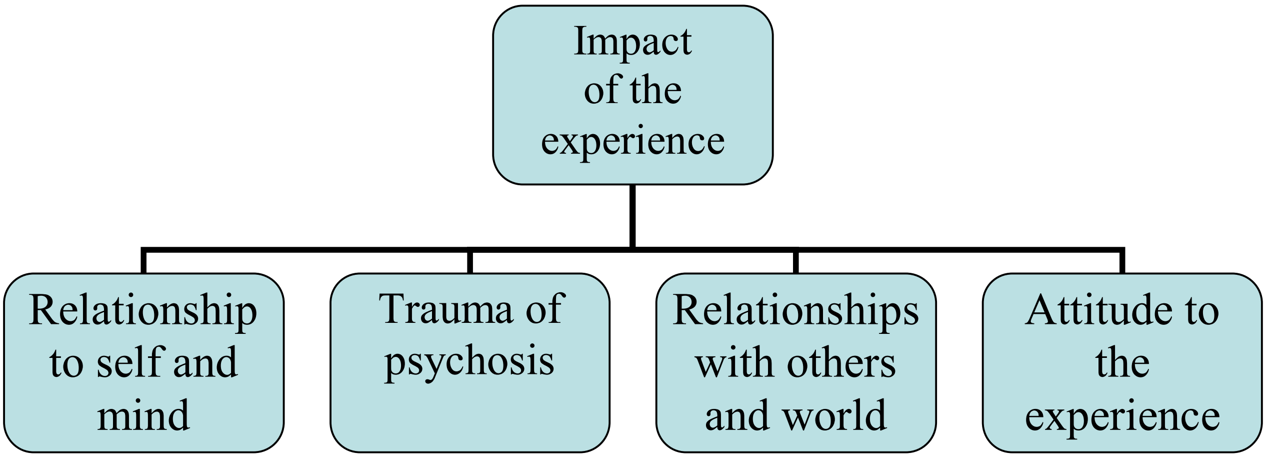


Figure 13: Impact of the Experience

9.4.1 Relationship to self & mind (P10; C114)

Participants reported that the experience of psychosis had a major impact on how they viewed themselves and their minds. This extended to some of the most fundamental aspects of being, such as how individuals viewed their own capacity for accurately construing the world and indeed how they construed themselves. As my analysis developed, I came to think of this as relating to important philosophical and psychological principles that govern how we go about the business of living. I came to view the impact on self/mind as relating to what I think of as 'personal epistemology' (one's views of one's own ability to acquire trustworthy knowledge) and 'personal ontology' (one's personal view about how one can go about 'being in the world': the nature of one's personal being). Both of these were significantly impacted on by the experience of psychosis, which often left the participant facing quite profound challenges. The components of impact on self and mind are shown in figure 14.

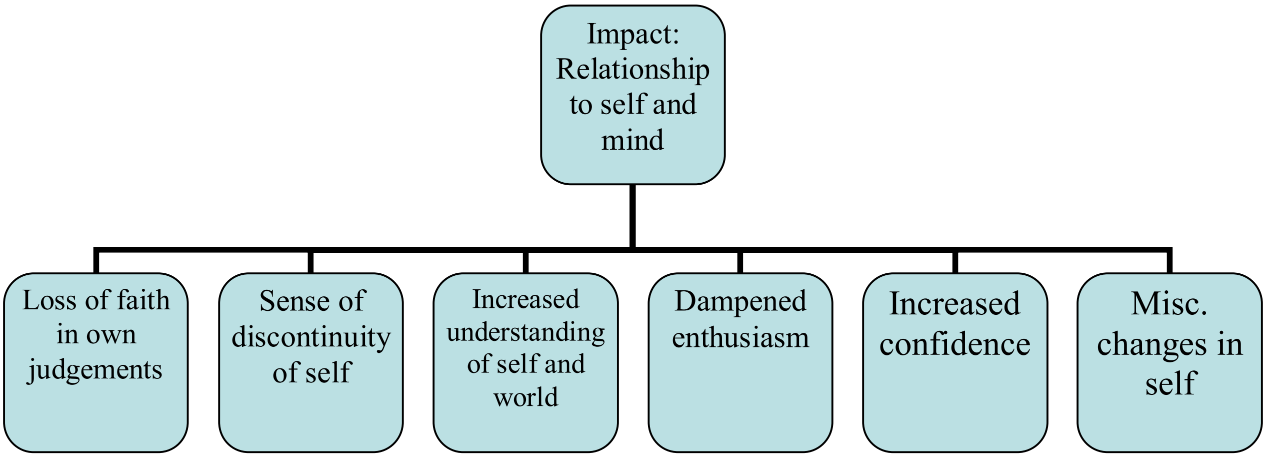


Figure 14: Impact: Relationship to self and mind

9.4.1.1 Loss of faith in own judgements (P7; C51)

One of the most pervasive and troubling ways in which participants noted that being psychotic had impacted on them was in their coming to doubt their own perceptions and/or their thoughts about the nature of reality. Often, this extended to feeling quite unsure about being able to distinguish reality from 'non-reality'. Whilst in the literature this is often considered an aspect of psychotic experience itself, here participants are commenting on an impact of having had psychotic experiences. This was an issue for many of the participants, and seemed a central aspect of the impact of psychosis.

Many participants had, during their period of psychosis, developed ideas about how the world is, or what is going on in the world, that were quite different to the beliefs they had held before becoming psychotic and also different to the beliefs of those around them. For many, when this period of life passed, and they came to doubt much of what they had held to be true whilst psychotic, they found themselves confronted by doubts about their own ways of making sense of and understanding the world. This commonly led to questions for the individual about their own judgements, and a loss of faith in one's self. The loss of faith in one's own judgements extended to different aspects of experience. Though these clearly overlapped, I will present them separately here for ease of understanding.

- General loss of faith

For many, the experience of loss of faith in judgements about the world seemed to pervade many aspects of one's being and cast doubt upon many areas of life, leaving the individual feeling very uncertain and rather fragile. This doubt generally developed shortly after the individual had emerged from a period of psychosis, and lasted for a period of time while the person gradually reacquired confidence in him or her self. The pervasive nature of this loss of faith in oneself is conveyed by Paul, who was troubled by this immediately after having a brief, but pronounced psychotic episode:

> *'I think that's sort of shaken my belief system and my direction in life, you know my purpose in life. Sort of like my belief system, my self, my personality you know.'*

That this experience was one he saw as being attributable to the psychosis, is made clear in the following quote:

> *'The realisation that it was a dream or a made up reality, makes you lose all the foundation, and you don't know what to believe anymore. And now you basically seem like you have to start form scratch, your life, because everything was shaken around you.'*

Mark described feeling in a remarkably similar predicament shortly after emerging from a psychotic episode which had been characterised by his developing quite unusual persecutory beliefs:

> *'I extremely became very doubtful of my own judgements, my balance, my perceptions. Probably just like starting again and retraining myself, even in the normal things of life like driving and reading. Am I perceiving them right, understanding when I read? Like, life's just completely starting again in primary school [laughs].'*

Margaret felt troubled about her ability to identify what is 'real' in the world, which she saw as a natural consequence of having been psychotic:

> *'Suddenly finding out that what they thought was real isn't. That would frighten or disturb anybody. What the hell am I supposed to believe? I can't even trust myself any more.'*

She went on to ponder:

> *'How in the future am I going to know what's real and what isn't?'*

While some expressed general doubts about their judgements, others focussed more on one particular aspect of being that felt most affected by this.

- Emotions

Michael felt somewhat uncertain and estranged from his own emotional world:

> *'It's like I'm incapable of feelings. I don't know if my feelings are fake or not.'*

This contrasts with Margaret who felt that while she doubted many aspects of her being, feelings were the one thing she could rely on as being accurate:

> *'I do know feelings are real. You can't create those. That's impossible. That's one thing. I will always rely on how I feel. The mind is a write off as far as I'm concerned.'*

- Imagination

Moana described her uncertainty about her own judgements in terms of her ability to discriminate the real from the imaginary, something she had not previously had difficulty with:

> *'I find it really, really hard to go back to the way that I used to think, where imagination was just imagination. It was purely daydreaming; there was nothing tangible about it or anything.'*

However, these days, when she continues to have intermittent hallucinations:

> *'I find it really hard to draw a line between what's real and what's not real. I can't help it: my imagination is so lucid at the moment.'*

- The past/memories

Moana also identified struggling to distinguish memories that related to real events from memories that related to experiences that she had made up. As part of her psychotic experience, she had developed a very detailed belief in an alternative, spiritual world and she had created fantasies about this imaginary world which felt very real to her. When reflecting on her 'memories' she felt unsure about which belonged to which world:

> *'One of the hardest things for me at the moment is because I've made so many memories, I've made so many, I can't make a differentiation between some of the things that have really happened and some of the things that definitely haven't. I can't even tell which are memories and which aren't memories. I'm not absolutely certain any more.'*

- Re-acquiring trust in oneself

The usually gradual process of rebuilding trust in oneself was often a focus of psychotherapy, and commonly something that participants spoke about. Mark explains the way in which he developed this trust in himself again, through evaluating how he dealt with situations, and gradually learning to trust himself (at other times he spoke at about checking out his perceptions with trusted others as being an important part of this process):

> *'Well, as life goes by one day at a time and you do the normal things that you should do, it's coming back just by maybe a little repetition of maybe the same thing. Or simply that nothing has actually gone wrong while I have been trying to get myself back on track. And so if I can trust, "OK that went all right", so I can try doing the next thing. OK that went fine. That means I can*

> *trust myself in those two avenues. The next one and the next one, just like steps.'*

9.4.1.2 Sense of discontinuity of self (P3; C19)

Another significant impact on the sense of self was the sense of discontinuity of self over time. For some participants, the experience of psychosis fractured the sense of continuity of self, such that they felt quite changed from how they had previously viewed themselves. Here, Michael expresses this discontinuity, which he, not surprisingly, found quite disconcerting:

> *'I don't know if this is all normal or not. I can't remember what it used to be like. I can't remember anything about what life was like before.'*

Paul:

> *'I can see the world and everything, but I don't seem to, you know, see it with the same eyes as I used to before, you know. So, I think that maybe, you know, as a result of what I went through, maybe I have changed, but I don't know what has changed about me.'*

9.4.1.3 Increased understanding of self and world (P7; C18)

Not all of the ways in which psychosis affected the individual were of a negative nature. Some reported that they felt that as a result of having had a psychotic experience, they now had a different and richer awareness and understanding of themselves and of the world. Reflecting on the impacts of psychosis, some participants reported that as a result of the psychosis they felt that they now more aware of their own internal experiences. This was seen by participants as being a positive effect that the psychosis had had upon them. Michael reports that as a consequence of the psychosis:

> *'My senses have been heightened since I became psychotic. I am more sensitive now to moods and stuff. I sort of found out that I've gotten really sensitive to my state. Like, if I get into a really good state, it's like whoaa..that's amazing!'*

Tony commented that as a result of hearing voices, he pays for more attention to himself generally, and more specifically his thought processes:

> *'I never studied myself that hard until I had the psychosis. I have never really em..never really listened to myself talking.'*

For others, the impact was not only on awareness of internal experience, but on their understanding of experience. Isa:

> *'If I hadn't gone into that black hole [psychosis], I truly believe I wouldn't be where I am now. I feel like I know myself better, understand myself better. And, I know it sounds funny, but I feel like I understand people better too.'*

Isa was not alone in feeling that he now had a better understanding of the interpersonal world as a result of psychosis. Others also reported that they felt that they now looked at the world quite differently, adopting a fresh perspective. Michael:

> *'It sort of opened my mind up to way different perspectives, like healthy ones. Some of them are healthy and I would have thought about it very much.'*

Moana:

> *'It's like this whole experience has made me look at things that I've never looked at'*

9.4.1.4 Dampened enthusiasm (P2; C6)

Two individuals reported that since recovering from psychosis, they felt that their enthusiasm for life had been somewhat dampened, which they clearly felt as a loss. This loss was noted when the person compared their current post-psychotic self with how they felt before they had had any mental health troubles. Michael struggled with this feeling often:

> *'It's like it's taken my whole self and just dampened everything so nothing can happen. I'm not able to work things out, it's like my brain isn't doing anything.'*

Paul:

> *'I go to the beach maybe in summer, but my eyes don't see what they used to see before. I don't seem to see all that energy around me, all that sort of, all these paths, all these people, this energy of the birds or whatever, the ocean and stuff. It's like I don't seem to feel that energy.'*

9.4.1.5 Increased confidence (P3; C6)

Another example which illustrates that participants did not see the experience of psychosis, and its effects on them, as wholly negative is found in those who reported that as a result of the psychosis they now felt more confident in themselves. Moana:

> *'The hardest thing about my situation now, because I've come out of it, is like now that I've come out of it, I'm like really, really strong.'*

Leon notes a similar increase in confidence since he became psychotic, although he points out that he's not sure exactly what brought this about:

> *'I've got more confidence than I had before I went into the em, before I had psychosis. I dunno why, I think it might be just like medication. Going along to the groups and stuff was quite good as well.'*

9.4.1.6 Miscellaneous changes in self (P7; C14)

In the final subcategory of impacts on self I gathered comments by participants that related to miscellaneous changes in various aspects of self. These comments related to aspects of personality as well as behaviour which did not readily fit within one of the more specific categories. Examples of these comments include Moana:

> *'Through my sickness I've become less superficial in terms of looks, clothes and so forth.'*

Spencer:

> *'I think after the episode, I started looking at myself and what I was doing wrong and how, how much of what I did was actually good-natured.'*

Finally, in this section, illustrating the variety of ways in which the experience effected how participants saw themselves is another quote from Moana, explaining that the experience had made her more mature and also had an impact on her thoughts about career choices:

> *'Because, you know, I really want to go into psychiatry myself, and I think it's made me more open-minded. I think in its own way it's made me maturer. It's taught me a lot of things.'*

9.4.2 Impact of experience: Trauma of psychosis (P6; C18)

As may be apparent from some of the above quotes, participants often found the experience of psychosis had a number of negative effects on them. Some reported that they found the experience of psychosis itself traumatic. Tony:

> *'But now it's when there isn't a focus there is the negative of the past and just remembering psychosis is enough to start a small panic.'*

Paul also felt traumatised by his experience:

> *'All that experience has in a way made me less of a person, or has scarred me on the inside, or has damaged me in a way.'*

Another common fear, related to the feeling of being traumatised, is that of the symptoms returning. Mark:

> *'I suppose I am still fearful of the symptoms coming back.'*

9.4.3 Relationships with others and with world (P7; C47)

We have seen that the experience of psychosis had a significant impact on various aspects of the person's relationship with him or her self. But, clearly, psychosis does not happen in a vacuum. Rather, it always occurs in some kid of social context. Not surprisingly, when we look at how participants spoke about the impacts of psychosis, they spoke also about how going through this experience had affected their relationships with other people and more broadly with their world. Aspects of this are shown in figure 15.

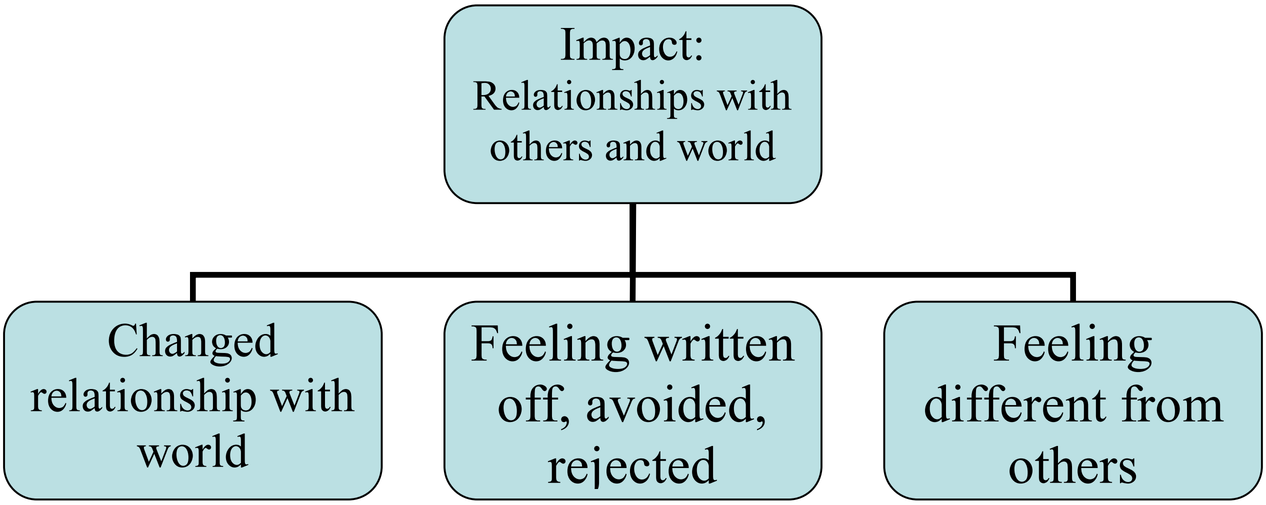


Figure 15: Impact: Relationships with others and world

9.4.3.1 Changed relationship with world (P3; C22)

Some participants reported that they felt that their relationship with the world in a broad sense (including both the material and the interpersonal world) had been affected through the psychosis. Generally, the direction of this impact was for the person to feel a greater distance between self and world, although this was not always the case. For example, Paul, for whom this issue of feeling distanced was of considerable importance, noted, when reflecting on the time he first had psychotic experiences:

> *'My impression is that my involvement, my experience of the world was increased.'*

However, this contrasted sharply with how he felt in his post-psychotic state:

> *'It's almost like I've been cut from the world.'*

This state of affairs caused him considerable distress. Others also expressed feeling detached from the world and also found this distressing. Moana:

> *'I feel, everything feels kind of surreal and I feel like I'm floating around in some magical bubble.'*

9.4.3.2 Feeling written off, avoided, rejected (P3; C17)

One of the more specific interpersonal consequences of having been psychotic was a kind of social stigma, which includes the sense of having been written off by other people; the feeling that others no longer considered the individual to have a valid contribution to make to discussions. Margaret, who was a member of a religious group, felt this acutely. She struggled with feeling that her experiences were seen by other members of the group purely as signs of psychosis, with none of the spiritual significance she believed the experiences to have:

> *'Well, I feel very rejected at the group because I've not been validated when I thought I was having true experience.'*

However, her sense of being invalidated by others extended far beyond just feeling that others did not accept her understanding of her experience. She felt that, as a result of having had a mental health problem, she herself had been written off:

> *'Well, I feel like I've been written off as a bloody nutcase, like my mother was written off too. But my mother was having very profound experience.'*

Mark also felt that his experience of psychosis had influenced how some friends viewed him:

> *'I meet people they are sort of looking at me like "he's had a bit of a breakdown; he has had psychosis; he was a bit nutt"' [laughs]. So, I have got*

> *to put up with the fact of people looking at me and thinking is that strange or is that normal?'*

Others reported that one aspect of this was that others would now keep more of a distance. Spencer noticed:

> *'My neighbours have backed off from me since I've been unwell, that's ok.'*

Margaret noted one consequence of being treated in this way:

> *'It's left me feeling very very mistrusting now of people. I find like it's part of me. I say"yes I do trust God, the Divine, all this", but there's a part of me that's pulled right back from everything and everybody. It's like I don't know who I can trust any more.'*

9.4.3.3 Feeling different from others (P3; C8)

Another important impact of psychosis, which had implications in the interpersonal world, was a sense that having had psychotic experience makes one quite different from others. This was often associated with a sense of social isolation, as if a barrier now existed between the individual and others. Paul specifies that this began at the time he became psychotic:

> *'And, I guess from that moment on I felt much more different from other people. Like, it's like something has been taken away from me, that's how it feels. Like it's put a wall between me and you know maybe, in a way, other people.'*

Tony:

> *'It's kind of with the psychosis, I don't feel like I fit in, into like what everybody else is doing, in just relating what they do and that. I feel out of place, and em, then I feel regression, I think, and so I try to crawl under my shell.'*

9.4.4 Attitude to experience (P8; C28)

Under the category of 'impact of psychosis' I have also collated comments which expressed the individual's general attitude to the psychotic experience. While it is important to acknowledge that every participant experienced some distress associated with the psychosis, we see also that some expressed both positive and negative aspects of the experience. Generally, it was easy to divide these into those which expressed a more positive attitude and those which were more negative in nature. It is somewhat surprising, given the range of negative effects of psychosis on the individual, that there were many more positive comments then negative ones. Eight participants expressed comments that conveyed their attitude to psychosis. Seven of this group expressed comments of a positive nature, and four expressed negative attitudes. One person expressed only a negative attitude to the experience, four expressed only positive, and three expressed both positive and negative attitudes.

