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GROWING UP WITH A HIDDEN DISORDER:
AN ETHNOGRAPHY OF THE METABOLIC CONDITION
MCADD IN NEW ZEALAND

Pauline Herbst

Abstract

Medium chain acyl-CoA dehydrogenase deficiency (MCADD) is an inborn error of metabolism that was included in newborn screening programmes in New Zealand in 2006. Before this time, one in four undiagnosed babies died because the enzyme to metabolise fat was missing or damaged. Once diagnosed, children may never become symptomatic due to ongoing treatment, which is as simple, and as complicated as eating regularly. Childhood illnesses that cause vomiting, high fever or loss of appetite necessitate hospitalisation until the child is well again. Although studies have assessed the impact on families immediately after MCADD diagnosis, less attention has been paid to the effect on children’s developing personhood. This nationwide New Zealand study examines the daily lived experience of the first generation of children to be diagnosed with MCADD via newborn screening and uses a variety of methods to capture children’s perspectives across the age range, from newborn to age 10, along with those of family members and health professionals. These methods include participant observation, semi-structured interviews, photovoice, metaphor sort technique, body mapping, and storyboarding. Drawing on Bourdieu’s concept of habitus I show that a body diagnosed with the potential for illness has as much capacity to transform a young life as illness itself. The diagnosis creates a medicalised body in need of preventative treatment, while outpatient clinics and hospital admissions help construct the impression of a pathologised body. This thesis finds that personhood, as embodied and situated, is affected by the experiential, sensory knowledge of MCADD treatment (feeding and hospitalisation) in the first few years of life and that a shadow habitus remains even after moving through this phase of early prevention. The thesis structure itself reveals the shifting and elusive nature of the porous boundaries between illness, health and dis-ease, circling through a variety of situated perspectives and modes of storytelling.

Keywords: metabolic disorders, habitus, personhood, children, New Zealand, embodiment
Acknowledgements

Caminante, no hay camino,
se hace camino al andar.

Wanderer, there is no path,
the path is made by walking.

Antonia Machado

These lines have been tacked up on a map of New Zealand, my field site, for the duration of this study. For me, this poem encapsulated the fine level of detail that you need to undertake with fieldwork, and that writing up ethnography, despite or perhaps because of its methodological and theoretical underpinnings, can only be done step by step, word by word. I think by writing. And once written, thoughts are shared and circulated, feedback is given, and the work gets stronger and more robust over multiple drafts. Like any pilgrimage, any rite of passage, I was guided on the route — this is not a journey that a single person can take credit for.

First, I would like to thank the families and medical professionals that participated in this project and shared their knowledge and experiences with me. While I am unable to name many for reasons of privacy, I am grateful to them for welcoming me into their homes, lives and practices. Some have become firm friends and I treasure the memories of our work together. This research would not have been possible without the gracious help of the team at Starship Metabolic Services. While some would prefer to remain anonymous I would like to thank Callum Wilson and Emma Glamuzina for their insights and for their assistance at the crucial early stages of this research. Bec Nicol was integral to helping me navigate the intricacies of the health system services, thank you.

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it takes today. More than that, they imparted valuable lessons on collegiality and scholarship through impeccable example. I cannot thank them enough for their time, thoughtful oversight and wise words. Any errors or omissions are my own.

Towards the end of the thesis, I was fortunate enough to obtain a Medical Anthropology Fellowship at the Institute of Innovation + Improvement (i3) at Waitemata District Health Board. The i3 was generous in its support of my professional development, and allowed me time to work on the final stages of the thesis. The experience of working within the health system also honed my thinking about chronic illness and the work medical professionals and anthropologists do in this area.

My doctoral studies have been financially supported by the Auckland Medical Aid Trust (AMAT), an AMP National Scholarship, the Elizabeth Ewing Memorial Scholarship in Adolescent and Young Adult Health, and the University of Auckland. Thank you to artists William Calleja and Daniele Sapuppo, who illustrated the comic in Part III, and Tim Mackrell who helped photograph the children’s body mapping exercises.