9.4.4.1 Attitude to experience - positive (P7; C23)

Sometimes a positive attitude to the experience was expressed in a quite unambiguous fashion, where the experience of psychosis was clearly highly valued. Raj had had an intense, but relatively brief, episode of psychosis, characterised by ideas of reference and delusions which had a strong spiritual theme. While Raj believed that these did develop into psychotic experiences he remained convinced that the initial phases of the experience were spiritual in nature and were a positive experience for him:

> *'It felt so comforting. Like I had done the greatest thing in the world, or I'd been blessed by the greatest thing in the world.'*

Margaret also viewed much of her experience in spiritual terms:

> *'I was the happiest I've ever been in my life. It was the best thing in my life that had ever happened to me, that I had experienced.'*

Others expressed a positive attitude to the experience, albeit a more partial view, which implicitly recognises that there were aspects to the experience which were not viewed so positively. Moana often spoke about how interesting she found her psychotic experiences:

> *'Sometimes I find that there is a part of me that does like it and that's purely because my imagination is quite stimulated. It's like that whole creative side of me is stimulated.'*

Some spoke about finding their psychotic experiences inherently entertaining, both concurrently and in retrospect. Leon had developed ideas of reference in relation to television programmes, which he took to be referring to people around him. He notes that he enjoyed this experience, though adds an important caveat:

> *'Watching the TV and reading into it and just cracking up about all this stuff was quite funny. But, you wouldn't want to be thinking like that all the time.'*

Tony also initially welcomed his experience of hallucinations as he had long been curious about such experiences:

> *'I always wanted to experience hallucinations.'*

9.4.4.2 Attitude to experience – negative (P4; C5)

Tony’s curiosity about hallucinations, which meant he initially welcomed these experiences, did not last long:

> *‘The visual hallucinations I just have no concern over, like they can’t hurt me, but the audio ones are really distressing to me.’*

Moana also found aspects to her ‘imaginings’ difficult:

> *‘It's really annoying, because em, because nobody wants to sit around imagining cutting people up.’*

Janet was perfectly clear that she disliked her experience:

> *‘It's quite..it's bad. It's like really..I just want it to stop.’*

9.5 Responses to and Coping with the Experience (P12; C136)

Another area of great practical concern to participants was how to respond to and/or cope with the experience of psychosis. This is, of course, to be expected, given that all participants were clients of a mental health service and that these comments come from psychotherapy sessions, where the focus would often be on coping with difficult aspects of the experience. Under this broad heading, I have included the individual’s own strategies for dealing with the experience, as well as their comments on interventions (such as medication and psychotherapy) provided by the clinical team. Figure 16 shows the range of subcategories under this heading.

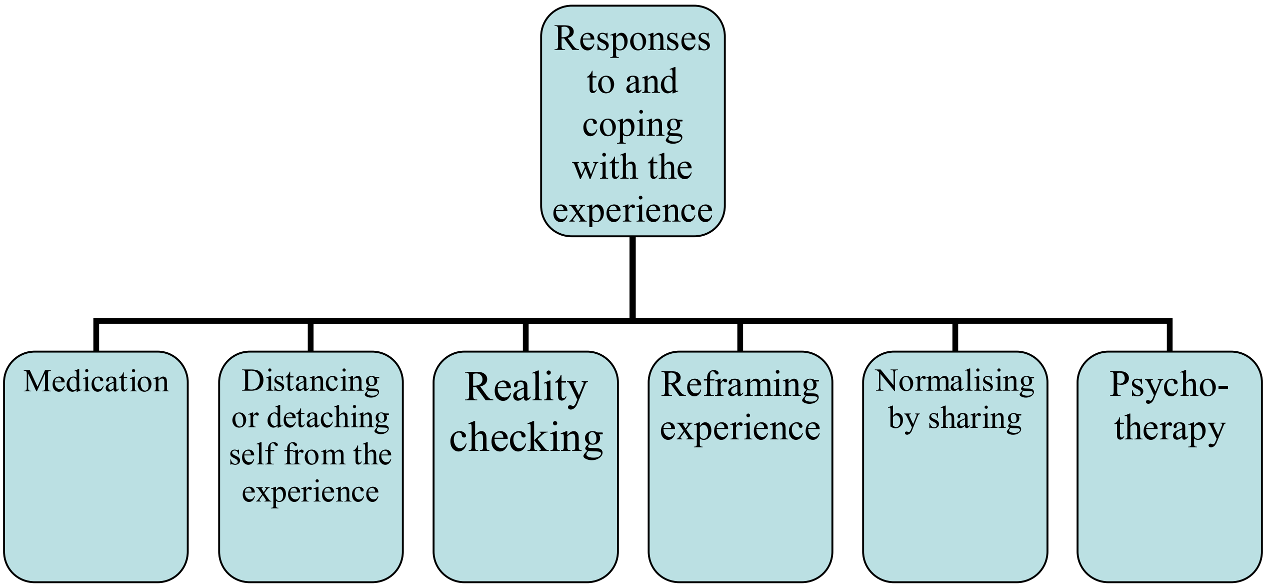


Figure 16: Responses to and Coping with the Experience

9.5.1 Medication (P8; C36)

The majority (approximately 80%) of participants of the first episode psychosis team will be on psychiatric medication at any one point, with an even higher percentage having been on medication at some point in their involvement with mental health services. It is not surprising therefore to find that participants often spoke about medication matters in the interviews (even although every participant was well aware it was the team psychiatrist who had responsibility for prescribing medications and recommending any changes in medication). One of the ways in which participants spoke about how they respond to and cope with psychosis involved them expressing their thoughts and attitudes about the role and impact of medication in this. Participants expressed a range of opinions about the role of medication, with sometimes the same individual expressing quite different positions at different times.

- Uncertainty

One aspect of how participants spoke about medication was to express some uncertainty about how it actually works. This was not necessarily considered a distressing matter, rather more a mysterious one. Leon, who generally felt the medication helped him and took it as prescribed almost all the time, said:

> *'I'm not sure what my medication is doing though.'*

He later expanded on this uncertainly:

> *'I am a lot more relaxed now than I used to be, and I don't know if it's the medication making me like normal, or just like sedating me.'*

- Ambivalence

It was more common for participants to express some ambivalence about the use of medication to help cope with their psychosis. This often involved weighing up the perceived benefits and disadvantages of medication, and using this balance in deciding whether or not they would continue using the medicine. Here, Michael explains his decision-making process:

> *'I've weighed them [pros and cons] up and I think it may as well be better than what it was before I was on drugs [medication].'*

Leon also used a kind of cost-benefit analysis to govern his decision regarding using medication:

> *'It's not good, the bad things that happen. It's not good being on medication or anything. But it's quite good em..like I feel like I'm better off now that I was before.'*

- Negative

Some were clear that the medication had a significant negative impact on them. This did not always translate into the individual stopping medication, but was certainly an important influence on how they felt about the medicine. Spencer expressed his concern that the medication is a way of avoiding difficulties, something which he saw as inherently problematic:

> *'I thought that medication is more of an automatic run away from the situation.'*

Others, such as Michael, were more negative about how taking the medication made them feel. Though Michael continued to use medication consistently, he complained:

> *'It's like it's taken my whole self and just dampened everything so nothing can happen. I'm not able to work things out, it's like my brain isn't doing anything.'*

- Positive

At other times, a more positive attitude to the medication was expressed. Tony expresses this in a straight-forward manner:

> *'All I really know is the pills work.'*

Michael, despite feeling that the medication turned him into a 'bit of a zombie', nonetheless noted:

> *'I'm feeling better. It's because of the medication, I'm pretty sure.'*

Isa was also clear that the medication helped:

> *'I think that medication is one of the things to help, at least take away some of the symptoms. But, I haven't been taking it as well as I should.'*

- Not taking

Isa was not alone in saying that the medication did help, but that he still did not take it consistently. Somewhat like Spencer, he felt that the medication did not truly help him tackle his problems. Isa clearly felt proud about managing his difficulties without the use of medication:

> *'I've been feeling quite good about myself, yeah and about not taking medication.'*

This helps convey a position that many participants expressed regarding medication: namely that they saw it as one of the ways in which they could cope with the psychosis, though generally a strategy that had some disadvantages.

I will now present some of the other ways in which participants responded to, or coped with their experience of psychosis. It is interesting to note that the strategies do not involve trying to directly alter the phenomenological aspects of the psychotic experience, but rather the focus tends to be on how the individual views and relates to this experience.

9.5.2 Distancing or detaching self from experience (P6; C36)

One commonly adopted strategy for dealing with psychotic experience was to try to detach or distance oneself from the experience psychologically (this could also be referred to as 'distracting'). Sometimes this was achieved purely by switching one's attention. At other times participants would deliberately engage in an activity that prevented them having the kinds of thoughts they found distressing. Michael was, at times, quite clear that he found talking about his psychotic experiences distressing:

> *'I sort of sometimes feel that if I stop talking about it, and stop thinking about it, it'll just go away.'*

Moana was equally clear that being engrossed in her 'imaginary world' was not good for her, and she endeavoured to distance herself from this:

> *'It's like when I'm in the moment of imagining things, that's when I think things are real. But when I get some distance from them, then I know they're not.'*

Moana was able to achieve this distance using purely psychological strategies (such as deliberately viewing her experience from another perspective). Others, such as Margaret, used more behavioural strategies to achieve this distancing:

> *'I've got to get my attention away from my mind. If I'm sitting at home, what I've got to do is make sure that I'm not in any position at home or anything where I can be sitting there and go back into the mind. Because that's when it starts.'*

Spencer used distancing strategies at times, but clearly felt some ambivalence about this as he saw this as a denial of his feelings:

> *'I suppose it's like turning my back on things. I feel like I'm lying to myself about feelings that I just blocked.'*

9.5.3 Reality checking (P7; C30)

Other ways of dealing with the experience involved some kind of investigation of the experience, or what we might call 'reality checking'. This consisted of using another frame or reference (either within the self, or from another person) to evaluate the experience.

- Sensory correspondence

Janet found that she could check out whether her visual experiences were real or hallucinatory by using 'sensory correspondence': that is, by seeing if she also perceived the experience through the more reliable (to her) modality of touch:

> *'Em, I know that touching things helps.'*

Margaret used the same approach – relying on her visual experiences to help her judge if a voice was internal or external, real or imaginary:

> *'I'm not ever listening to this [points to head] again. I'll never ever in my life listen to another voice. For it to be God or somebody, I have to see it. It's gotta be in front of me. I'll have to see them like I'm seeing you.'*

- Evidence

Moana sometimes adopted a somewhat broader perspective when she applied what she called a 'scientific perspective' to her experience. This involved her weighing up various pieces of evidence, or deliberately seeking contrary evidence, which helped her decide whether or not the notions she had about the harm she felt she had done to others actually corresponded to real events. It did not, and she generally found a lack of evidence to suggest that she had caused any harm:

> *'I had to sit down and I had actually to tell myself, you know, it's not true. I had to find evidence, I had to find, you know, flaws in, you know, the whole story and just focus on those.'*

While Moana reported that this approach often helped her, she noted it was not foolproof, as sometimes she found that even when confronted with contrary evidence, this did not persuade her that she could, or should, dismiss her original thoughts about having harmed others:

> *'Even though things haven't corresponded out here, I find a way of looking at it so that there's an explanation of why that hasn't happened. I can make an excuse to myself. I can alter things to protect my theory.'*

- Check with others

Another way of checking one's experience was to ask another person to see if they had, or hadn't, perceived what the participant had perceived. Leon did not hesitate using this approach the very first time he heard a voice:

> *'Oh, I asked a friend the first time.'*

Mark also found this approach helpful, explaining that when he had ideas that he felt were unusual, he did not find it helpful to work these out on his own, but this didn't trouble him as he found asking another trusted person worked well for him:

> *'Because I was starting to think you can't always change the way you feel but you don't have to, do you? You just get a more reliable opinion.'*

9.5.4 Reframing experience (P3; C11)

Some participants found that an effective way of dealing with psychosis was by looking at the experience differently, or by reframing the experience. This may have involved, as for Moana, trying to develop a whole new way of looking at the world and processing information:

> *'I feel like I'm reprogramming my brain. I feel like I'm having to reprogramme the way that I used to…to get back to the way I used to think.'*

Participants also spoke about feeling they benefited from construing their psychotic experienced differently, explaining that this often alleviated some of the associated distress. Paul found it helpful to simply label his psychotic experiences as 'not reality':

> *'Everything I perceive as reality is not reality, it's just my thinking.'*

Margaret was even more specific. She came to see her troublesome voices being an expression of her own guilt about having been sexually abused as a child. While this didn’t have an impact on the voices themselves, it meant she was far less troubled by them:

> *‘I found myself sitting on the bed saying to myself this morning, “don't worry Margaret, it's just the guilt coming up, let it go, focus on something positive”. I'm talking like that to myself “it's just your past coming up, guilt, just let it go, let it go”.’*

9.5.5 Normalising by sharing (P4; C12)

Some found sharing the experience of psychosis with others very helpful to them. This sharing sometimes involved simply speaking with a sympathetic friend or hearing about the stories of other service users. The common thread was coming to see psychosis as being a shared human experience, which seemed to help normalise the experience and so make the individual feel less troubled by it. Janet found that telling her friend about her experience had been helpful to her:

> *‘I said to my friend “Oh, they've classed me as psychotic”. And she went, she asked like what I mean. And I said “Like, I hear voices and I see things and I feel like I could quite easily go out and harm someone”. And she goes “Oh, I think everyone can do that”. And it was like, oh well, maybe I just don't have anything wrong with me.’*

Some participants attended FEP team groups involving discussions about psychotic experiences. Leon was clear that he found hearing about others’ experiences was particularly helpful:

> *‘Going to the groups and stuff, and you hear about people having the same sort of thing and you think oh, they've all had the same experience. I suppose it just lets you know that it's psychosis, that it's not just you. You know, it's like, other people have had it.’*

One of the things Moana found most helpful about being in hospital was hearing other people talking informally about their own experience:

> *‘And I heard stories about other people; that just brought me back down to earth.’*

Moana felt quite inspired by others' stories, so much so that she sought out first-person accounts of psychosis available in the literature and used these to help her conceptualise her own experience:

> *'The only reason I wanted to read about other people, was to see some examples that would blend in with mine.'*

9.5.6 Psychotherapy (P3; C9)

All the participants in this study were engaged in psychotherapy. Participants sometimes spoke about how they saw the process of psychotherapy and how they felt this related to their ways of coping with psychosis. Moana saw one of the functions of psychotherapy being to allow her to tell her story in-depth, in a way she felt her friends would not tolerate, given its length:

> *'You know I'm actively sitting down and discussing some of the things. You know just someone to voice these things with, because it's all really, really difficult to talk to someone about, because I don't have a problem with it, but it's so long.'*

Others thought of psychotherapy as way of dealing with issues from the past, which had contributed to the psychosis, but which had not been properly processed. Leon:

> *'You know you come across past worries and stuff, and you have to sort them out, but it's like you can't really sort them out properly, that's why we have counsellors and stuff. That's what I think.'*

Another notion was that psychotherapy helped focus on the personal meaning of the experience of psychosis. This was how Tony thought of psychotherapy:

> *'Talking about it [the psychosis]. Yeah, you talk about it and you seem to think about what it is to you.'*

Moana explained that sometimes she thought of the psychotherapy sessions as allowing her to make amends for 'sins' she felt she had committed in the past:

> *'I feel that by coming to these counselling sessions I'm kind of like making amends to show that I am sick. It's kind of like a confessional for me to tell you the truth.'*

9.6 Spirituality (P9; C113)

The final major categorisation relates to the role of spirituality in the experience of psychosis. This was an issue for most participants, though in quite different ways and to differing extents. Relationships between psychotic experiences and spiritual matters were often of central importance to participants. I have already discussed participants' views on spiritual contributions to causality (section 9.2.4). However, there were other important connections between psychosis and spirituality in the participants' stories, as shown in figure 17.

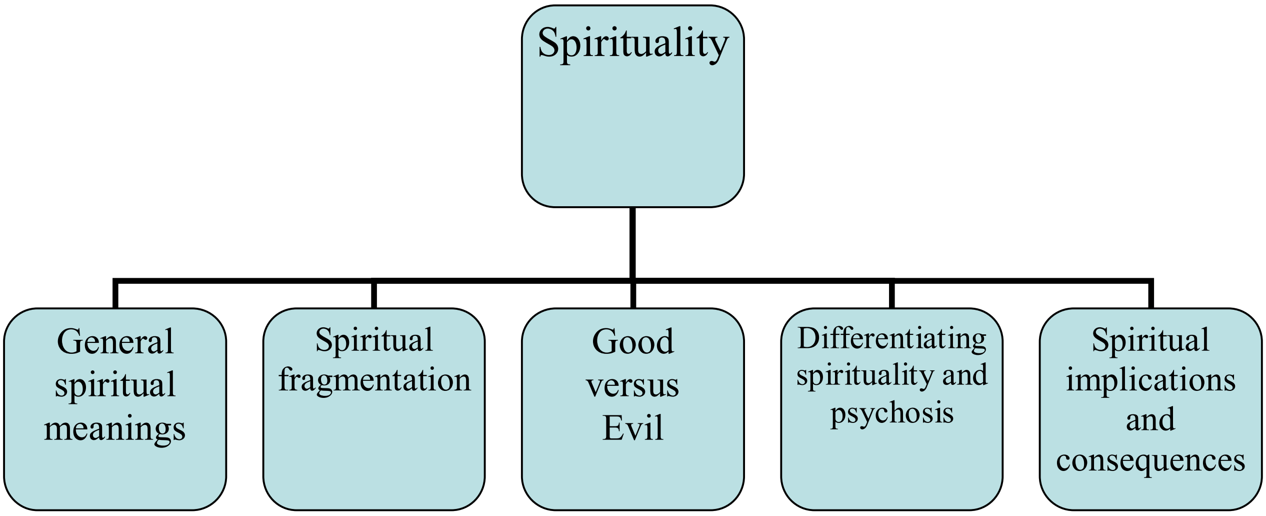


Figure 17: Spiritual Aspects of Experience

9.6.1 General spiritual meanings (P7; C36)

The broadest aspect of the spirituality-psychosis connection in participants' accounts was the tendency to view the experience of psychosis in a spiritual framework without necessarily specifying details of the nature of this relationship. Here, psychosis was seen as somehow bound up with the spiritual world which provided a framework which helped render the psychosis meaningful and sometime manageable. Moana was particularly interested in spiritual matters, despite her lack of clear-cut religious beliefs. When discussing her psychotic experiences she often mentioned spiritual themes. Her perspective on this matter is summarised in her brief comment on her psychosis:

> *'There's a whole spiritual story surrounding all of this.'*

In many ways this comment provides a useful summary for the position of many participants, who viewed their experience in broad spiritual terms. Isa:

> *'Now I see my voice as being like a spiritual journey.'*

Some participants expressed their positions with less certainty. Leon:

> *'I don't know why people get it [psychosis] eh? It seems like, you think it'd be something, eh, I've always thought, you know, I think it's something religious or something, or like you know.'*

Spencer mentioned that in the midst of his psychotic experience, God played a prominent role, which was quite different to his usual way of thinking:

> *'I had a real different way of looking at life, like eh, as if I was the only person on the planet, and everybody else was kinda extensions of God. And whatever they said, I had to tell them it was an illusion.'*

There were aspects of viewing the experience in spiritual terms that caused some dilemmas for participants. This was particularly the case for Moana. Though she generally found her psychotic experiences troublesome and wished she could prevent these happening, she found herself asking of her experience:

> *'But, I keep thinking, what is that? What if that's my soul?'*

This caused her considerable ambivalence about having the experience 'treated'. Another aspect to this for Moana was feeling somewhat 'stuck' in that it was only within a spiritual context that she could see her experience as being genuinely meaningful, yet she herself had never been spiritual:

> *'But when I keep looking at it from a spiritual perspective and when I look at it from a spiritual perspective, that's when I get stuck. I get really stuck. I keep thinking how can something like that happen and not have some meaning? But then, that contradicts itself, because my whole life, I mean my whole life, I haven't led a life of spirituality.'*

9.6.2 Spiritual fragmentation (P4 C21)

Some participants reported that since having their psychotic experience they felt less 'together' or less integrated spiritually, somewhat out of sorts with themselves on a spiritual level. This was something that seemed not easy to convey, but was clearly a troublesome matter. Michael:

> *'That's why I sort of say that I am in a zombie state. It's like I'm not conscious to everything, that I don't feel in sync with my spirit, I guess.'*

Margaret, who had long-standing and deeply held religious beliefs, experienced a similar sense of being out of sorts with herself spiritually, a matter compounded by her receiving what she perceived as conflicting explanations from others regarding her experience of hearing voices:

> *'I was convinced 150% it was them [spiritual voices from her group]. Then I get told by my teacher and the channel it was not. Then I get told one minute it's a psychotic breakdown. Then I get told you're not hearing them. Then I get told it's your own mind talking to itself. Then I get told it's your higher self. I don't know quite frankly what to believe.'*

9.6.3 Good versus Evil (P4; C19)

Moral matters overlapped with spiritual matters in some aspects for participants. The perennial issue of 'Good versus Evil' was one which permeated some participants' stories. Sometimes this issue was expressed as a deeply personally matter, where participants found themselves confronted with questions regarding viewing themselves as either 'good' or 'bad'. At other times, these notions were expressed in a more universal fashion, relating to the abstract concepts of 'Good and Evil' often conveyed in terms of 'God' and 'the Devil'.

Some participants struggled with how they viewed themselves in a moral sense as a result of having been psychotic. This was particularly the case for participants who felt that their experience, or the content of it, had traversed moral boundaries. Moana:

> *'Because from a spiritual perspective, then I have to say that the universe has told me that I'm bad or something.'*

Michael also struggled with how he should view himself morally, an issue which was more pronounced when he was psychotic, at which times he identified himself with religious figures, and their moral qualities:

> *'One time I was purely convinced that I was Satan, another time I was convinced that I was Jesus, another time I was convinced that I was Adam and these were all in like short periods, like one after another.'*

God and the Devil often played prominent roles in participants' experience, both during the psychotic episode and sometimes when reflecting on this experience. For Moana this was sometimes so intense that she saw it as constituting her 'sickness':

> *'I'm not like religious or anything like that, but my whole sickness it is. It revolves around God and the Devil, and eh, it's really hard.'*

9.6.4 Differentiating spirituality and psychosis (P3; C19)

Participants who held strong spiritual beliefs and who felt that spiritual matters played a major role in their psychotic experience often struggled to clearly differentiate these domains of experience. Some flip-flopped in terms of how they construed the experience, at times seeing their experience in terms of spirituality, at other times in terms of psychosis. Commonly participants found it very difficult to make a clear demarcation between psychosis and spirituality and put forward arguments that it was, in fact, impossible to differentiate these experiences in terms of phenomenology. Margaret was particularly vociferous about this matter. After much thought and discussion, she concluded:

> *'What is the difference? How do you differentiate between a true schizophrenic and a true spiritual experience? You can't.'*

Moana reiterated this position, though unlike Margaret, who saw this as a universal difficulty, Moana attributed this difficulty differentiating the spiritual from the psychotic to herself:

> *'The line between imagining things and things that are really happening in the spiritual world, which is what I keep thinking I'm playing around with. It's getting really hazy.'*

This was not a theoretical question for participants, but rather one with practical implications. After all, quite different responses would be indicated depending on whether one viewed the experience as psychosis or spirituality. Again, Margaret was able to convey the essence of this dilemma, when she posed what was a rhetorical question (as the context made clear: she had already concluded there was no answer to the question):

> *'You know, do I have to keep coming here forever every time I hear what I think is a spiritual voice? Does that mean every time I have a spiritual experience I'm gonna have to go on more medication?'*

9.6.5 Spiritual implications and consequences (P2; C18)

Finally in this section, we come to the participants' reflections on spiritual implications of having been psychotic. This was not a matter of concern for all participants Most did not appear to consider that there were any personal spiritual implications that derived from the psychosis. However, for the two participants for whom this was an issue, it was a particularly troublesome one. No-one expressed this more clearly nor more frequently than Moana. She felt convinced that as a consequence of having had (in her mind) immoral, unethical thoughts whilst psychotic, there would be a price to pay. The magnitude of her concerns is conveyed in her comment, which at the time she meant quite literally:

> *'I feel really condemned.'*

She elaborated on this later:

> *'But I know that if there is an after life, I know for a fact there are going to be really big repercussions when I come out. I can't believe that I would have gone through what I've gone through without it affecting my relationship with God.'*

Moana, was convinced that spiritual matters were often a major concern for people who had had psychotic experiences and that this was an area that was often overlooked by mental health services, a matter which she felt needed to be remedied. She suggested:

> *'But you guys [clinicians] have to educate yourselves [about spiritual matters] to some degree, because when I was in hospital there were a lot of people who were spiritual, who had become spiritual and who believed that their experience had some kind of spiritual element to it.'*

9.7 Maori issues (P2; C4)

As has already been explained (chapter 8), while Māori participants were not excluded from the study (and two participants identified themselves as Māori), on advice from Māori mental health services, issues specific to Māori culture were not the focus of the present study. Both Māori participants in the study did have contact with Māori clinicians for specific cultural support. However, despite this, and perhaps not surprisingly, there were times when issues which seemed to allude to aspects of Māori culture in relation to the experience of psychosis were mentioned by participants. Here, I want only to acknowledge the importance of these cultural issues, and to recognise that they did emerge in the clinical interviews with participants. I accept and agree with the advice given to me through the process of cultural consultation that a proper investigation of Māori cultural matters in relation to psychosis needs to be undertaken by someone who has a far greater understanding of Māori culture than I do. For the purposes of the present report, I wish only to respectfully mention these issues. Examples of the kinds of issues I am alluding to include references to Māori spirituality, such as this by Moana:

> *'There was this guy who em, he slept in a marae, and he ended up getting possessed. And when he was possessed, he started blurting out all these words of Māori, and he couldn't speak Māori. And, anyway, they basically got rid of the demon or whatever that had possessed him. Apparently, he'd slept under, you know how they have the Māori carvings, they're actually individual tribal leaders. And apparently, one of them was dark, and so he'd been possessed by, you know.'*

Michael also referred to a belief he had held previously that his head was being controlled:

> *'I thought there were all those Māori and Samoan people were controlling my head, and I got into a really weird state that I used to get into all the time.'*

Finally, Moana also spoke on a few occasions about her thoughts about the role that her ancestors (and sometimes also my Scottish ancestors) may have played in influencing things in the here and now, including matters relating to mental health:

> *'If there is a God he could be really brutal. He could've been throwing people into Hell for centuries, you know, and like, I mean many of our ancestors, yours in particular, I mean, they were really wary of...you know. You hear stories of people who thought they'd lost their soul to the Devil and you know.'*

This brings us to an end to this section of data analysis, where I have presented the descriptive and axial categories yielded by this analysis. These results indicate that participants held wide and varied thoughts on various aspects of the experience of psychosis. The analysis above is an attempt to impose some kind of helpful order on this vast array of opinions and comments on the experience of psychosis, while remaining true to the data itself. This analysis is more descriptive than explanatory, and as the comments from participants hopefully demonstrate, it is a 'data-near' level of analysis.

10 Results, part II

The previous chapter presented the descriptive and 'axial' level of data analysis, where the data was categorised into 'data-near' groupings organised according to thematic similarity, and relationships between these various categories were outlined. In the present chapter, I will present the 'analytic coding' of data. This relates to a more abstract, theoretical level of analysis, where constructs which aim to capture the essence of the data are discussed. These constructs are those of greatest theoretical significance, given that they move beyond being descriptive of the data to a more explanatory level of analysis, where the objective is to articulate important aspects of the essence of the experience of being psychotic as described by research participants. The analytic process whereby these constructs emerged was outlined in chapter 8. I will begin this chapter by discussing general features of the theoretical constructs, then move on to define and delineate each of the three theoretical constructs: fragmentation-integration; invalidation-validation; and spirituality.

10.1 Theoretical constructs

To begin with it is important to clarify the terminology used in this chapter. I will refer to the three analytic categories as 'theoretical constructs'. The 'theoretical' component of this term is used to emphasise their theoretical nature; both in terms of being not immediately contained within the data, but being abstracted from it, and also in terms of being explanatory terms which hopefully contribute to our theoretical understandings of the experience of psychosis.

I use the term 'construct' rather than 'category' to help distinguish these notions from the descriptive and axial categories in the previous chapter. More importantly though, I use 'construct' because of the overlap between the three theoretical concepts outlined in this chapter and Kelly's notion of a 'construct' (Kelly, 1955). Kelly's constructs form the basis of his theory of personal constructs, being the essential unit that he invokes to describe how we make sense of and relate to the world. For Kelly a 'construct' is a psychological process used to discriminate between, make sense of and relate to various aspects of the universe. In Kelly's theory, constructs are bipolar in nature and can often, but not always, be given verbal labels. Examples of common constructs might include 'good – bad', or 'edible – inedible'. While Kelly's (1955) theory goes into great detail about relationships between constructs and how these operate for the person, for the present purposes it is necessary only to note that constructs are ways of making sense of a given aspect of experience, that they are bipolar in nature and that they can be used to place the objects construed on a continuum between the two ends of the construct. Another aspect of Kelly's theory which is of relevance here is his notion of 'range of convenience'. By this, Kelly means simply that each construct has utility in a limited range of situations. For example, the construct 'edible – inedible' has clear utility in construing food-like items, but would be unlikely to have any utility in construing, say, movies or sporting events, which lie outside its 'range of convenience'.

The order in which I present the three theoretical constructs is not intended to indicate any particular relationship or hierarchy between the constructs. As we shall see, the first two theoretical constructs ('fragmentation – integration' and 'invalidation – validation') fit the bipolar format of a Kellyian construct, whereas the third, 'spirituality', does not fit this format. For each construct, I will give a brief definition of the construct followed by a consideration of its range of convenience. To illustrate and substantiate each of the theoretical constructs I will refer to the analysis in the previous chapter to show how the theoretical constructs capture central aspects of the experience of psychosis as presented there. I will also provide some examples of comments by participants to support and further explain the construct. Unlike in the previous chapter, numbers of participants and comments are not given here. This is because the constructs in the present chapter are abstractions from both the 'raw data' (the interviews) and from the analysis presented in the previous chapter. As such, they are not tied to specific comments or categories. Rather, these constructs reflect my attempt to capture and express the essential elements of the experience of psychosis as conveyed by participants. These are 'data-far' theoretical constructs, which aim to both traverse and subsume the analysis in the previous chapter. The value of these theoretical constructs lies in their explanatory power. Thus, it is neither possible nor appropriate to quantify these constructs in terms of numbers of comments or number of participants.

Each of the constructs covers aspects of experience which are experienced by participants as 'negative' and 'positive'. For the bipolar constructs, the more ‘negative’ end of the construct is indicated by the first of the two terms (that is, ‘fragmentation’ and ‘invalidation’). I have identified these ends of the constructs as the ‘negative’ ends based on the clear indication that they subsumed aspects of experience which were associated with increased levels of distress and increased symptomatology for participants. The opposite was true of the other ends of these constructs: ‘integration’ and ‘validation’ were associated with lower levels of distress and with fewer psychotic symptoms.

One question which can reasonably be asked of this analysis is ‘why these particular constructs?’ In terms of grounded theory, the response to this in found in the concept of ‘emergence’ (Glaser & Strauss, 1967). These constructs ‘emerged’ from my in-depth relationship with the data. This acknowledges a contribution from the data, but that the constructs are not totally independent of the researcher and that another researcher may have come up with quite different constructs. No claims that these are the only possible constructs that could emerge from an in-depth analysis of the data can be made. The issue ‘trustworthiness’ of this analysis will be discussed in following chapter.

10.2 Fragmentation – integration

10.2.1 Definition

This construct refers to a sense of a loosening (or, less often, tightening) of connections and associations between aspects of experience. This relates to a sense of ‘wholeness’, and the notion that a central aspect of psychotic experience is that this sense of wholeness can become ‘fragmented’, or, at the other end of the construct, that there can be a sense of ‘integration’, though it seems that this is less pronounced in psychosis. Largely, the experience of fragmentation is associated with a loss of harmony, whereas integration may be associated with a sense of well-being.

10.2.2 Range of convenience

This construct’s range of convenience includes the experience of self, of other people (the interpersonal world), and of the material world. Each of these reflects aspects of participants’ worlds which were implicated in the experience of psychosis in ways that can be subsumed by the ‘fragmentation-integration’ construct.

10.2.2.1 Self

Fragmentation of self is evident in a range of participants' notions of causes of psychosis. In particular, within the section 'Causes of Psychosis Psychological Factors' (section 9.2.1) we see numerous examples of experiences which seem to express some form of fragmentation of aspects of the self. Within those causes of psychosis under 'self' (section 9.2.1.2), we find many examples which seem to convey a sense of a self not at one with itself (such as 'disintegration of self' and 'leaky mind') and also the self attacking itself ('self-sabotage'). Similarly, much of the content within emotional causes of psychosis (section 9.2.1.1) can be viewed as reflecting some sort of discord or loss of harmony within the self. For example, 'guilt' suggests a person ill at ease with aspects of the self.

Also, in section 9.2.1.3, where information processing variables are seen as causing psychosis, there is a common thread running through this category of a mind (or 'self') at odds with itself. Many of the metaphors in 'Descriptions of Psychotic Experience' (section 9.3) also convey discord within the self (in fact, one such metaphor, from Leon, was of 'defragmenting' a computer). Fears about loss of control as conveyed in 'control and power' (9.3.6) also suggest a struggle within the self. Within 'Impact of Experience' we find further evidence of fragmentation as illustrated in the experience of 'discontinuity of self' (9.4.1.2). A sense of fragmentation is also conveyed by some of the ways of coping with psychosis (particularly those involving distancing and detaching self from the experience: 9.5.2). Within 'Spirituality' the notion of 'spiritual fragmentation' (9.6.2) clearly conveys a sense of personal fragmentation.

Fragmentation related to the experience of self in the here and now, where the self was felt not to cohere, not to fit together as it once had, as well as to the experience of self over time, where the sense conveyed was of there being discontinuity between the self felt now and the self in the past, with a sense that the notion of continuity which holds the self together had somehow been fractured. The extent of this sense of fragmentation, both in the here and now, and over time, varied from seemingly pervading the experience of self to being more limited to particular aspects of self. Both of these were distressing, troubling experiences for participants who expressed a sense of grappling with the very essence of the self, which was conveyed as ethereal, changing, and failing to provide firm ground upon which to stand. To illustrate this, I will now provide examples of how fragmentation manifested itself in participants' accounts of their experience of self both in the here and now and over time.

- Fragmentation of self in the here and now

A sense of the self in the here and now being quite out of synchrony with itself in a fairly pervasive way permeated participants' stories. The essence of this experience is captured in Michael's comment that conveys the intense existential discomfort associated with the experience

> *'I haven't got a personality or anything. I'm not in sync with my personality and my self or anything.'*

John expressed this sense of feeling internally disconnected, when he reflected on what had been going on for him when psychotic:

> *'I felt disconnected, more disconnected, when I couldn't work out what I was doing in the past.'*

Margaret acknowledged a similar lack of internal cohesion when explaining her auditory hallucinations:

> *'Those comments came up because I was unstable, out of balance.'*

Moana also saw a kind of internal fragmentation as being at the core of psychosis:

> *'It means that we're actually struggling with ourselves.'*

This sense of a fractured self, with different aspects of the self in some form of struggle is evident also in Michael's comment:

> *'I get tangled up in my thoughts, because I analyse everything too much, especially the voices in my head. Almost like I'm battling with them.'*

Another aspect to the fragmentation of self was the sense of being out of 'balance' with oneself, creating a sense of both unfamiliarity and unpredictability. Mark:

> *'I felt my balance has been out for a while and my balance as far as being sound in mind'*

- Lack of continuity over time

Another way in which the self seemed fragmented was over the course of time, where the continuity of the self was broken or interrupted as a result of the psychotic experience. This was not delusional in nature (for example, believing that the self had been replaced or altered by an external force), but rather related to the experience of the phenomenology of self and the sense that the individual struggled with the felt experience of continuity, such that the current self felt quite different from the self before psychosis. This sense of loss of continuity of self is expressed by Michael who laments that he finds it hard to recall how things were before he had his psychotic episode (the context here made clear that he was not literally talking about remembering events, but rather remembering how he used to feel):

> *'I can't remember anything about what life was like before.'*

The sense of confusion and loss associated with this disruption to the self is evident in Paul's comment:

> *'I can see the world and everything, but I don't seem to, you know, see it with the same eyes as I used to before, you know. So, I think that maybe, you know, as a result of what I went through, maybe I have changed, but I don't know what has changed about me.'*

- Integration

At the other end of the 'fragmentation-isolation' construct as applied to the self, there was the occasional sense that, through psychosis, the person came to feel more integrated, more at one with the self. This was much less pronounced in participants' accounts than was the sense of 'fragmentation'. Nonetheless, there were elements of participants' stories which did suggest that psychosis was, at times, associated with a sense of integration of the self. As is apparent in the quotes which follow, integration was much less distressing (and often not distressing at all) than the experience of fragmenting. For example, in Causes of Psychosis, both 'making sense of things' (9.2.5.3) and 'giving voice to suppressed thoughts' (9.2.5.2) suggest that, in some ways at least, there was a sense of a coming together, or integration, of aspects of the self. Moana noted:

> *'The way this sickness developed, it was so logical. It just came together and explained everything.'*

In this context, the 'everything' she referred to included a range of disparate thoughts and feelings she had been experiencing. Tony's comments also suggest that the experience of psychosis was associated with increased awareness of, and unity of the self:

> *'It [psychosis] made me just more aware of the mind I have.'*

> *'I never really studied myself that hard until I had the psychosis. I never really, em, never listened to myself talking.'*

Here, he is speaking of his own voice being a part of himself which he had hitherto ignored, but now, through his auditory hallucination, had come to attend more to this aspect of himself. A sense of integration (in terms of greater understanding of the self) is also conveyed by Isa:

> *'I have come to understand something about myself that I never could have understood if I hadn't gone through it. I now feel like a new person, almost like I had to go through it.'*

Finally, Michael here seems to also suggest a sense of greater integration through being more sensitive to aspects of himself:

> *'My senses have been heightened since I became psychotic. I am more sensitive now to [my] moods and stuff.'*

10.2.2.2 Interpersonal world

The 'fragmentation - integration' construct can also be applied to participants' experience of the interpersonal world. Again, we find that, as a result of the experience of psychosis, there is sense of social relationships being fractured or breaking up. In terms of the previous chapter, interpersonal fragmentation is evident under Causes of Psychosis, such as 'isolation' (9.2.2.2), 'abuse' (9.2.2.3) and 'interpersonal relationships' (9.2.2.4) all of which seem to indicate some difficulties or fragmentation of the interpersonal world. Similarly, when describing the experience of psychosis, the notion of this constituting a 'personal or different reality' (9.3.9) suggests a person cut off somewhat from other people. This fragmentation of interpersonal relationships seemed to vary depending on the particular phase of the psychotic experience. Margaret identified increased distance in relationships and associated isolation as having helped create the conditions within which psychosis could emerge:

> *'I was going home at night, spending a lot of time on my own, watching TV, shutting myself in the house for weeks and weeks. Now, when you do that you can get quite withdrawn and introverted, and you can..that's how I can see that I must have created it.'*

Paul also noted that in the period leading up to the involvement of mental health services, he had become increasingly isolated, which he felt had contributed to him appearing thought disordered when he tried to communicate. He notes that this situation perpetuated itself as his communication difficulties exacerbated the fragmentation of his interpersonal relationships:

> *'I guess maybe, probably, the reason for that is probably that I have been isolated maybe for some time, and I have lost that, you know, that touch for people and stuff. And, like, that has put a distance between me and other people.'*

This sense of finding it difficult to relate to others was reported as an important concurrent aspect of the experience of psychosis. That is, fragmentation of relationships was also part of the psychotic experience itself, not just a precursor to it. Sara expressed this when reflecting on her second psychotic episode and how removed from people around her she felt:

> *'Yeah, the second time I was feeling that I was the only person. I didn't belong to anyone. I was alone.'*

Tony also commented that in the midst of his psychotic episode he felt quite divorced from people round about him, including close friends and family:

> *'It's kind of with the psychosis, I don't feel like I fit in, into like what everybody else is doing, in just relating what they do and that. I feel out of place, and then I feel regression, I think, and so I try to crawl under my shell.'*

Sometimes the feeling of being different from others and therefore struggling to relate to others persisted beyond the psychotic episode itself and seemed to relate in a more enduring way to how the person had come to see him or herself as a result of having been psychotic. Paul:

> *'I guess from that moment on I felt much more different from other people.'*

He went on to explain the impact that this had on his social world:

> *'It's like something has been taken away from me, that's how it feels. Like it's put a wall between me and you know maybe, in a way, other people.'*

At the other end of the construct there is much less evidence of integration in the interpersonal worlds of participants. There may be some limited suggestion of integration in some ways of coping, such as 'reality checking' (9.5.3), which for some involved asking other people about experiences. Also, in 'normalising by sharing' (9.5.5) there is some sense of the importance of the interpersonal world and the need for at least a degree of integration for this to occur. There was the occasional comment that through the psychosis the individual felt more connected, or more integrated with the interpersonal world, although how far this translated into actual relationships was unclear. Michael felt that as a result of having been psychotic, he was now more tuned into aspects of interpersonal relationships that he'd been insensitive to before:

> *'I am more aware now of the unspoken connections between people.'*

10.2.2.3 Material world

Fragmentation also characterised aspects of the experience of the material world. Participants described feelings of being disconnected from a material world which seemed at times to be something they witnessed but felt quite cut off from. We see this in impacts of psychosis including 'changed relationship with world' (9.4.3.1). This sense of fragmentation in relation to the physical world is captured beautifully by Moana:

> *'I feel everything feels kind of surreal and I feel like I'm floating around in some magical bubble.'*

Paul felt similarly disconnected (or fragmented) from the material world around him:

> *'It's almost like I've been cut from the world.'*

He went on to explain this using an analogy:

> *'I would feel like I was put in some box, you know. And like I would just look in through this here, but I'm in a dark box and I'm looking somewhere outside.'*

The seriousness of this sense of being detached from the world is illustrated in the following quote, also from Paul, who explains in a matter-of-fact, detached way that he could easily have killed himself when he felt this way:

> *'Yeah it was really extreme. You just feel detachment. You just feel detachment. You just don't feel a part of anything. Just feel like maybe you'll go to a building and jump off.'*

These feelings of detachment for Paul seemed to characterise how he felt towards the end of, or shortly after, a psychotic episode. At other times, he reported that he had felt a much greater sense of connection to the world, a greater integration with the world. Here, Paul reflects on how he felt just as he was becoming psychotic:

> *'My impression that my involvement, my experience of the world was increased.'*

He went on to explain how intense this felt:

> *'I was so connected to everything, to the air, to like throughout the distance, like clouds and stuff, and to music.'*

Here, Paul's experience of the material world would appear to be located much more towards the integration end of the 'fragmentation-integration' construct. In Paul's case, there seemed to be a temporal effect, where the early phases of psychosis were characterised by a sense of integration with the world, whereas the latter stages where more fragmentary in nature. Of course, it is impossible to be certain about this based on the current research, though it does point to the possibility of a relationship worthy of further investigation.

10.3 Invalidation – Validation

10.3.1 Definition

The second theoretical construct, 'invalidation – validation' refers to the sense of feeling confident in one's ability to accurately perceive or construe experience and to convey this to self and others. The invalidation end of the construct relates to the experience of having one's authority (or 'authorship') over the interpretation of experience called into question, undermined, ignored or rejected, whereas the validation end of the construct refers to having one's understanding of experience supported, confirmed, or 'validated'. This construct relates not only to the actual sense that one makes of experience, but also more broadly to one's capacity to make sense of, or give meaning to, experience.

10.3.2 Range of convenience

This construct relates to both the participant's experience of self and to the interpersonal world.

10.3.2.1 Self

In terms of relationship with self, invalidation refers to the loss of faith in one's own judgements about the interpretation and meaning of experience. This is clearly a fundamental aspect of human existence: feeling that one can rely on the information received from the senses and also can trust what this information means to the individual. Personal invalidation can be seen clearly in Impacts of Experience, 'loss of faith in own judgements' (9.4.1.1) and refers to the personal loss of trust in one's own 'personal epistemology' (personal view of one's own ability to acquire trustworthy knowledge) and 'personal ontology' (personal view about how one can go about being in the world) discussed in section 9.4.1. Personal invalidation relates to doubts expressed about various aspects of one's personal ways of understanding and being in the world, including doubts about cognitive, emotional, and perceptual judgements.

Janet expressed doubts about her own cognitive capacities when reporting what was the worst aspect of psychosis for her:

> *'Doubting myself, my own judgements.'*

Similarly, Paul doubted himself:

> *'I have found myself always questioning my own thought processes.'*

Michael came to doubt the extent to which he could trust his own emotional responses, feeling uncertain about how 'real' these were:

> *'It's like I'm incapable of feelings. I don't know if my feelings are fake or not.'*

Perception was also called into question by those who had had perceptual disturbances (generally hallucinations) as part of the psychotic experience. Paul expresses the loss of grounding that this caused for him:

> *'Psychosis is like having your eyes closed. Nothing you see is making you grounded.'*

Others expressed this sense of invalidation within the self in a more general sense of coming to distrust of the self, without specifying particular faculties. Margaret:

> *'What the hell am I supposed to believe? I can't even trust myself any more.'*

At the other end of this construct, personal validation, we find an expression of need for this in participants' accounts of their experience. This is evident in the process of 'reacquiring trust in one's own perceptions' (in 9.4.1.1) as well as in participants' comments about the importance of putting their story together (9.1.1), not only for sharing with others, but also as a way of 'self-validating'.

John:

> *'I just hope I'll be able to make sense of the whole lot.'*

Raj:

> *'I just need to know what it is.'*

Neither of these, as the contexts make clear, is a request for an explanation to be offered, but rather is an expression of the desire for developing a personal understanding of the experience, a form of self-validation. We see the importance of developing a personal understanding of experience also in Sara's comment:

> *'I want to find out why it has happened and why it has happened to me.'*

10.3.2.2 Interpersonal world

In addition to the experience of doubting one's own judgements (personal invalidation), participants' accounts expressed a feeling of being confronted with invalidation in relationships with other people. This social (or interpersonal) invalidation consisted of feeling that others questioned or undermined one's capacity to adequately understand and communicate one's experience. As such, this has an overlap with elements of 'Storytelling and Authoring' (9.1), and in particular, the sub-section on 'de-authoring and invalidation' (9.1.3). This interpersonal invalidation extended beyond the feeling that one's capacity to explain the psychotic experience was being invalidated, to feeling that, more generally, one's entire self was being 'written off' or invalidated. This was how Margaret expressed this feeling:

> *'Well, I feel like I've been written off as a bloody nutcase, like my mother was written off too. But my mother was having very profound experience.'*

Raj felt that having his experience labelled as 'psychosis' by others was a form of invalidation:

> *'Telling me I've gone through psychosis and all this. And I just..it's made me worse in the last two years. I haven't done anything. It's got me so down and out.'*

Mark felt that he had to be extra careful with others as he believed them to be judging much of what he said and did in terms of his having been psychotic:

> *'I meet people they are sort of looking at me like "he's had a bit of a breakdown; he has had psychosis; he was a bit nutty" [laughs]. So, I have got to put up with the fact that yeah.."is he strange?" And people looking at me and thinking "is that strange or is that normal?"*

At the other end of the 'invalidation-validation' construct, some expressed the importance to them of the sense of being validated by self or by others, the sense of being recognised as a valid author of one's own experience. Here, Isa's comment seems to point to the contrast between the two ends of this construct:

> *'I feel down when I think other people are judging me or categorising me. I feel good when I feel validated.'*

In this context, validation referred to a combination of feeling that one's understanding of a given situation was accurate and reliable, and to having others accept, rather than question, one's understanding (that is, it contained aspects of both personal and social validation). The validation of others was an important consideration, expressed in a variety of ways. We could consider the enthusiasm participants had for telling their stories and the importance they attached to this (9.1.1) reflects a desire for validation. In addition to telling their stories, both Isa and Moana specifically requested that they could write down their story and, importantly, that the author would read them. This seems to be a clear expression of the importance of validation. Isa:

> *'I have never felt so right about anything as I feel about telling my story.'*

Leon commented on the importance of receiving validation from others also, although in his case he noted that he received this from attending one of the FEP team groups:

> *'Going to the groups and stuff [helped me] and you hear people having the same sort of things, like people, em, like people talking about you and stuff.'*

Moana also commented that she enjoyed reading first hand accounts of psychosis because this helped validate her own experience and understanding:

> *'The only reason I wanted to read about other people, was to see some examples that would blend in with mine.'*

10.4 Spirituality

10.4.1 Definition

The final of the three theoretical constructs is 'spirituality'. As already noted, this construct does not fit within the bipolar structure of the first two constructs as, unlike the first two constructs, this does not have an 'opposite' end. The definition of what I mean by 'spirituality' here is an inclination to view the experience of psychosis, or aspects of it, in terms of a broad framework of meaning, pertaining to how the individual views his or her relationship with the universe. That is, a tendency to place the psychotic experience in a metaphysical context where it is considered to reflect something of existential or moral significance for the individual (e.g., relating to the purpose of life or to the nature of 'Good and Evil'). Generally, this involved moving beyond explanations of psychosis which locate it purely within the material world (though this is not to imply that these explanations were rejected by the individual), to seeing psychosis as having, in one way or another, a bearing on the individual's understanding of the meaning of life and relationship with the universe in the broadest sense. Sometimes this involved the participant referring specifically and explicitly to external spiritual beings (such as God, the Devil, or simply 'spirits', as in spiritual causes of psychosis: 9.2.4), or to non-physical aspects of self (such as 'the soul'). At other times no such specific beings were invoked, though it was clear from the context that the participant saw the psychotic experience as being of some relevance to metaphysical matters.

10.4.2 Range of convenience

In the present context, I am using this construct to relate specifically to the meaning and significance that the individual attaches to, or derives from, the experience of psychosis. As such the range of convenience of this construct covers all areas where the meaning and significance of the psychotic experience is relevant. These have already been discussed, with examples of quotes from participants, in the previous chapter, under Causes of Psychosis (9.4.4) and in a whole section dedicated to Spirituality (9.6). These included general spiritual matters (9.6.1), such as the nature of the soul, or one's relationship with the universe; spiritual fragmentation (9.6.2); ethical and moral questions regarding the nature of 'Good' and 'Evil (9.6.3)'; the overlap and relationship between psychosis and spirituality (9.6.4); and spiritual implications of psychosis (9.6.5). As spiritual aspects of the participants' experiences have already been illustrated with comments from participants in the previous chapter, and this notion is not substantially changed here, I will provide only a few such comments here to illustrate the construct. The spiritual framework is conveyed succinctly in Moana's comment:

> *'There's a whole spiritual story surrounding all of this [psychosis].'*

Isa:

> *'Deep down, I think it's spiritual.'*

Raj also explained, regarding his ‘ideas of reference’:

> *‘I was getting a lot of signs everywhere. Everything was for a reason. That there’s something out there. Sort of made me believe in a higher power once again.’*

And finally, Moana’s profound and pragmatic question, reflecting on her psychotic experiences:

> *‘What is that? What if it’s my soul?’*

11 Discussion

> 'When I began work on this presentation, I felt threatened with overwhelming panic at the unorganized vastness and complexity of the subject; I had not too little, but too much – far too much – clinical data, and these data seemed so entirely unorganised. I felt at a loss for any coherent, organizing principles to grasp and communicate the essence of a large number of clinical experiences which have been, to me, fascinating, and, often, deeply moving.'

The quote above, by Howard Searles (1967; p.119), introducing a paper on the subjective experience of schizophrenia based on his reflections on his many years of working clinically in this field, conveys sentiments uncannily similar to those experienced by the author in carrying out and writing up the present research. I too felt overwhelmed by the 'unorganised vastness' of the material, which as Searles points out, is often of a 'deeply moving' nature. It is my hope and belief that the three theoretical constructs (fragmentation-integration, invalidation-validation, and spirituality) introduced in the previous chapter offer some possibility of imposing order on the 'unorganised vastness' of the material one will encounter in any investigation into the subjective experience of psychosis. As I noted in chapter 1, the present study was designed with a view to shedding light on the subjective experience of psychosis in a way that enhances our theoretical understandings and, crucially, that points to practical implications for clinical practice in this area. In this chapter, I will consider how the findings from the present study relate to previous contributions to the study of psychotic experience and discuss some of the theoretical, clinical and research implications which emerge from the present research. Before doing so, I will discuss this issue of the 'trustworthiness' of this research, then outline some of the limitations and strengths of the study.

11.1 Establishing the trustworthiness of the analyses

I have already outlined some of the complex issues relating to the evaluation of the trustworthiness of qualitative research (7.2.4). As a piece of qualitative research, the present research project enjoys many of the advantages of qualitative research (such as focussing on interpretation and meaning) at the same time as being subject to many of the limitations of such research (in particular, the difficulties associated with establishing the validity, or more accurately the 'trustworthiness', of the research as well as questions regarding how generalisable the results are). As Tappan (2001) comments:

> 'Perhaps the most vexing problem facing interpretive psychologists is the question of how to evaluate a particular interpretative account.'

I have already commented (7.2.4) on how it is not appropriate to simply import methods of evaluation from quantitative research (reliability and validity) and assume they can do the same job in qualitative research. As Hirsch (1967) notes, demands for 'validity in interpretation' of qualitative research often assume a correspondence theory of truth (or a form of realism), yet the qualitative framework eschews just these assumptions in favour of constructivist epistemologies.

Fish (1980) has pointed out that interpretation of data in qualitative research involves the interpreter constructing (not 'finding') meaning, based on his or her response to the data and suggests that the best way to guard against bias in a particular interpretation is to try to achieve 'interpretative agreement' among the relevant 'interpretative community', and suggests that this is a good way of evaluating a particular account. Dale (1999; p.58), reflecting on evaluation of qualitative research, comments:

> 'Ultimately, the validity of qualitative research rests on transparent methods and the plausibility of analysis'.

With these ideas in mind, I will now consider the evaluation of the present research in terms of trustworthiness, using methods of evaluation suggested by Lincoln and Guba (1985).

11.1.1 Transparency: personal orientation and audit trail

An important component of the evaluation of qualitative research is for the researcher to be transparent in terms of his or her personal orientation towards the research (to allow others to consider if and how this may have impacted on the analysis) and to make clear the process by which the final analysis was reached (that is, an 'audit trial'). I have already outlined my personal orientation towards the area being investigated (8.6) and noted how this changed over the course of the study. Also, I have discussed (8.5) the process of reaching the descriptive and theoretical levels of analyses in this research, and reiterated this in the previous chapter. I have provided a comprehensive account of the contents of the descriptive and axial coding of the interview material (chapter 9), as well as for the theoretical constructs (chapter 10). Such detail does, I hope, make transparent the 'audit trial' of this research and analysis.

11.1.2 Interpretative agreement

As noted above an important consideration in evaluating the trustworthiness of a particular interpretation is to consider the extent to which this interpretation reaches agreement within the particular 'interpretative community' (Fish, 1980). This is one means of achieving the goal of 'triangulation' (Bryman, 1988), through using multiple perspectives in reaching the final analysis. In the present research, the relevant interpretative community includes: the research participants; other participants of first episode psychosis services; clinicians working in this area; researchers in this area. Feedback on this research and the ongoing analysis has been sought in a number of areas and incorporated into the analysis presented here.

11.1.2.1 Feedback from participants ('respondent validation')

Unfortunately, most of the participants in this research had left mental health services (having been discharged by the clinical team) prior to the final analysis being reached. As ethical approval had not been sought to contact participants after discharge from the service, and participants had not been informed that this might occur, it would not have been appropriate to contact participants who had already left mental health services, simply to ask for their feedback on the research results. This limited the extent of the feedback from those who had taken part in the research. However, a small number of participants did continue with the clinical team, and remained engaged with the researcher in his role as the psychologist in the team and, as such, it was possible to seek feedback from them as the analysis progressed. Feedback was also obtained from other clients of the early intervention service, through groups for clients run by the clinical team, which the author helped facilitate. One function of these groups involves providing clients with information about psychosis, such as different ways of understanding the experience. Notions from the present research (in particular, the theoretical constructs) were incorporated into these groups, with clients' full knowledge of their source. More generally, feedback from current and former clients of mental health services has also been obtained through conference presentations (Geekie, 2003; 2004b; 2005; 2006), where current or former users of mental health services were present as delegates.

The feedback from service users in each of the above mentioned settings has been very positive. Common feedback included a sense of relief at having been ‘listened to’ and at having personal stories of psychosis elevated to a position of greater prominence than they have traditionally occupied. Current and former service users often made comments about the inclusion of spirituality in the analysis, the universal sentiment being that spirituality is of central importance to the client’s experience, but that it has rarely been acknowledged as such, without being pathologised, by clinicians. Suggestions by service users included the importance of recognising the role of the researcher in the ongoing development of participants’ understandings of, and relationships with, psychotic experiences: that is, to stress that the researcher/clinician is not a passive observer of this, but rather is an active participant in the development of these matters through the psychotherapy process. Feedback from service users about the other two theoretical constructs was also positive (though perhaps less pronounced than that for ‘spirituality’), with these being described as both accurate and helpful constructs for making sense of the subjective experience of psychosis.

11.1.2.2 Feedback from other clinicians and researchers

This research has been presented to other clinicians and researchers, in various stages of data analysis, in a number of informal and formal settings. These have included clinical team meetings for various clinical services, small group meetings (such as the Regional Auckland Psychosis group), and at national and international conferences (Geekie, 1998a, 1998b, 2003, 2004b, 2005. 2006). Again, the response to these presentations has been positive, with a number of comments and suggestions having been made. Both supervisors to this research project are clinicians and researchers with extensive experience in the area of psychosis. They too have described the theoretical constructs as meaningful and accurate, both in terms of the data presented here and of their own experience working with clients who experience psychosis.

Feedback received from clinicians included an important point, raised on more than one occasion, on the role of culture in influencing the individual’s experience and understanding of psychosis. This is a point with which I am in full agreement, though, as I have pointed out, investigations into the roles of factors such as culture, gender, age, etc., lie beyond the scope of the present research, partly because of the sample size. This is clearly an area where future research could be conducted. Other suggestions have included those aimed at making the 'spirituality' construct bipolar, so matching the two other theoretical constructs. One suggestion, from a conference delegate, was that perhaps 'phenomenology' (meaning an experience devoid of a meaning-framework), might be an appropriate opposite end of the 'spirituality' construct. Another suggestion, from one of the supervisors of this project, was that the other end of a putative bipolar construct would be 'material'. While both of these suggestions do indeed have some merit, I elected not to adopt either within my analysis. This is because, while both suggestions do seem to suggest possible opposites to the notion of 'spirituality', they do not do so in a way which seems justified based on participants' notions of spirituality in relation to their psychotic experiences. That is, none of the participants in this research viewed their experience as being devoid of meaning, nor did they seem to be using notions of spirituality as a contrast to 'material' factors. In short, it seemed more appropriate for the 'spirituality' construct to be presented as it is, without trying to force it into a bipolar structure, which the data did not support.