Writing is done in isolation for the most part, but it also benefits from the support of other writers, thinkers and places dedicated and protected for writing, away from daily life. The importance of writing groups and writing retreats cannot be underestimated. I am indebted to many people for providing a quiet space in their homes for the final stages of writing: Jeannie McLean and Steve Bovaird’s tranquil home, a stone’s throw from a yoga studio; and Judy Huntsman, in her attic lined with knowledge. I also valued the mentorship and time spent at the University of Auckland Faculty of Arts Writing and Research retreat in Ngaruawahia and with Julie Bhosale at her retreat in Matakana. Writing groups that provided stimulating debate and companionship at various points included the University of Auckland Anthropology Postgraduate Writing Group, the Audacious Rogues and the Virtual SUAW - Parents Edition.
It takes a village to raise a child: in this case there were two children plus a thesis and I am extremely grateful for the unwavering support and assistance given by numerous friends and family; in particular Wunmun Harman for her unwavering friendship and baking, my parents Karin and David Herbst, Elaine and Robert Elmer-English, Tamsyn Almond, Bryan and Bridget Robbins, Vanessa and Alex Filkin, Anya Xia and Kori Follas. I consider myself fortunate to have a compassionate and generous network of friends and I apologise to those I have left out; you are too numerous to list and you have all made a difference in so many ways. Lynda Wackrow and staff of Gulf Harbour Preschool went above and beyond, particularly in the early phases of this research.

Finally and most importantly I would like to thank my husband Richard Elmer-English and children Sinjin and Paige; for supporting this mammoth endeavour that eclipsed many hours of family time, for distracting me when needed, and for reminding me that families are what this research is all about.

This thesis is dedicated to Julie Park.

Caminante no hay camino
sino estelas en la mar.

Wanderer, there is no way
Only wake-trails on the waters.

Antonia Machado
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Glossary

CF  Cystic Fibrosis
CVS  Chorionic Villi Sampling
Drip   A synonym for IV, often used by children and families
ED   Emergency Department
IV   Intravenous, usually used to refer to a catheter
kapa haka  A group which performs traditional Maori dancing and chanting
luer  Staff and families when referring to an intravenous catheter, which is inserted into a vein to administer fluids or medication.
MCADD  Medium chain acyl-CoA dehydrogenase deficiency
MST  Metaphor Sort Technique
NICU  Neonatal Intensive Care Unit
OE  Overseas Experience
PKU  Phenylketonuria
PART I:

HOW DIAGNOSIS CONSTRUCTS MCADD
Diagnosis:
Medium chain acyl-CoA dehydrogenase deficiency [MCADD]

Thank you for coming to see us in the Paediatric Metabolic clinic today to discuss the recent diagnosis of your daughter of MCADD. As we discussed the level on the newborn screening Guthrie card showed significant elevation of the acylcarnitine profile with a C8 of 36.39 (normal range 0 - 0.99) with a C10 of 2.96 (0 - 0.99), these results are highly suggestive of MCADD and we repeated these investigations today.

I understand Lola is your first child. She was born after a normal pregnancy but a complicated delivery with failure to progress thus leading to an emergency caesarean section. She weighed 4370gm at birth. Her Apgars were 9 and 10. She was initially well but there were problems establishing feeding and on Day 2 - 3 she was very unhappy and reluctant to feed and was crying a lot. She seemed irritable. She was weighed, I think around Day 4 and it appeared she had lost 10% of her birth weight. She was given some top-up feeds when she was transferred through to Children's Hospital. From Day 5 onwards she started gaining some weight. She is now 9-days of age and is feeding very well. You Wendy have got a very good milk supply and Lola has well and truly got the 'hang of feeding'. She is feeding on demand 2-6 hourly.

You are unrelated. There is no family history of note. We went on to discuss what MCADD is. We talked about how the energy our bodies are using is usually from the food that we have just eaten and when that food runs out we get hungry and we eat again. If we skip a meal or starve for any period of time we firstly use our glycogen stores and then after a few hours we start using our fat stores. People with MCAD deficiency have a relative inability to use the fat stores as a form of energy during periods of starvation. Thus people with MCADD when they are starved, which during childhood is usually during an infection, can become hypoglycaemic and unconscious, and if left alone long enough can eventually die from the condition. The treatment of MCAD deficiency is to prevent starvation. The basic rule is to never go to bed at night without food in your tummy and this is especially important when children are unwell and especially when they have gastrointestinal vomiting and diarrhoea like illnesses.