Feedback from Māori clinicians who attended presentations of this research supported the advice given at the outset of this study through consultation with other Māori clinicians. That is, I have been given positive feedback about including comments by Māori, and acknowledging the central role of cultural factors, while emphasising that proper investigations of Māori understandings of psychosis would need to be carried about by Māori researchers.

Another notable aspect of the feedback received from clinicians was the attention given to spirituality. As with participants, a number of clinicians commented that they felt it was 'brave' of me to raise the issue of spirituality as they felt it was an issue of considerable importance but one that was somehow 'taboo' for clinicians to mention. A typical comment in this area was that of a clinician working in the area of early intervention:

> 'That's the first time in my 12 years working in mental health that I have ever heard a clinician acknowledging the role spirituality or just speaking about it in a positive way'.

Questions raised about the analysis by clinicians included a suggestion that clients who engage in psychotherapy may not be typical of early intervention clients, and that therefore these results may have limited generalisability to other clients with a first episode of psychosis. This is impossible to refute based on the present research, and is something which would require further research to fully evaluate. Indeed, it seems reasonable to consider the possibility that those who engage in psychological therapy are more eager to explore the meaning of their experience than are those who do not engage in, or who decline, psychological input. This point will be discussed further below, when I consider some limitations of the research. However, given that the majority of clients of the early intervention service do engage with the psychologist, and with the only exclusion criteria for participation in this research being currently under the Mental Health Act, or having engagement difficulties with the service, it seems reasonable to assume that views in this research are representative of at least a substantial portion of clients of early intervention services.

Another question raised was the extent to which the experience of psychosis distorts the participant's thinking, such that comments made in the sessions reflect only the psychotic process rather than participants' 'true' understandings of the psychosis. In response to this, I point out that no participants were floridly psychotic for the whole duration of the research, and that the purpose of this research is to look at the range and complexities of participants' understandings of psychosis, not to judge these understandings as 'true' or not, nor to identify which factors contribute to the participant's understanding at any particular time (again, this is something which could be researched in the future). Another area of feedback received from clinicians was to point out similarities and overlaps between aspects of my analysis and other concepts from the professional literature, such as between my notion of fragmentation and the concept of dissociation. These overlaps will be considered more fully below.

11.1.3 Utility of the analysis

As noted (7.2.4), Mischel (1990) and others have argued that the practical utilisation of an analysis is also of importance in evaluating the research: that is, the extent to which the research produces results which are acted upon. These results have already had some practical, clinical utility. The theoretical constructs have become important components of my own clinical practice in my continuing work with psychotic participants. I have found these of great use both in guiding my own thinking and, when appropriate, in sharing these ideas with clients as a possible way of making sense of the experiences they discuss with me. To date, I have found these constructs of great clinical utility, though I have not yet evaluated these in any formal way. Also, aspects of this research have been incorporated within the group programme of the FEP team. In fact, over the course of this research, and influenced by the findings from this research, the service has developed a new group which is run two or three times per year and offered to participants of the service: a 'Storytelling' group. This group focuses specifically on the notion of telling one's story. Participants develop their own story (using a variety of media, such as narrative, photographs, music, etc.) and then share this with other participants who provide feedback and 'validation' of the individual's story. This group has been well received and, as a new clinical intervention, has been presented at both national and international conferences (Rook & Geekie, 2004; Rook & Geekie, 2006).

11.1.4 Coherence and plausibility of the analysis

Feedback received from the 'interpretative community' of participants, clinicians and researchers in this field, leads me to believe that this analysis is both coherent and plausible. Certainly, I was never faced with questions which suggested that this analysis was either difficult to understand or implausible in terms of the steps involved in the process of reaching the analysis presented here. Clearly though, this is an ongoing process subject to ongoing evaluation from interested parties, which may involve more rigorous testing of the concepts (particularly the theoretical constructs), possibly through the use of quantitative methodologies more suited to such evaluations.

11.2 Limitations and Strengths

- Limitations

Many of the limitations of the present study are those that are common to qualitative research discussed in chapter 7. Chief among these limitations are questions regarding the generalisability of findings and the influence of the investigator's subjectivity on data analyses. In terms of the generalisability of these findings, the fact that this is a study with a sample of only fifteen participants means that it is impossible to be confident about how far the present findings may be generalisable to the larger population of people who have psychotic experiences. As noted above, one important consideration, which may indeed have implications for the generalisability of this research, is that those who participated in this study were already engaged with a clinical psychologist and therefore were amenable to a psychological approach to their experience. There were, of course, good pragmatic and ethical reasons for choosing this group. After all, it would hardly be possible to glean information about the subjective experience of psychosis from those who are reluctant or unwilling (at that time) to discuss this with the researcher/clinician. As discussed in chapter 4, those who experience psychosis may have different ways of relating to the experience, with some people tending to 'seal over' (that is, deny the experience has any personal significance) and others tending to 'integrate' (that is see personal meaning in the experience) in their way of responding to psychosis (Levy et al., 1975; McGlashan et al., 1975). It seems likely that most, if not all, of those who participated in this study were closer to the integration end of this particular construct. Caution is therefore needed in making any generalisations from these results that assume they apply to all clients of a first episode service. While the majority of clients (approximately 70%) of the service where this research was conducted do choose to engage with the psychologist, there remains the possibility that those who do not do so may indeed have quite a different way of relating to their experience of psychosis. Further empirical research would be required to consider if and how the findings from the present study may, or may not, apply to this group of clients.

While there are no reasons to assume that the participants in the present study were anything other than 'typical' clients of a first episode psychosis service, the possibility that the ways in which these participants relayed their experience of psychosis are not representative of the whole group of clients cannot be ruled out completely. In some ways, this is an inevitable aspect of any qualitative investigation where the focus is on depth of investigation, rather than 'representativeness' of the population being studied, and where a requirement of participants is that they are able and willing to discuss the experience concerned. While the question of generalisability of these findings cannot be answered by the present study, the findings do nonetheless point in the direction of how this could be evaluated in future research, an issue which will be discussed further below.

The other major limitation common to qualitative research relates to the potential influence of the researcher on data analysis. Again, this is something that cannot be fully eliminated in qualitative research, where the researcher is inevitably deeply involved in the data gathering and analysis. Indeed, the researcher's interpretations of the data are at the very heart of qualitative research. It is, therefore, neither possible nor desirable to ever fully eliminate the role of the researcher in the project. Rather than endeavouring to eliminate this, the most appropriate response (as discussed in chapter 7) is to try to make this as transparent as possible, thus allowing readers to evaluate the researcher's role in the project. To this end, I have commented on my position vis-à-vis the research (8.6) and also I have detailed the process of data analysis (chapters 9 and 10). Aspects of my personal orientation which may have influenced my approach to this research and data analysis may include the fact that I work as a practising clinical psychologist. This may be reflected in my focus on clinical matters and may also mean that I have greater sensitivity towards and affiliation for psychological ways of understanding distressing experiences. My background in studying philosophy may also have impacted on the analysis, making me more likely to pick up on philosophical issues in participants' stories. Hopefully, these explications of my position are sufficient to allow the reader to consider if and how this may have contributed to the final analysis.

In addition to the limitations common to most qualitative research projects, there are some limitations which are more specific to the nature and design of the present study. In terms of the study design, perhaps the most obvious limitation is that deriving from the nature of the relationship between participants and researcher. That is, participants in this research were in a client/therapist relationship with the researcher, and this client/therapist relationship was primary, both in terms of predating the research and in terms of taking priority over the participant/researcher relationship. This dual relationship clearly brings with it the possible complications that may not be found in research where there is no such dual relationship. The power dynamics in a client/therapist relationship (chapter 1) may be different from those in a purely participant/researcher relationship. It is impossible to rule out completely (or to quantify) any contribution this may have made to the findings. While the researcher went to every effort to ensure that clients did not feel any coercion to participate, it remains possible that some participants did experience an element of this. Also, the aims of the research and the aims of therapy may not always have coincided. As previously noted (chapter 8) clinical needs were always given priority over research aims, which, at times, may have compromised the research (by, for example, the researcher focusing on an issue unrelated to the research as this was indicated clinically). These issues are inevitable aspects of the design of this research project, and, as such, they need to be acknowledged. On balance, however, it was felt that the unique strengths (discussed below) afforded by this dual relationship were such that these outweighed these potential weaknesses.

Another point to acknowledge relates to the issue of the heterogeneity of participants. As previously noted (2.2.3) questions have been raised about the validity of terms such as ‘psychosis’ and ‘schizophrenia’. Participants in this research had experiences which were diverse in nature, and as such, there were many ways in which one could approach research in this area. For example, one might choose to investigate the experience of specific symptoms, such as hallucinations or delusions. Alternatively, it would be possible to look at differences within subgroups (for example, according to gender or culture) in the experience of psychosis. However, as this was a small-scale, preliminary study it was felt appropriate for this to focus on the subjective experience of psychosis, while acknowledging that there are some problems with this term and that there are other ways in which one could go about investigating the diverse experiences which are subsumed by the term ‘psychosis’.

Two limitations of the data analysis also need to be acknowledged here. These relate to the three theoretical constructs outlined in chapter 10. Firstly, the three constructs do not ‘capture’ or subsume all of the descriptive and axial categories presented in chapter 9. For example, the three theoretical constructs do not readily subsume much of what is categorised as biological causes of psychosis (9.2.3). While one could argue, at a stretch, that attributing psychosis to 'the brain' (9.2.3.2) may reflect a form of 'fragmentation', this would not be so easy for the most frequently cited biological cause, 'drugs' (9.2.3.1). Secondly, these three constructs do not apply to all participants' narratives. This is most apparent in respect to 'Spirituality', with 11 participants in total (from both 'Spiritual Causes of Psychosis' and 'Spirituality') invoking notions of spirituality in their accounts of their experience. The general point here is that the three constructs do not apply universally to all participants' stories. While both these limitations in the data analysis merit recognition, neither critically undermines this analysis. The purpose of a grounded theory analysis is to elaborate the theoretical construct or constructs which capture and convey the 'essence' of the experience being investigated. To do this does not require that these constructs subsume *all* of the data (but rather, as stated, the 'essence' of it). Inevitably, there will be aspects of participants' narratives that lie outside the 'range of convenience' of the theoretical constructs. That certain aspects lie outside the theoretical constructs should imply that these aspects are not central features of participants' narratives. Indeed, this was the case in the example given above (biological causes of psychosis): while participants did allude to biological factors (mostly 'drugs', with other biological factors being mentioned much less frequently: 'brain' by three participants and 'heredity' by two), these factors were peripheral to the main thrust of their narratives. As such, I believe that their not being subsumed by the three theoretical constructs, while being worthy of mention, does not undermine my central argument here. My contention is that the theoretical constructs do indeed capture the essence of the experience of psychosis and that they illuminate the experience in a clinically and theoretically helpful way.

A final limitation worth noting here is that participants in this research were already involved with mental health services and had, therefore, been exposed, in various ways, to their clinicians' ways of understanding the experience. For example, each of the participants had regular contact with the team psychiatrist, and some had contact with other members of the clinical team, depending on clinical need. This factor (contact with other mental health clinicians) is not controlled for in the present research, yet is likely to have had some influence on the participants' ways of talking about their experience. As participants in the present research were presenting to mental health services for the first time, they had relatively limited exposure to clinicians' perspectives. In reading the transcripts of the participants' accounts, it seems clear that these are very much the participants' personal ways of narrating their experiences. No doubt these narratives, as with all narratives, have been subject to many external influences which contribute to the final narratives. These influences include, but are not limited to exposure to clinicians' perspectives, which did not appear to dominate participants' stories. Nonetheless, the influence of exposure to clinicians' frameworks of understanding madness is of some importance. This may be a useful avenue to be explored in future research. Such research would require a different research design, looking at the development of clients' understandings of their experience over time and with exposure to various influences.

- Strengths

Many of the unique strengths of this study are corollaries of the limitations noted above. One obvious strength is the 'ecological validity' of the study. This is a naturalistic study which took place during the normal course of a psychotherapeutic relationship. This would be impossible to conduct unless the researcher is also the clinician (any alternative design would which did not have a single person in the roles of both researcher and clinician would inevitably have an impact on the psychotherapeutic relationship). The psychotherapeutic relationship is a unique relationship which allows in-depth exploration of the issues concerned. The present study has the strength of being carried out within this therapeutic relationship, allowing investigation of the experience of psychosis in a manner and to a degree which would be more difficult to achieve in any other research design.

One function of the ecological validity of the study is the potential practical application of the results. Taking place within the clinical setting and with the focus specifically on clinical matters, the results of this study have clear and relatively easy to implement clinical implications (discussed further below). Also, in relation to my comments above regarding whether or not these findings can be generalised to those clients who do not engage in psychological therapy, it would be reasonable to hypothesise that the three theoretical constructs may help shed some light on some of the reasons behind the reluctance of some clients of early intervention services to discuss their experience in this way (for example, if they expect further invalidation of their understandings of the experience). This too, could have implications for how therapy is offered to clients. Further empirical investigations would be required to substantiate this position.

Another strength of the study relates to the fact that multiple interviews with participants were carried out. This allowed participants to explore and express their understandings of their experience, hopefully within a safe and ‘validating’ relationship. This may have made it easier for participants to express the complexity and variety of their understandings of psychosis, in a way which one-off interviews may have inhibited. Multiple interviews also made it possible for the researcher to check out interpretations with participants as the research developed, thus adding an extra element of ‘trustworthiness’ to the data. Another important strength of the study is that the findings easily lend themselves to empirical evaluation using more stringent statistical methods (discussed further below).

11.3 Relationship to previous findings

This research clearly fits within a particular research framework and relates to a variety of other theory and research relating to the nature of psychotic experience.

11.3.1 Role of lived experience

The present research, as indicated in chapter 1, can be located within the interpretive approach to social sciences, and in particular within the storytelling framework, which stresses the importance of first-hand lived experience, as well as the utility of the narrative approach. Findings from the present study are consistent with the principles of this approach. The importance of the contribution that first-hand knowledge can make to our understandings of psychotic experience is clearly evident in the vast diversity and sophistication of participants’ accounts of their experiences. Much of this knowledge, seen throughout chapter 9, is necessarily first-hand knowledge, by which I mean it is only available through the subjective encounter with psychosis. This research demonstrates, I believe, the invaluable contribution that knowledge derived from subjective experience can make to our understandings of psychosis and the requirement, therefore, that somehow we incorporate objective, ‘scientific’ approaches to psychosis with the knowledge that those who have first-hand acquaintance with the experience can also contribute. As Fadiman and Kewman (1973) note:

> 'A realistic comprehension of the meaning and value of insanity must include close examination of the experience itself.'

The findings of this research also lend weight to the importance to the individual of developing a meaningful narrative of psychotic experience. The issues of 'storytelling and authoring' were of central importance to participants, in terms of making sense of the whole experience, and in coming to terms with the distressing aspects of the experience through creating and sharing their 'story'. Participants welcomed the opportunity to discuss their experience in depth, and spoke clearly about how important this is to them. Other researchers have found this to be an important wish of users of mental health services, though one which is often overlooked, as Wagner and King (2005; p.144) found in their study of in-patients' wishes:

> 'People with schizophrenia may frequently wish to discuss their subjective experiences with their clinicians, but such themes are thought irrelevant.'

11.3.2 Clients' understandings of psychosis

Research into clients' understandings of psychotic experience (chapter 6) consistently shows that clients have multi-factorial (Dittman & Schuttler, 1990), diverse (Weinstein, 1974) ways of understanding the experiences, which commonly stress psychosocial (Angermeyer & Klusmann, 1988) and spiritual (Heery, 1993) matters as likely causal factors in psychosis. Saravanan, Jacob, Prince and David (2004) suggest that holding multiple understandings may act as a 'buffer' against stigma. While the present study is qualitative rather then quantitative in nature, the findings are, nonetheless entirely consistent with those earlier studies. Participants expressed 36 distinguishable factors seen as causally implicated in their experience of psychosis and 9 different ways of describing what the experience of psychosis was like, clearly indicating the preference for multi-factorial accounts. Perusal of the factors identified as causal by participants shows a strong emphasis on psychosocial and spiritual variables, a finding consistent with previous research in this field.

Interestingly, there are some parallels between some of the theories of psychosis espoused by participants and professional or scientific theories of psychosis. While some of this overlap may be attributable to the participant having had contact with mental health services (and so adopting aspects of clinicians' views), this is clearly not always the case. Some participants expressed considerable surprise to hear that the theories they had developed had been proposed by others and had some empirical support. For example, Tony, who articulated his theory of 'subvocalisation' as a cause of auditory hallucinations (9.2.3.4) was surprised to hear that there had been scientific studies which showed that this may be a factor in hallucinations (McGuigan, 1978). Similarly, Isa posited metacognitive processes as causal factors in his psychosis (9.2.1.3.4) without ever having encountered Bentall's (2003) thoughts on this matter, and was equally surprised, and validated, to be made aware of this.

Examples of other areas where one can see parallels between participants' accounts of psychosis and professional theories include sensitivity to stress, evident in participants' notions of causes of psychosis such as 'stress' (9.2.1.1.4), 'interpersonal relationships' (9.2.2.4), and 'abuse' (9.2.2.3). These factors are also implicated in professionals' 'scientific' theories, such Read et al.*'s* (2001) traumatogenic theory, and Zubin and Spring's (1977) stress-vulnerability model. Looking at the role of information processing (9.2.1.3), we can see similarities between participants' notions of causes and Frith's (1994) neuropsychological theory. A range of other parallels is evident between participants' and professional accounts, including biological, psychodynamic, developmental, sociological and spiritual factors. Limitation of space does not allow a full exploration of these parallels here.

As noted above, the present research does not address the sources of participants' understandings so (except where this is obvious, as in the examples above, where the participants had clearly had no exposure to the clinical theory) one cannot comment on the nature of these parallels between participants' and clinical frameworks other than to note that clinical perspectives did not dominate participants' accounts. The way in which participants expressed their understandings of psychosis, does, I believe, make clear that these understandings are deeply personal reflections on the experience, rather than simply repetitions of information provided through mental health services. Indeed, the importance of developing a personally meaningful understanding of the experience was stressed by participants (9.1).

One point I wish to make here is that parallels between participants' understandings and professional, scientific theories do exist and that at least some of the ideas found in participants' accounts of their experience derive from participants' own reflections on their experience, rather than being merely repetition of theories learned from mental health professionals. This should draw our attention to the important contributions that clients of mental health services can make to understandings of psychosis. The theories espoused by participants in this research provide sophisticated and helpful insights into the nature of the experience and these insights may have valuable contributions to make to our understandings of psychotic experience. As Jaspers (1963; p.417) pointed out:

> 'Much can be learned from the *patients' own interpretations*, when they are *trying to understand themselves*' (italics in original)

Similarly, the findings of this research are consistent with Kelly's (1955; p.322) advice:

> 'If you do not know what is wrong with a person, ask him: he may tell you.'

One possible difference between participants' and professionals' understandings of psychosis, is that participants seemed comfortable holding multiple, seemingly incompatible perspectives on psychosis simultaneously, in contrast to scientific theories which tend to stress consistency in this area. This is a well-recognised difference between lay and expert theories, discussed by Furnham (1988) and Furnham and Bower (1992).

11.3.3 The centrality of meaning

The search for meaning in the experience was a central concern for participants. Indeed, the three theoretical constructs each relate in different ways to the meaning of the experience. Loss of meaning is a key feature of the experience of 'fragmentation' and having one's meaning-making (or 'authoring') capacity undermined is central to 'invalidation'. And, in 'spirituality' we can see a key component in the search for meaning of some form pertaining to the experience of psychosis.

Other research in this area reports similar findings about the centrality of meaning for psychotic clients. For example, Roberts (1999; p10) notes:

> 'The primary anguish of the psychotic is in just this dissolution of meaning and inability to make sense of his experience.'

This is backed up by a range of investigations, using different methodologies, which have consistently shown that understanding the experience is of central importance to those who experience psychosis. Wagner and King (2005), studied psychotic clients in Brazil, and found that clients embrace the notion of exploring the meaning of their experience and that (p.142):

> 'Existential needs were the most important and pressing theme for people with psychotic disorders.'

They report (p.144) that this was an issue rarely addressed adequately in clinical settings:

> 'The overriding issue for patients was dissatisfaction with their existence and a lack of meaning.'

Larsen's (2004) study of first episode psychosis clients in Denmark also found that making meaning of the experience was a central concern from clients, and further, that clients in that study, as in this, showed considerable flexibility in the meanings constructed. In Canada, Gregoire (1990) reports that for hospitalised patients, the second most common expectation from admission (after 'control of symptoms') was to develop greater understanding of the experience. Corin, Thara and Padmavati (2004) report similar findings from South India. They report that the search for significance and meaning was one of the main themes for first episode psychosis clients, although this contrasted with family members who saw this as unimportant. Similar to the present research, they report that clients describe a loss of meaning (fragmentation) and loss of position (invalidation) as well as spiritual concerns. They suggest that there is something about the nature of psychosis that makes it resistant to understanding within a single frame of reference.

Therapeutic approaches which focus on the meaning of the experience have reported that this can be the basis of an effective intervention. For example, Mosher (2001; p.400) reflecting on the success of Soteria House (California), a facility which offered an alterative to hospitalisation for first episode psychosis clients (who were deemed in need of an admission) notes:

> 'This approach focuses on understanding and trying to find meaningfulness in the subjective experience of psychosis.'

Turkington, Kingdon & Weiden (2006; p.367) in a review of effective psychological interventions for psychoses (with an emphasis on cognitive-behavioural therapy) note that meaning-making is a central component of these interventions:

> 'The goal is to find explanations of the patient's experiences that are acceptable to both patient and clinician.'

As we see, the search for meaning and the struggle that this can entail is a common finding of research into the experience of psychosis, including the present research. I will now discuss how the three theoretical constructs outlined in chapter 10 relate to previous research findings. As previously discussed (10.1), the two bipolar constructs have a 'negative' end (more associated with distress and with symptoms of psychosis) and a 'positive' end (less likely to be associated with distress, more commonly associated with recovery). In this section when discussing the two bi-polar constructs my focus will be on the 'negative' ends of the constructs (that is 'fragmentation' and 'invalidation') as these have most relevance for the psychotic experience and also have clear connections to the literature. Later in this chapter (11.6), when discussing clinical implications of this research, my emphasis will be on the 'positive' ends of the constructs ('integration' and 'validation') as these are more associated with reduced levels of distress and so have relevance to clinical interventions which are aimed at reducing distress..

11.3.4 Fragmentation

Fragmentation refers to loosening of the connections that hold experience together, a breaking up of both intra- and inter-personal aspects of experience. While the exact nature of fragmentation varies from participant to participant, general features of this include a fracturing of the person's emotional and cognitive worlds, when different parts of the self do not seem to be operating in concert, giving rise to a sense of self that feels as if it lacks coherence in here and now and over time. In the interpersonal and material areas of life, fragmentation refers to feeling somewhat disconnected from other people (with an associated sense of isolation) and detached from the physical world. In the present research, psychotic experiences were more associated with the fragmentation end of the 'integration-fragmentation' construct. This is also evident in the research literature on psychosis, where we find similar concepts.

Writers from outside the field of psychosis have pointed to the importance of fragmentation for understanding human experience in general. For example, Nietzsche (1980) describes a kind of 'fragmentation of belief' as one of the symptoms of the modern age (in his case, late 19th century). Also, 'fragmentation' is a central feature of Kelly's (1955) theory of personal constructs, referring to the (not necessarily problematic) distance between different components of the individual's construct system.

Within the field of psychosis, we find many of the classical writers in this area invoke notions similar to my concept of fragmentation. Kraepelin and Bleuler, both of whom based their theories of psychosis on qualitative reflections on their experiences with patients, propose that fragmentation is a central feature. Kraepelin (1896) suggests that a central aspect of dementia praecox (schizophrenia) is the loss of inner unity of consciousness (using the metaphor 'orchestra without a conductor' to illustrate this). Bleuler (1911) also invokes a similar notion when he speaks of the 'breaking of associative threads' being at the core of schizophrenia. Indeed, it was this notion of fragmentation of aspects of the self which gave rise to the term 'schizophrenia'. Janet (in Leudar & Thomas, 2001, chapter 4), writing in mid 19th century France, proposed that hallucinations represent a failure to integrate past traumatic experience into the self. Mead (1934) suggests that the breaking up of the self into components and a failure to integrate these is an underlying cause of psychotic experiences. Similar sentiments are found in more recent contributors to conceptualisations of psychotic experience, particularly those who write from the psychoanalytic perspective (2.3.5). For example, Schultz (1975) comments that psychotic patients show fragmentation and a lack of an integrating function. Arieti (1966) suggests that a process of 'perceptual fragmentation' may underpin psychotic experiences, while Jung (1967) proposes that 'fragmentation of consciousness' is the basis of psychosis. More recently, Cutting (1985) describes psychosis in terms of a 'breakdown of the Gestalt', and Osatuke et al., (2005) develop their 'assimilation' theory, which suggests that internal voices will only be experienced as problematic if there is a lack of assimilation (or integration) of these voices. It is evident that each of these writers identifies a central feature of psychosis which bears close resemblance to the notion of fragmentation as articulated in the present research.

Recent empirical investigations also identify a similar process in the experience of psychosis. Mills (2001; p.211), reflecting on published first hand accounts of schizophrenia, notes:

> ‘disintegrating, fragmented, out of my body, floating, all over the place are some of the words that came up again and again’

Mills uses the general term of ‘fragmentation’ for this process. Wagner and King (2005) report that service users commonly said they felt ‘disorganised’ in themselves. Moller and Husby (2000) investigated subjective experiences in the period leading up to a full blown psychotic episode. They identify changes in the perception of self as central to this, particularly a feeling of being ‘detached’ from previous identity cornerstones. Again, there are clear parallels in these findings to those of the present study, where fragmentation of self was a central aspect to the experience of psychosis.

Parnas, Jansson, and Sass (1998) report on a study of 18 psychotic patients admitted to hospital for the first time. They report that ‘fragmentation of meaning’, relating to both self and world, is a subtle, but significant change which may predate the onset of psychosis. Sass and Parnas (2003) follow up on this, suggesting that such disturbances of self and a loss of the ‘taken-for-grantedness’ of experience underpin psychosis. This loss of the ‘taken-for-grantedness’ of experience is also found in the present study, where participants report a loss of faith in their own ways of knowing (‘personal epistemology’) and their own ways of being (‘personal ontology’). Parnas and co-workers argue that these subtle changes in self may become obscured as the psychosis develops and that it is only through in-depth qualitative studies (like the present research) that these important changes in subjective experience may be apparent.

There are also clear parallels between the concept of fragmentation used here and the experience of ‘dissociation’, more commonly implicated in diagnoses such as dissociative identity disorder and post-traumatic stress disorder (see Ross, 2006). This is an area receiving increasing attention, which has raised important questions regarding the specificity (or lack of it) of diagnostic terms, with some arguing that identifying a dissociative subtype within schizophrenia could have important theoretical and clinical implications (Ross, 2006). The findings from the present research do support the notion that aspects of the experience of psychosis ('fragmentation') are similar, perhaps even identical, to the experience of dissociation. However, as a qualitative study, the present research cannot comment on whether this helps identify a distinct subgroup within schizophrenia.

Fabrega (1989a, 1989b) offers an interesting suggestion from an anthropological perspective. Agreeing with the notion that sense of self is fragmented in schizophrenia, he goes on to suggest that it is cultural boundaries which give coherence to the sense of self, and notes that this varies across cultures (Fabrega, 1989b; p.54):

> 'If the self and behavior are integrated, and if schizophrenia disturbs this integration, one might expect differing people to behave differently when manifesting a schizophrenic illness.'

Such a framework may be useful in investigating the commonly found differences between cultures, such as the oft-noted finding that patients in less developed countries tend to have better outcomes than those in the developed world.

11.3.5 Invalidation

The second theoretical construct from the present research, invalidation-validation, relates to trust or faith in one's ability to accurately construe and make sense of experience and to share this sense with others. Invalidation entails both the individual's own personal loss of faith in his or her capacity to accurately construe experience as well as having this capacity questioned or undermined by others. In the present research, the 'invalidation' end of this construct was most clearly associated with psychosis and with distress. As we shall see, this is reflected in the research literature in this area, where concepts similar to invalidation have been invoked in relation to the experience of psychosis. In the literature, as in the present research, validation is mentioned more in the context of recovery from psychosis. For that reason, I will focus on invalidation when considering the experience of psychosis, and validation when considering clinical implications (11.6.3).

In terms of connection with other concepts from the literature, this construct incorporates aspects of Shotter's (1981) notion of 'authoring' as well as Kelly's (1955) concept of 'validation' (the capacity to make accurate predictions). The interpersonal aspects of invalidation have some similarity to Fromm's (1991) notion of ‘asymmetrical connectedness’, which can be a product on an imbalance in a relationship and consists of one person having his or her ‘unique subjectivity’ denied by the other. Fromm argues that this can lead to the person feeling in a position of separateness and isolation. Fadiman and Donald Kewman (1973) argue that just this kind of denial of subjectivity characterises how the ‘madman’ is treated in USA:

> ‘In the United States, we find it difficult to accept the possibility that the madman’s mode of perception may be not only different from ours, but also, at times, clearer and more profound. Instead of granting the congruity of his internal world, we see it only as a symptom of sickness and assume nothing can be gained from so unusual a perspective. We invalidate his experience and coerce him, through detention, drugs, and various forms of therapy, to deny his own internal world and accept ours. While this is undoubtedly beneficial in some cases, it does not lead to understanding the world-view of the disturbed individual.’

This sentiment is echoed by Roe and Davidson (2005) who review the literature on schizophrenia and conclude that the individual with this diagnosis:

> ‘is viewed as lacking the essential prerequisites for being a narrator of his or her own experience’ .

There are clear parallels here to the experiences of interpersonal invalidation expressed by participants in this research.

Participants in the present research expressed mixed feelings about receiving a diagnosis (9.1.4), with some suggesting it provided reassurance that one was not alone, whereas others saw being diagnosed as undermining their own ability to author their experience, so contributing to the experience of invalidation. This is a finding which has been reported by others who have researched this area. Knight and Bradfield (2003) and Barker et al. (2001) both report that clients felt invalidated by professional explanations and by being diagnosed. Similarly, Estroff (2004) notes that in first-person accounts of psychosis, there are often references to the feeling of having one’s subjective experiences invalidated, by reducing these experiences to brain chemistry. This issue of invalidation is also evident in the literature on stigma associated with mental illness (5.5). Deveson (1992) provides an account of madness within the family and argues that the experience of madness is invalidated in Western culture, a stigma which leads to people with a mental illness being 'silent and silenced'.

The issue of personal invalidation, perhaps most clearly recognisable in the present research (9.4.1.1) in the matters of doubts regarding 'personal epistemology' (ways of knowing) and 'personal ontology' (ways of being) has a few parallels in the literature. As noted earlier (2.3.9 and 11.3.4), Sass and Parnas (2003) invoke similar notions in their conceptualisations of psychosis, when they suggest that loss of the 'taken-for-grantedness' of experience is implicated in the genesis of psychosis. In a similar vein, Laing (1967) proposes that 'ontological insecurity' is central to the experience of psychosis. Bannister's (1960; 1968) empirical investigations into thought disorder found that 'serial invalidation' was both a precursor to the experience and that further invalidation led to an exacerbation. Leudar and Thomas (2001; p.145) discuss a client, 'Peg' who experiences psychosis. Though they use different terminology, notions of both fragmentation and invalidation are very clear in their discussion.

11.3.6 Spirituality

The final of the three theoretical constructs is spirituality, which relates to the tendency to locate the meaning and significance of the experience of psychosis within a broad framework pertaining to how the individual views his or her relationship with the universe. This may invoke metaphysical matters (such as 'other beings' or God, or abstract notions such as 'Good and Evil'). The issue of spirituality has some mention in the literature on psychosis, although commonly this is to bemoan the lack of acknowledgement of spiritual issues in psychosis. Despite this phenomenological overlap between psychotic experiences and schizophrenia (discussed below), there has been relatively little research into the area of psychosis and spirituality. Indeed, many recent commentators note the lack of attention shown to spirituality. In New Zealand, Randal and Argyle (2005) suggest that this absence is a reflection of the times we live in:

> 'We live in an age of spiritual illiteracy (both within and outside psychiatry).'

Sims (1994; p.444) also identifies spirituality as being commonly overlooked in psychiatry:

> 'Psychiatrists have too often concentrated exclusively upon the mental, and ignored, to the extent of denying its possibility, a spiritual dimension.'

He goes on to argue:

> 'However, we need to understand our patients, and they often take spiritual issues seriously.'

Though, as these commentators note, spirituality has been neglected, it is not completely absent from the literature. An early reference to a connection between psychosis and spirituality is made by James (1902), who saw them as intimately related, describing psychosis as 'diabolical mysticism'. This overlap between psychosis and spirituality was one of the themes that emerged in the present research. The essence of this issue for participants in the present research is expressed in Margaret's comment:

> *'What is the difference? How do you differentiate between a true schizophrenic and a true spiritual experience? You can't.'*

This question, of how to distinguish psychotic and spiritual experience, has received some attention in recent years. Jackson (2001) refers to this as the 'spirituality-psychosis paradox', noting the phenomenological similarities between experiences labelled 'psychotic' and those labelled 'spiritual', as demonstrated by research such as that by Greenberg, Witzum and Buchbinder (1992) and Jackson (2001) who compared such experiences and reported many commonalities in phenomenology. Randal and Argyle (2005) suggest that psychosis may often be mistaken for what they refer to as a 'spiritual emergency'. This notion, which derives from the work of Grof (1986), posits that the normal course of spiritual development may interrupted by sudden growth spurts which can be overwhelming and which may result in the individual having experiences which, on a phenomenological level, are identical to psychotic experiences. Randal and Argyle (2005) suggest that it may be only at the level the explanatory model used to account for the experience that we see a difference in these cases:

> 'The phenomenology of what might be interpreted as a 'spiritual emergency' by the person or by an informed clinician can be identical to other psychoses.'

Clinical implications of this perspective are considered below (11.6.4).

That clients take spiritual issues seriously is supported by the research which, like the present research, reports that spiritual matters are an important feature of the subjective experience of psychosis. Research into the subjective experience of psychosis (6.1), consistently reports that spiritual themes are of considerable importance for clients. Examples of this research include Larsen's (2004) study of Danish first episode clients who expressed strong spiritual aspects of the experience and Estroff's (2004) report that spiritual factors are central to many written accounts of psychosis. Heery (1993), reporting on in-depth interviews with 9 voice-hearers, notes that they viewed voices as emanating from 'fragmented parts of self' located in the spiritual realm. Jones, Guy, and Ormrod (2003) and Romme and Escher (1989) report that spiritual understandings of voice-hearing are associated with less distress. Lindgren and Coursey's (1995) attempted to quantify mental health serivice consumers' interest in spiritual matters. They found that the majority of consumers saw spiritual matters as important, with 74% saying that it had been helpful in dealing with their difficulties. Recent research in New Zealand has found that spiritual issues are seen as important aspects of the experience of hearing voices (Beavan, 2006), and also that Māori understandings of psychosis are commonly informed by notions of spirituality (Taitimu, 2006).

Spiritual factors are also pronounced in non-Western conceptualisations of psychosis. I have already reviewed this literature, and noted that in Maori (5.6.2), Pacific Island (5.6.3), and other non-Western cultures (5.6.4), spiritual considerations are central to understandings of psychosis. Examples of research in this area include Corin, Thara and Padmavati's (2004) study in South India, which found that patients' understandings of psychosis were permeated with spiritual and religious themes.

As is evident from the above discussion, the three theoretical constructs which emerged in the present research are closely related to concepts which have been used in the literature on psychosis (albeit only rather recently in the Western world in relation to spirituality). This is particularly the case regarding research into the subjective experience of psychosis, where concepts very similar to these theoretical constructs are identified as being core features of the experience of psychosis. This commonality in findings adds some substance to the notion that these constructs do indeed express important components of the experience of psychosis. With this in mind, I will now consider some of the implications which emerge from these findings. I have organised these implications in different domains, beginning with theoretical implications, before moving on to consider implications for future research, for clinical practice and for training.

11.4 Theoretical implications

There are a number of theoretical implications from the present research. These implications derive from both the method used in this research and from the research findings. I consider these implications to be theoretical in nature because they relate to how we conceptualise those who experience psychosis and to our conceptualisations of psychotic experiences.

11.4.1 The role of subjective experience

In terms of the method of this research, there is a very clear indication that people who experience psychosis can be articulate commentators on the experience, whose reflections can make important contributions to our understandings of psychosis. This is an important consideration given that these voices have been largely excluded from contributing to discussions around how we can understand and respond to these experiences: a state of affairs that seems to the detriment of clients of mental health services as well as researchers and clinicians in this field. Incorporating the perspective of those who have first-hand lived experience with the phenomenon being investigated is a pressing need within the area of psychosis which, as the present research indicates, is feasible and has much to offer our understandings of psychosis. Conceptually, therefore, a shift is required in how we approach research into psychotic experience, such that we recognise those who experience psychosis have a major role to play in our developing understandings of these experiences.

11.4.2 Processes versus symptoms/diagnosis

In terms of the findings of the present research, there are also theoretical considerations relating to how we conceptualise the experience of psychosis. As discussed in chapter 2, the dominant modes of conceptualising psychosis are driven by symptoms. This is true of both diagnostic approaches (APA, 2000) as well as individual symptoms approaches as suggested by Persons (1986). Though participants in the present research were identified based on symptomatic presentation (being part of a first episode psychosis service), the findings identified important psychological processes which are evident in the client's experience of psychosis. For example, when discussing auditory hallucinations (9.3.7), participants identified different underlying processes which seemed to lead them to view particular experiences as ‘hallucinations’ (see 11.6 for clinical implications of this). On a broader level, the three theoretical constructs (chapter 10) relate to processes which may underpin psychotic experiences and may help us conceptualise the experience of psychosis quite differently. This presents us with an approach to conceptualising psychosis, based not on phenomenology, symptomatology or diagnosis, but on the underlying process implicated in the development of these experiences.

This approach may present a quite different way of thinking about psychosis in particular, possibly mental health difficulties in general. By this, I mean that focussing on the underlying psychological processes may provide a different perspective on mental health difficulties, giving different insights into the experience and different implications for treatment. This need not be instead of diagnostic or individual symptom approaches, but as well as, providing a different conceptualisation of the experience. Some of the advantages which may develop from conceptualising mental health complaints in this way might include allowing exploration of relationships between different diagnostic categories, where underlying process may be similar.

Within the area of psychosis, examples where this approach might be useful include identifying those who are vulnerable to developing psychosis, an important consideration, as early detection may help reduce the impact of psychosis, or even prevent psychosis emerging. Research does suggest that prevention is possible. Yung, Phillips and McGorry (2004) showed that use of anti-psychotic medication and cognitive-behavioural therapy combined can help prevent the development of psychosis, while Morrison et al (2004) showed this was possible using cognitive-behavioural therapy alone. Both these studies were carried out on individuals identified as ‘ultra-high risk’, based on symptom presentation and a family history of psychosis.