We thus recommend that all children with MCADD should be fed at least 6-hourly up until 6-months of age and then from 6 - 12 months they can fast overnight for 1-hour per month of age ie a 9-month-old child could fast for 9-hours and a 12-month-old child could fast for 12-hours. After this age we should never fast for more than 12-hours. These rules however only apply when children are well and do not apply when they are unwell. By unwell I mean fevers, vomiting, diarrhoea etc. If the child has just a bit of a mucky nose but is essentially well you can treat them as more or less normal.

Another general rule is, that if a child has one vomit you should observe and feed again and if they have two vomits then you should bring them into hospital. Obviously if there were any concerns we would like you to contact us by phone.

We discussed how some children with MCADD can become low in their carnitine levels. Carnitine is a form of a vitamin which is required for fat metabolism and if you become low in carnitine as well as having MCADD it can be particularly concerning. Thus we regularly measure carnitine levels and if they are low we supplement carnitine.
We then went on to briefly discuss autosomal recessive inheritance and how you are both carriers for the faulty MCADD gene and by chance have both passed on this faulty gene to Lola. I explained how with further children you will have a 1 in 4 chance of having another child with MCADD. We very briefly discussed forms of pre-natal diagnosis such as chorionic villus sampling or pre-implantation diagnosis and I suggest that if you wanted to talk about this further I would refer you for formal genetic counselling.

You both seem to have an excellent understanding of the condition having a previous background knowledge of biochemistry and having done some reading on the internet. We talked about how the prognosis of MCADD is excellent and we would expect Lola to grow up to be a normal, healthy girl and have a normal life-span. In general, patients with MCADD do not have any particular exercise intolerance.

We would not have any problems with Lola doing normal physical activities, playing sport etc but generally we recommend like in all children, that they should have a meal before they play sport and if the sport is any more than an hour or so's duration, they should have a supplementary drink throughout.

We explained how we will plan to see you in clinic in around a month's time.

Kind regards
Yours sincerely

Dr Petra McGowan - Metabolic Consultant
National Metabolic Service

This document was dictated and approved by the author

**Reason for Referral**
- vomiting - metabolic hx

**Diagnoses**
- **Primary Diagnosis**
  - Vomiting

- **Allergies**
  - NKDA. Allergies to dairy & egg.

**Clinical Management**
Patient not known to me, discharge summary completed from clinical notes.

**Background**
**MCADD**

Presented to CED with 1 day of vomiting and fevers and lethargy. 1 week history of cough and coryza.
On admission she was afebrile with obs in normal range, examination unremarkable, no obvious source of infection. Bloods showed mildly elevated neutrophils, otherwise normal. **MSU** negative. Blood cultures negative.

Admitted to the ward overnight for observation. Was improved symptomatically the following day, eating well with no further vomits. Parents confident to manage at home.

**Plan:**
- Discharged home
- Encourage oral intake
- Routine OPC followup

**Advice To GP**
Thank you for your ongoing care of this girl.

**Advice To Patient / Family**
We wish you all the best with your recovery.
Chapter 1:

Healthy but diseased – the framing of a genetic diagnosis

Illness is the story that results when an individual sees the interpretation [that the
doctor makes of their illness narrative] in terms of health and medicine. In contrast
diagnosis is the story of medicine, told in the language of disease. (Jutel 2011, 65)

The preceding clinic letters frame the start of this thesis; this is the material form of
Jutel’s “story of medicine”. The first letter details diagnosis of the metabolic disorder
medium-chain acyl-coA dehydrogenase deficiency (MCADD), the example used in this
study; the second, the hospital discharge of a child with MCADD. What do these letters
show? The child as a National Health Identity (NHI) number; a case, catalogued. The official
details of the disorder: the missing enzyme, management, risk. Later, the unspecified nature
of a hospital admission. It is a representation of Foucault’s (1994) clinical gaze at work, of a
biomedically oriented viewpoint that underpins the individual’s illness narrative. But in this
case, the diagnosis precedes the illness narrative. There are no symptoms to decipher and
decode, this is disease uncovered by a molecular lens after the routine screening most
children have at birth — before illness has manifested.