However, for such preventative strategies to work, it is necessary to first identify those are risk of developing psychoses. In routine practice this proves very difficult (as it is in research that does not use family history to identify those are risk). This is because the earliest symptoms shown by those who later go on to develop psychosis are not specific to psychosis, making it difficult to differentiate those in whom psychosis may develop from the much larger population who experience these non-specific symptoms (McGorry, 1995; Yung et al., 2004). It may be that were we to conceptualise psychotic experience in terms of the underlying psychological process, this may afford greater opportunities for reliably identifying the emergence of psychosis at an early stage.

Another area where focusing on underlying process has important theoretical implications is in considering possible overlaps between different diagnostic categories. Identifying common underlying processes may help explain the relationships commonly found between various diagnostic categories and symptom clusters. For example, recent years have witnessed a growing interest in the relationship between trauma, dissociation and psychosis (Read et al., 2005). It may be that this relationship can be better understood by considering possible common underlying psychological processes implicated in both dissociation and psychosis. As discussed (11.3.4), Ross (2006) suggests just this, when he proposes that underlying process of 'fragmentation of the self' may help unite both concepts. Certainly, in terms of the present research, it is difficult to imagine an experience which could be more invalidating of previously held ways of understanding the world or more likely to induce a kind of psychological fragmentation than childhood sexual abuse.

11.4.3 Conceptualising schizophrenia

Another theoretical construct which developed through the process of conducting this research was the notion that schizophrenia might best be thought of as an 'essentially contested concept' (chapter 2). This is a notion which could have major theoretical implications as it presents us with a fundamentally different way of conceptualising schizophrenia, providing us with a 'meta-theory', which might help make sense of the multitude of theories proposed to explain schizophrenia/psychosis. To recap, this notion entails viewing the 'contested' nature of psychosis/schizophrenia as being an integral aspect of the concept. Some of the implications from this perspective have already been discussed (2.4.2).

11.5 Research implications

There are a number of avenues of future research that could be explored in relation to the current research findings. As a grounded theory study, the present research endeavoured to contribute to the development of theory and taxonomy in the area of the subjective experience of psychosis. The findings of this research are, inevitably, tentative in nature, and point to a range of ways in which these findings could be elaborated through future research. Here, my focus will be on the three theoretical constructs as they have the broadest scope, although many of these suggestions could relate equally well to other findings, such as the role of 'authoring' (9.1) or 'personal epistemology' and 'personal ontology' (9.4.1).

11.5.1 Operationalising and measuring the constructs

Perhaps the most obvious implication for future research is the need for investigation of the generalisability of the three theoretical constructs. This was a small-scale qualitative study, and, as such, one must be cautious making claims about the generalisability and the validity of the three theoretical constructs. Future research is required to evaluate these constructs more fully. Quantitative methods of research would be appropriate for these tasks. This would entail operationalising the constructs, through defining more clearly their component parts, based on the definition, range of convenience and the examples provided in chapter 10. This could lead to the development of measures of fragmentation, invalidation and spirituality. These measures could take the form of a psychometric instrument, such as a questionnaire or a standardised interview schedule (or a combination of both), though whatever form this took, it would be essential that it is sensitive to subjective experience, so self-reports by clients would be a crucial requirement. This research would need to investigate the reliability and validity of the instruments developed for measuring fragmentation, invalidation and spirituality.

11.5.2 Investigating the constructs

Another avenue for future research would be to investigate the three theoretical constructs in more detail. Such investigations would be greatly facilitated by the development of reliable and valid measuring instruments, as suggested above. This research could investigate relationships between the three constructs themselves, between the constructs and other clinical variables, and between the constructs and personal or social variables.

Research into relationships between the three constructs could investigate if and how these three constructs relate to one another. For example, one might hypothesise that invalidation and fragmentation might be closely correlated. Further, one might predict that experiences of invalidation might lead to increases in fragmentation for the individual. Exploring such hypothesis would be possible were the measures mentioned above available as well as information regarding the clients' exposure to invalidating experiences (which would, of course, also have to be defined).

There are myriad possibilities for exploring the relationship between the theoretical constructs and other clinical variables. It would be possible, for example, to explore the relationship between the constructs and levels of distress. I have reported (10.1; 11.3) that fragmentation and invalidation were more associated with distress for participants. This is a hypothesis which future research could investigate. This could be done by using measures of fragmentation and invalidation and comparing these to measures of distress. Such research could be carried out with both clinical and non-clinical samples of people who have psychotic experiences, and might, thereby, also shed some light on differences between those who receive mental health care and those who do not. Other clinical variables which could be investigated in this way include symptoms and diagnostic categories (to identify differences and commonalities in terms of the three constructs); coping strategies and ways of responding to psychosis. It would be interesting to investigate what, if any, relationship might be found between Levy et al.'s (1975) concepts of 'sealing over' and 'integration' as ways of responding to psychosis and the theoretical constructs from the present research. Similarly, measures of the three constructs might allow investigation of the questions such as how universal these constructs are in the experience of psychosis, do they relate to clinical outcomes for the client, and are they (particularly invalidation) associated with experiences of stigma?

Another fruitful area for future research would be to consider the three theoretical constructs in relations to social and individual characteristics. For example, measures of the constructs would allow investigation into cultural differences in the experience of psychosis. Similarly, one could investigate any relationship between the constructs and variables such as gender, age, history of trauma, or any other variable considered of significance.

11.5.3 Researching spirituality

I have noted (11.3.6) that qualitative research into the clients' experience of psychosis commonly finds that spiritual matters are of great importance to clients, who see it as implicated in the experience of psychosis. This is an area of growing interest in mental health care that could benefit from future research. Recent years have seen the development of formal measures of spirituality (Eager, 2005; Fallot, 1988; Zohar & Marshall, 2000) which could be used to investigate the relationship with psychosis. For example, it would be useful to quantify the extent to which spiritual frameworks of understanding are used by people who have psychotic experience. Formal measures of spirituality would also allow investigation of relationships between spiritual beliefs and other relevant variables, such as levels of distress associated with psychotic experiences, or ways of responding to or coping psychotic experiences.

11.5.4 Developing and evaluating clinical interventions

Further research would also need to be undertaken to fully investigate the utility of the three theoretical constructs in clinical settings. Doing this might involve developing more formal therapeutic interventions derived from these constructs and evaluating if these interventions prove useful clinically (for example, in helping alleviating the distress associated with psychotic experiences, or increasing a person's sense of agency, depending on the specific intervention being evaluated). I discuss clinical implications of this research below, some of which have already been implemented, although not formally evaluated. Future research could usefully evaluate these clinical implications in terms of their effectiveness.

11.6 Clinical implications

This brings us to another set of important implications from this research: the clinical implications. These are the implications that relate to how clinicians and clinical services could respond to people who are troubled by psychotic experiences. I will first discuss some of the general clinical implications from the research, before looking more specifically at clinical implications associated with each of the three theoretical constructs. The implications presented here are, of course, somewhat tentative in nature and are suggested as guidelines based on the findings of this research. Further empirical evaluation of these constructs (as suggested above) as well as evaluation of the impact of these clinical implications would be required before one could be confident about their utility. It is important to bear in mind that, as with all psychosocial interventions in the field of psychosis, the individual needs of each client must be paramount in ascertaining which interventions are suitable for which clients.

11.6.1 General clinical implications

One of the most fundamental findings from the present research is that those with a first episode of psychosis welcome the opportunity to discuss the nature and meaning of their experience in some depth and they see this as an important component of understanding and coming to terms with the experience. As noted above (11.3.3) this is a consistent finding in research which asks clients about what they would like from clinical services. There is, therefore, sufficient evidence from both the present research and from previous research findings to state with some confidence that finding personal meaning in the experience of psychosis is an important part of dealing with the experience for many of those who have such experiences. Clinical services should therefore ensure that clients are offered the opportunity to explore this with suitable clinical staff who may help clients develop helpful ways of understanding their experience. The corollary of this is that services should be careful not to close down clients' efforts to express what their experience means to them, through ignoring this or, worse, telling the client that he or she is wrong (this will be discussed in section 11.6.3). The opportunity to explore the meaning of the experience in a safe and helpful way should, therefore, be routinely offered to clients, many, if not all, of whom see this as important.

Another general implication from the present research derives from the finding that a number of clients report positive aspects to their experience of psychosis and hold a positive attitude to the experience, at least some of the time. This is an important clinical consideration which services need to respect and address in clinical settings. It means that clinical services can't assume that the experience is wholly negative in the client's perspective. This could be of crucial importance in many aspects of the client's care. For example, if the client views some or all of the experience positively he or she may be ambivalent about the offer of treatments which are aimed at eliminating this experience. If clinicians are cognisant of this, at the very least this will help them understand the client's ambivalence. So, another clinical implication from the present research is that clinicians should explore the client's attitude to the experience of psychosis as it may prove to be fallacious if clinicians assume that the client views the experience wholly negatively.

In participants' ways of explaining the experience of hallucinations (9.3.7) I noted that different participants used quite different criteria to identify an experience as a 'voice' rather than a thought (theoretical implications related to this have already been discussed: 11.4.2). The criteria used by clients in making this differentiation included perceptual qualities (voices sound different from thoughts), intentionality (voices are not produced intentionally), content (voices contain content the person would not normally think), and familiarity (voices contain unfamiliar words or grammar). Clearly, should the individual be troubled by these experiences and seek a psychological intervention, the clinician should consider not only the symptom but also the underlying process which underpins the client's labelling an experience as a voice. Thus, it is important for clinical services to recognise that similar symptoms may have resulted from different underlying psychological processes and this needs to be taken into account in the intervention offered. For example, for a client whose voices are auditory in nature, interventions such as earphones or distractions may be appropriate, whereas if the client construes an experience as a voice based on lack of intention, it may be that information about intrusive thoughts (how common they are, and the forms they can take) would be a more useful component of therapy.

On a broader level, there are also implications from the present research that relate more to the level of service delivery and policy. One such implication is that the present research indicates that clients are keen to be active participants in their treatment rather then being passive recipients of treatment. Services should endeavour to involve clients both in their individual treatment plans, and also more broadly in terms of service planning and delivery. The present research illustrates the importance of first-hand lived experience as a way to understanding. If clinical services hope to meet the needs of their clients, then this perspective needs to be represented at the level of service planning and delivery to ensure that clients' needs and wishes are more fully incorporated within services.

A consideration for service delivery that is of particular relevance to first episode psychosis (or early intervention) services relates to the issue of fragmentation. As noted in chapter 10, the feeling of personal and interpersonal fragmentation is one of the central features of the experience of psychosis. First episode psychosis services tend to work with clients for a limited period of time, commonly about 2 years. After this time clients are discharged from this service, and transferred to another mental health team if required. This runs the risk of replicating the client's experience of fragmentation and for some clients this could be of particular significance. This is an issue which first episode services need to address, perhaps through identifying those clients for whom interpersonal fragmentation is pronounced, and considering extending the duration of involvement with those clients. Within the clinical service where the current research was undertaken, this point has been taken on board, with the service extending its availability to clients from 2 years up to 3 years where this is indicated (of course, this in itself does not fully resolve this problem as there may be clients who can benefit from a longer duration of consistent contact).

This leads to a more general point about implications from the findings of this research. The three theoretical constructs indicate core features of the subjective experience of psychosis. I have already commented (10.1; 11.3.) that one end of each of the bipolar constructs (fragmentation and invalidation) tended to be associated with increased distress for participants. A general recommendation, therefore, is that clinical services should endeavour not to replicate these experiences for clients. That is, clinical services should ensure they do not replicate fragmentation, invalidation and a denial of spiritual concerns. Rather, services should aim to promote a sense of integration, validation, and the opportunity to explore spiritual matters. I will now consider the clinical implications of each of these theoretical constructs in turn. When discussing the two bipolar constructs, my emphasis here will be on the 'positive' ends of the constructs ('integration' and 'validation') as these are more in keeping with therapeutic goals.

11.6.2 Integration

The clinical implications from the 'fragmentation-integration' construct essentially relate to promoting 'integration' as well as preventing further 'fragmentation' for the client. Support for the importance of promoting integration clinically is found in Rufus May's (2003) account of his experience of madness. As a clinician with his own personal experience of psychosis he is in an excellent position to comment. On his own experience he describes what sounds like fragmentation:

> 'My own "madness" was about disconnecting from a world I struggled to identify with.'

He goes on to suggest:

> 'The way to combat this isolation is to create safe spaces where unusual experiences can be shared and made sense of.'

Other researchers have also identified integration as an important component of coping with psychotic experiences. Romme and Escher (1993) refer to the importance of 'integration' as central to accepting and coping with voices, and Roe and Ben-Yashi (1999) found 'integration' of self and illness to be helpful in recovery. Mahoney (2002; p.57), reflects on the experience of psychosis from a constructivist framework and suggests that

> 'During periods of intense destabilization, clients may need highly structured experiences to help them deal with phenomenological chaos.'

Clinical implications derived from this construct include those that would promote integration on an individual level as well as interpersonal or social integration. In New Zealand, Lapsley et al. (2002) report that those who have recovered from mental health problems identify rebuilding of relationships (social integration) as being central to the recovery process. In terms of promoting personal integration, May (2003) suggests a safe environment to explore the meaning of the experiences is helpful. This is entirely consistent with the recommendation (11.6.1) that clinical services ensure that clients are routinely offered the opportunity to explore the meaning of their experience. Integration could be promoted through exploring congruence between the psychotic experiences and other life events (see Brabban & Turkington, 2002). The Trauma Model (Ross, 2006) may be a useful therapeutic framework here as it delineates ways of working sensitively with traumatic experiences to help the individual integrate these in ways which cause less distress.

Similarly, attributional therapy (Kinderman & Benn, 2002) also promotes integration, by encouraging the client to recognise and evaluate attributions made about particular experiences. A central consideration in all of the above recommendations is that these interventions take place within a reliable and enduring therapeutic relationship, which provides the context within which these interventions can be incorporated.

In terms of interpersonal and social integration, therapeutic interventions which encourage integration within the family may be particularly useful (Aderhold & Gottwalz, 2004) as these can help the family identify and tackle dynamics within the family, so promoting a greater sense of integration. Interventions from the narrative therapy framework, such as 'externalising' the problem may be useful here as they can promote a common framework of understanding within the family as well as encouraging a united approach to tackling the problem (White & Epston, 1990).

Group programmes run by clinical services may also be a useful way of enhancing integration, both on an individual and an interpersonal level. These can include groups which aim primarily to provide opportunities for social contact through social activities, as well as discussion groups which incorporate aspects of relevance to integration. Groups which encourage clients to construct and share their stories of psychosis can promote integration by helping clients see commonalities in their experience (Rook & Geekie, 2004, 2006). Similarly, groups which incorporate the philosophical inquiry method (Clayton, 1996), which encourage a process of philosophical reflection, designed to encourage clearer analytic skills through the guided exploration of philosophical issues can also promote integration (Burdett, 2001; Burdett & Geekie, 2003).

In terms of service delivery, and as noted above (11.6.1), clinical services may reduce the risk of further fragmentation by ensuring continuity of care for the client. Further, it is important for clinical teams to model integration to clients by operating in a consistent way. Given the diversity of ways of understanding psychotic experience (chapter 2), teams may need a framework which allows them to hold and respect this diversity of understandings (which is likely to be manifest in any multi-disciplinary clinical team), while working effectively clinically. A 'meta-theory' of schizophrenia, such as the one outlined in chapter 2, that schizophrenia be viewed as an 'essentially contested concept', may provide a framework which fosters an acceptance of this diversity in an integrative fashion.

11.6.3 Validation

As with the previous construct, the clinical implications which derive from the 'invalidation-validation' construct relate to services doing what they can to prevent further experiences of invalidation while endeavouring to promote validation. Participants in the present research expressed the sense that invalidation was a central feature of their experience of psychosis, and that this had both personal (9.4.1) and interpersonal (9.1.3; 9.1.4; 9.4.3.2) aspects. Validation was also clearly expressed as an important part of responding to psychosis (9.1.1; 9.1.5; 9.5.3). These findings regarding the roles of invalidation and validation in psychosis are reported by others who have investigated the client's experience of psychosis (Lapsley et al., 2002; Romme & Escher, 1993; Vellenga & Christenson, 1994).

Promoting validation while avoiding invalidation may not always be an easy path to follow when working clinically with clients who experience psychosis, who may express some unusual ideas. There is a risk that services may, inadvertently, replicate the experience of invalidation for clients. This could include, for example, informing the client that he or she simply does not accurately understand his or her experience ('you lack insight'). On a more subtle level, challenging how the client construes the experience runs the risk, if done insensitively, of further undermining the client. Challenges to the client's explanatory model (Kleinman, 1988) however well intentioned, may be experienced as further invalidation. At the other end of the construct, there are also risks associated with validation, particularly as this relates to the content of the experience of psychosis. For example, it would clearly be clinically inappropriate to validate a client's belief that he should harm himself, or others, in response to command hallucinations. This tension is expressed nicely by Power and McGorry (1999; p159):

> 'A balance needs to be struck between respecting the patient's interpretation of their psychotic experiences while conveying to the patient one's own clinical judgement and advice regarding treatment.'

The clinical implications here are that services need to be aware of this tension and find ways of achieving this balance, where the client can feel personally validated, while aspects of the psychotic experience may be questioned. This is a tension that is well recognised within Dialectical Behavioural Therapy, now used extensively in the treatment of Borderline Personality Disorder (Linehan, 1993), where invalidation is seen as a risk within therapy and validation of the person and his or her distress is seen as a pre-requisite for change. With the area of psychosis, mutual, respectful exploration of the meaning of psychosis, within the context of a trusting relationship and with recognition of the plurality of perspectives on schizophrenia may help clinicians achieve this balance. Genuine collaboration in exploring the nature and meaning of the experience may be a requirement here. This may necessitate a shift on the part of clinicians, away from the position of believing that we already know what the experience means, to recognising that we bring one way of understanding psychosis, and that this is but one among many useful and valid ways of construing psychosis. If clinicians were to embrace the notion of 'essential contestedness' this may reduce the risk of invalidating the client in clinical encounters. Roe and Davidson (2005) suggest that accepting plurality may help avoid unnecessary and unhelpful invalidation by clinicians:

> 'Acknowledging the existence of multiple, diverse views may be a necessary precondition for encouraging people with schizophrenia to compose and share their narratives.'

A specific aspect of this relates to the impact of being diagnosed, which, as noted above (11.3.5) can have a negative impact on clients. Perhaps the important issue here is that clinicians should recognise that offering a diagnosis runs the risk of undermining client's own attempts to make sense of their experience. Perhaps if this was done in the spirit of plurality, seeing the diagnosis as one way, though not the only possible way, of construing the experience, this risk would be reduced.

May (2003) proposed that one way to approach the tension between validation and invalidation is for clinicians to recognise the importance of 'emotionally validating' client's experience, by acknowledging the impact of the experience and through exploring the personal meaningfulness of beliefs and the relevance to the individual's life history. This can be done without necessarily validating other aspects of the content of the client's psychotic experiences. Cognitive-behavioural approaches to psychosis recommend a similar approach, where the importance of establishing a therapeutic relationship (which provides a form of validation) is a pre-requisite for introducing gentle challenges to client's beliefs (Fowler, Garety and Kuipers, 1988; Turkington et al., 2006).

The current research also points to the importance of one particular aspect of validation: being 'author' of one's own experience (Shotter, 1981). This was conveyed by participants in this research in the emphasis placed on 'storytelling' where the importance of narrating one's own experience was expressed (9.1). Others in this field have also noted the importance of clients' being author of their own experience. Roe and Davidson (2005) argue that the process of regaining ownership of narrative competence is a central part of recovery. Clinical services therefore have to provide opportunities for clients to maintain or regain this narrative competence. Putting this into practice may involve providing the client with opportunities to explore and express the meaning of the experience, as discussed above. This could be done in individual or in group therapy. In the clinical setting where the current research was undertaken, a 'storytelling' group is offered, developed partly in response to the findings from this research. This group has the explicit purpose of promoting the notion of client as author of his or her experience and provides clients with an opportunity to construct their own 'story' and to share this with others in the group. Such a group provides both personal and interpersonal validation (Rook & Geekie, 2004, 2006).

Another clinical implication from this construct is the need to address some of the fundamental implications of the client feeling personally invalidated, in particular the client's loss of faith in his or her ways of perceiving and making sense of the world (9.4.1.1). Interventions need to help the client identify ways of reliably checking out perceptions and understandings of experience, a strategy found helpful by some participants (9.5.3). This may involve encouraging the client to use trusted individuals (possibly including the therapist) to test out perceptions: where there is congruence between the client's and the trusted individual's perceptions or understandings, this may help the client build confidence in his or her own perspective. Other ways of evaluating perceptions and understandings of experience may include considering some of the practical implications of adopting a particular position or developing ‘behavioural experiments’ to test out competing understandings. If this process of evaluation takes place within a trusting relationship, this may make less threatening the re-evaluation of certain perceptions without risking a sense of invalidation of self. That is, the therapeutic relationship may validate the client’s sense of self while simultaneously allowing the client to test out perceptions and understandings of the world.

One way of addressing some of the issues above in clinical settings may be through the use of the already mentioned philosophical inquiry method (Clayton, 1996): a process of philosophical reflection, designed to encourage clearer analytic skills through the guided exploration of philosophical issues. This has been trialled in the service where this research was undertaken, where joint clinician-consumer facilitated philosophical inquiry groups were run for clients, with feedback from participants being encouraging (Burdett, 2001; Burdett & Geekie, 2003).

11.6.4 Spirituality

The issue of spirituality was a prominent theme for participants in this research, a finding consistent with other research into the subjective experience of psychosis. This is the aspect of psychosis most neglected by clinicians and researchers, as indicated by the literature in this field. In terms of clinical implications, perhaps the most obvious and most simple implication is that clinicians acknowledge spirituality as an important and legitimate aspect of the experience for clients and provide an opening for this to be discussed safely, without risk of further invalidation. Mutual exploration of such issues may enhance the relationship between service and client as well as point to avenues of intervention that would otherwise be overlooked. While formal ways of assessing spirituality have been developed (11.5.3) and are of potential use in research settings, Culliford and Johnson (2003) suggest that a straight-forward way to open discussion about religion and spirituality in clinical work is simply to ask, ‘What sustains and keeps you going in difficult times?’.

While a question such as this may help provide an opportunity for clients to express some of their spiritual concerns more clearly, there remains the question of how clinicians should respond to this, given that this may be an area with which they have little expertise. A rare exception to the tendency to overlook this matter in the literature is the work of Randal and Argyle (2005). They provide some guidelines for clinicians in this area, suggesting that the client could be supported in expressing the content of their experience and inner world at their own pace and time, and that the psycho-spiritual roots of the problem could be explored in the clinical setting. One reason why this might not be done may be that clinicians do not feel confident in this area. It may be that clinicians could consider using outside agencies, such as chaplaincy services, or other appropriate experts in the particular form of spirituality of concern to the client, where the client's spiritual musings lie beyond the clinician's level of expertise.

11.7 Training implications

This brings us to the related issue of training implications from the current research. I will touch only on two such issues here. Following on from the previous paragraphs, it seems clear that clinicians working in the field of psychosis need some training in assessing, and in responding to, clients' spiritual concerns. This was exactly the point made my Moana, when she commented:

> *'But you guys [clinicians] have to educate yourselves [about spiritual matters] to some degree, because when I was in hospital there were a lot of people who were spiritual, who had become spiritual and who believed that their experience had some kind of spiritual element to it.'*

The form and content of this training would need to be given considerable thought. Based on the present research, there are indications that this could include assessing spirituality, exploring spiritual meanings in psychotic experience, recognising the spirituality/psychosis overlap (and, if possible, differentiating these) and the experience of feeling spirituality fragmented. No doubt there are other matters that need consideration too. The point I wish to make here is simply that training for clinicians needs to give more attention to the issue of spirituality.

Another implication for training, related to the present research, concerns the more general issue of attending to subjective experience. As noted in chapters 1 and 6, subjective experience is somewhat marginalised in the literature on psychosis, a surprising state of affairs given that subjective experience is a central component of psychosis (as with other mental health difficulties). It may be that training courses for clinicians have a role to play here. Generally, clinical training involves first providing trainees with a professional framework for construing mental health difficulties (this may be medical, psychological, psychotherapeutic, occupational, social, etc.) and then instructing the trainee to look at the clients' experiences through this lens. It may be that this approach leads to the development of clinicians who can easily lose sight of the client's subjective experience as the professional frameworks come to dominate. Perhaps, were trainee clinicians exposed first to clients' stories of their experience (through having more service users involved in their training, through meetings with clients, or if that is not possible, through reading first-hand accounts) and only later to their own particular profession's way of construing these experiences, this may make it less likely that clinicians lose sight of the client's subjective experience. Kaplan (1964; p.vii) made this point some time ago, in the introduction to his compendium of personal accounts of mental illness when he commented:

> 'There is no better starting point for those seeking to understand this strange and baffling phenomenon than accounts of the experience.'

This is certainly a recommendation that is consistent with the present research findings.

11.8 Obstacles to overcome in implementing these recommendations

I have now outlined a range of theoretical, research, clinical and training implications from the present research. These implications derive, essentially, from viewing those who have psychotic experiences as experts of their own experience, whose expertise can contribute to the more general task of making sense of psychosis. There are, no doubt, a number of obstacles which would be faced in putting these implications into practice.

11.8.1 Existential/human

One such obstacle may be at the existential level. Many of the implications above rest on the assumption that psychotic experiences are an aspect of our humanity, and, as such, not something to be feared or avoided at all costs. Clearly, this applies not only to psychotic experiences, but to those who have such experiences. However, as Mosher (2001) has pointed out, many of our clinical approaches to psychosis seem to have been designed 'to allow the rest of us to avoid having to deal with these persons' humanity – that is, their subjective experience of psychosis and its effect on us.' Mosher suggests that this may reflect a fear of the unknown and the unpredictable, as well as our own fear of our own 'disintegration'. Searles (1961) made a similar point when he suggested that working clinically with psychotic patients may induce intense anxiety in the therapist (resulting from a fear of change) and may lead to a tendency to avoid aspects of the experience. This tendency to avoid coming close to the subjective experience of psychosis is likely to prove an obstacle in implementing some of the implications from the present research. Clinicians may also share some of the prejudices and fears held by the general public (chapter 5), which could also contribute to avoid working with this client group. Strategies for overcoming such obstacles may include destigmatisation campaigns (chapter 5) which help to portray those who experience psychosis in a more positive and less threatening light, to counter the negative stereotypes often perpetrated in the media.

11.8.2 Financial

There are also financial obstacles to the implementation of some of the implications from this research. This applies in particular to the clinical implications. The bulk of clinical services for those who experience psychosis depend on public funding for their survival. This, inevitably, imposes limits on the kinds of services which will be funded. The provision of services which provide clients with opportunities to explore the meaning of their experience in the context of a reliable and enduring relationship with appropriate clinicians is a potentially costly exercise. Tackling this issue may require further research in this area, to evaluate the clinical utility of different clinical interventions. Such research may be helpful in lobbying for further funding for particular services. This raises the question of whether research funding is as readily forthcoming for this kind of investigation as it is, say, for drug-efficacy studies.

11.8.3 Political

There are also powerful political issues which provide significant obstacles to the implementation of some of the suggestions in this research. The contest for the meaning and control of schizophrenia takes place within a social environment where particular groups have strong interests in maintaining their positions within this context. Two such groups merit mention here: professional clinicians and the pharmaceutical industry.

Many of the implications from the present research revolve around clients of mental health services having greater say in the services they receive. This poses a threat to the position of professionals who have traditionally exercised control in this area. Implications from the present research point towards a redressing of the power imbalance that has existed between clinicians and consumers of mental health services. Resistance to this is likely from those who enjoy privileges under the current arrangement.

Another, perhaps even more powerful interest in maintaining the status quo, is identified by Mosher, Gosden and Beder (2004) and Sharfstein (2005), who have discussed the role of Big Pharma in mental health research and service provision. Implications from the present research, such as consumers having greater say in the services they receive, and providing services which are less medically oriented, pose a challenge to the dominance of the pharmaceutical industry. Similarly, in the area of changes in the kinds of services offered we may expect challenges. As noted by Holmes (2000):

> ‘resistance to the implementation of psychosocial interventions in schizophrenia arises in the context of a pharmaceutical industry which invests vast sums in order to influence doctors to prescribe its neuroleptic treatments’

Tackling both of these issues may involve political activity, supporting the role of the consumer moment in mental health and advocating for a greater role for consumers in mental health services (Chamberlin, 2004). Research such as the present study shows clearly that users of mental health services who experience psychosis are keen to have an active say in understanding and tackling psychosis, and that they have much to offer these endeavours.

11.9 Conclusions

To conclude, I would like to share my own personal reflections on the research presented here and to point out what I see as the most significant findings. Firstly, I would like to note the great sense of privilege I feel at having been privy to the precious stories that participants in this research shared with me. This is an aspect of my day-to-day role as a clinician which the present research highlighted for me. The process of analysing the interviews in such depth, which clinicians can never do on a regular basis due to the time commitments involved, allowed me to appreciate more fully the richness of the material that is shared between client and clinician on a daily basis.

The most significant findings from the present research relate to theoretical and empirical matters. Theoretically, the notion that schizophrenia, psychosis, or madness (however we choose to refer to these experiences) may be thought of as an ‘essentially contested concept’ is an indirect product of this research project, emerging from my immersion in both the literature and in participants’ stories. I believe that this is a new way of conceptualising madness which could have far-reaching implications for our thinking and our research in this field. One such implication is that this potentially opens a door for those who have such experiences to contribute more fully to discussions around the nature of madness and how best we might respond to those who find themselves troubled by such experiences.

Regarding the empirical findings of this research, it is the clinical implications that I see as being of most significance. The present research indicates convincingly that those who experience psychosis can provide coherent and perceptive accounts of their experience, and therefore have a unique contribution to make to our understandings of psychosis. Further, clients being given the opportunity to make their own personal accounts a central aspect (perhaps *the* central aspect) of their involvement with mental health services is, for certain clients at least, an important factor which could have major ramifications for clinical care. I believe also that the three theoretical constructs (fragmentation – integration; invalidation – validation; spirituality) could prove very useful for both clinicians and clients in allowing an understanding of processes which may be implicated in the client’s experience. Certainly, I can state that on a personal level, I find these constructs helpful in my own efforts at navigating the stories that clients continue to tell me. We should not lose sight of the fact that psychotic experiences can be bizarre and distressing (as well as occasionally dangerous). The need for helpful ways of construing these experiences is therefore of paramount importance. I believe that the three theoretical constructs which emerged from this research may provide useful guidelines for making sense of these experiences.

As well as providing a loose map for understanding the experiences, I hope that these constructs can, as they have for me, lead to new ways of working clinically with those who experience psychosis, which helps clinicians and clients work more fruitfully together in tackling these, at times, confusing and distressing aspects of what it is to be human.

Appendix 1: Participant Information Sheet

HOW PEOPLE UNDERSTAND THEIR EXPERIENCE OF A FIRST PSYCHOTIC EPISODE

A STUDY BY JIM GEEKIE,
CLINICAL PSYCHOLOGIST, ***** CMHC

(SUPERVISED BY DR JOHN READ, DEPARTMENT OF PSYCHOLOGY, UNIVERSITY OF AUCKLAND, AND DR NICK ARGYLE, CLINICAL DIRECTOR, MENTAL HEALTH, AUCKLAND HEALTHCARE SERVICES)

INFORMATION SHEET

I would like to invite you to take part in a study into how it is that people who have had a psychotic episode understand or make sense of this experience.

WHAT IS THE STUDY?

The study is a PhD project concerned with the way in which patients understand their own experiences of what mental health workers sometimes call ‘psychosis’. Often, the patient’s understanding of his or her experience is a part of health care that is overlooked and I would like to develop my understanding of this important aspect of a person’s experience.

WHO IS RUNNING IT?

The study is being run by Jim Geekie, who is the clinical psychologist working with the ****** First Episode Psychosis Team. The project is being supervised by Dr John Read, who is a senior lecturer in psychology at the University of Auckland, and by Dr Nick Argyle, who is the Clinical Director for Mental Health Services for Auckland Healthcare Services.

WHAT WOULD BE INVOLVED?

As part of the work we do together in our psychology sessions, it is usual for me to speak with patients about how they understand their experience of psychosis. What I would like to do, is to make an audio (sound only, not video) recording these parts of our discussions, so that I can look more closely at the recordings later. This might mean that we record part, or all, of some of our sessions together. It is difficult to know exactly how many sessions this will be as that will depend on how useful you find it to talk about this.

I will discuss my interpretations of the recordings with you to check that I have understood properly. As the study goes on I will be happy to discuss my findings with you. I will also invite you to give me some feedback on my findings. At the end of the study I will send you a summary of my findings.

HOW WILL INFORMATION BE USED?

The information from the tape recordings I make will be kept secure then typed up to help me analyse them. I will interview a number of patients, then look at the different interviews to see if I can find some common ways in which people make sense of their experiences of psychosis. Of course, the information you give me will be *confidential* and only I (or other members of the First Episode Team, if it is important to your care), and the supervisors of this research will have access to it. Consent forms and tapes will be stored in locked cabinets. I will not put your name on the tape, but will use an identification number instead. I hope to publish the findings in scientific journals, though I will make sure that no information which could personally identify you will be used in any reports of this study. If you wish, you may have your tape when I have typed it up and a summary of the findings when the study is completed..

YOU DO NOT HAVE TO TAKE PART

This is an invitation to take part in this study. Your participation is entirely voluntary (your choice). **You do not have to take part in this study**. If you chose not to take part you will receive the usual care from the First Episode Psychosis team, including me as your psychologist. There may be any number of reasons you may have for not taking part. I understand this and I won't want to know your reason/s for choosing not to participate.

If you do agree to take part you are free to withdraw from the study at any time, without having to give a reason. This will in no way affect your care from the First Episode Psychosis team, and I will continue to work with you as your psychologist.

ANY QUESTIONS?

If you have any questions you would like to ask, I would be happy to answer them, or to discuss this study with you. You can call me (Jim Geekie) on 846-4116. This study has received ethical approval from the Health Funding Authority (Northern) Ethics Committee. If you have any queries or concerns about your rights as a participant in this study you may wish to contact a Health Advocates Trust, telephone 0800 205 555.

PEOPLE YOU CAN CONTACT IF YOU HAVE ANY QUESTIONS OR CONCERNS:

Jim Geekie, Main Researcher and Clinical Psychologist. Phone 09 846 4116
Dr John Read, Senior Lecturer, University of Auckland, Phone 09 373 7599 ext 5011
Dr Nick Argyle, Clinical Director, Auckland Healthcare Services Phone 09 623 4646
Dr Graham Vaughn, Head of Department, Department of Psychology, University of Auckland Phone 09 373 7599 ext 8557

Appendix 2: Consent Form

CONSENT FORM

Title of study: How People Understand their Experience of a First Psychotic Episode

Principal Investigator: Jim Geekie. Contact phone: (09) 846-4116

Name of participant: ______________________________________

English	I wish to have an interpreter.	Yes	No
Maori	E hiahia ana ahau ki tetahi tangata hei korero Maori ki ahau.	Ae	Kao
Samoan	Oute mana’o e iai se fa’amatala upu.	Ioe	Leai
Tongan	‘Oku fiema’u ha fakatonulea.	Io	Ikai
Cook Islai	Ka inangaro au i tetai tangata uri reo.	Ae	Kare
Niuean	Fia manako au ke fakaaoga e tagata fakahokohoko vagahau.	E	Nakai

I have read and I understand the information sheet for volunteers taking part in this study of people’s experiences of first time psychotic episodes. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given. I understand that taking part in this study is voluntary (my choice), that I may withdraw from the study at any time and this will in no way affect my continuing 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 whom to contact if I have any questions about the study.

I consent to my interview being audio-taped. YES / NO

I wish to receive a summary of the results. YES / NO

I wish to receive the audio tape of session. YES / NO

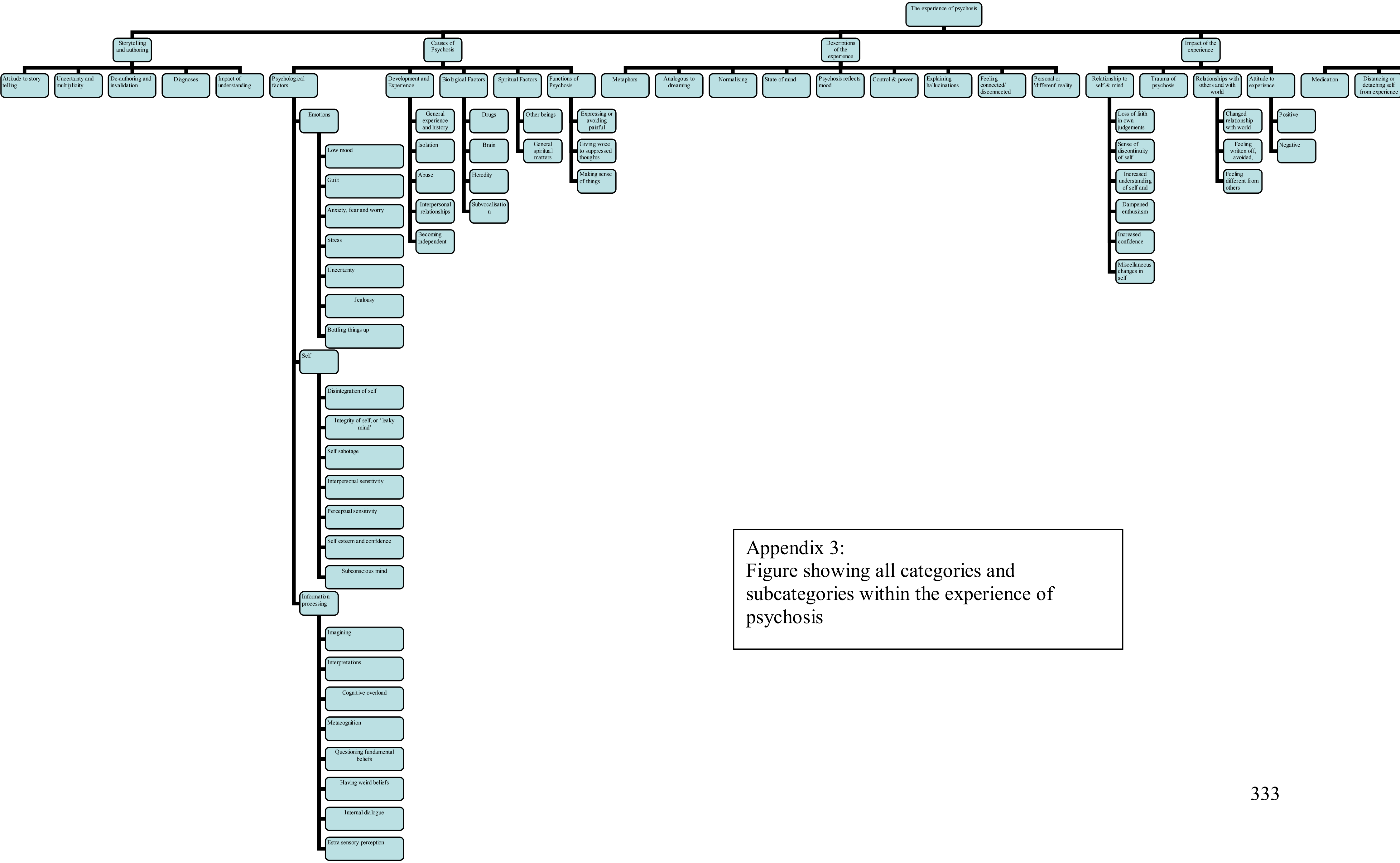
I, ____ (full name) hereby consent to take part in this study.

Date: _____/_____/_____

Project explained by __ ____

Project role ____

Signature ____ Date ___/___/___



Appendix 3:
Figure showing all categories and subcategories within the experience of psychosis

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