This thesis is an ethnography of life after this diagnosis of MCADD. It examines
whether individual personhood can be affected by the lived experience of a potential, future
illness; particularly one diagnosed at the start of life. I ask how these children’s health
identities are constructed after diagnosis, how this differs from family expectations prior to
diagnosis and what children’s narratives reveal about their understanding of their diagnosis.

MCADD is a compelling example as it is one of the metabolic disorders that is
biomedically presented as having the least impact on ‘normal’
life since the inclusion in the
expanded newborn screening programme: prior to diagnosis, a child has a 25 percent risk of
death, after diagnosis none, and all the child has to do is eat, as would any other child. I use Bourdieu’s (1977) concept of habitus to explore how MCADD is constructed to be embodied by diagnosed children as disease, and as illness, and how these are not experienced as discrete categories by children. I argue that the primary habitus in which food is a preventative, and the embodied, affective experience of being in hospital, construct the social and sensory experience of MCADD for these children.

To foreground this claim I first present the questions that shaped my investigation; second, I situate how MCADD has been understood and presented since its inclusion in expanded newborn screening programmes in New Zealand and other countries, and third, I outline competing definitions of ‘the child’ and what this means for one’s developing personhood. In addition to examining the lived experience of children with MCADD, I experiment with how to access that experience using a variety of methods and how to communicate that experience effectively. One of the aims of this thesis is therefore to theoretically explore ethnography as both method and practice, and the fourth part of this chapter speaks to a contemporary debate within anthropology as to the role of ethnography as more than method and how this work progresses that debate. I conclude with a structural examination of this text and show how the structure supports the claims of the thesis.

1.1 MCADD in Aotearoa and beyond

From the start of this research, I hoped to discover if and to what extent children diagnosed with MCADD shaped their developing sense of personhood and identity through an examination of how the child's own illness narrative and the narratives of parents and caregivers change from conception to pre-adulthood, (from urgent and life-threatening as an infant and child, to manageable with diet as they grow older). I aimed to use these results to examine the impact of diagnosis on the broader social understanding of genetic disorders and
expanded newborn screening. This study is consequently concerned with the stories described in Jutel’s extract at the start of this chapter, the shifting construction of MCADD and illness that is most illuminating in three areas: the spaces between home, clinic and hospital; over the developmental period of childhood; and during an episode of childhood illness. It asks how children growing up with these diagnoses experience these spaces and periods and is concerned with the shadows cast by stories of illness and stories of medicine, especially where those intersect. It is also interested in silence and how the language of disease (like most languages) is not understood in the same way by all those who use it.

A series of questions shaped this study: what are children’s stories; how do children conceptualise, describe and redefine MCADD and how it affects them? What medical narratives do biomedical practitioners relay to parents or caregivers, how are these transformed as they are reconstructed by parents to tell to children and other parties, and how do children themselves interpret and retell the narratives of their disorder? How do children interact with and embody the technologies used in diagnosis and during hospitalisation? What explanatory models do these children use to understand MCADD? What expectations do parents have about their newborn prior to diagnosis and, in the case of those expecting a second child, how do assisted and new reproductive technologies (ARTs and NRTs) contribute to these expectations and the resulting decision-making? How is MCADD constructed at various stages of a child's life and in different contexts?

I wanted to discover whether these children identify with their disorder in the face of the trials of daily growing and living: asserting agency, negotiating peer relationships and the myriad ‘small battles’ they encounter every day; particularly in an age where difference can be highlighted and even celebrated. I also sought to discover what these answers can tell us about personhood in a future in which genetic testing and screening could identify some disorder or risk thereof in everyone?
This line of enquiry speaks to a debate within medical anthropology's subfield of the anthropology of reproduction that has critiqued the social consequences of postnatal biomedical testing, particularly the potential of genomics to reshape individual personhood in unintended or unforeseen ways (Lock et al. 2007, Novas and Rose 2000). To find the answers, I needed to first engage with how MCADD is presented as both ‘easily managed’ and ‘life-threatening’ and define what it means to be a child in the particular context of New Zealand and the New Zealand health system. This study starts at that point, applying the body of social knowledge about genetic disorders such as PKU and cystic fibrosis to the relatively understudied group of fatty oxidation disorders, specifically MCADD. As one of the more common rare disorders to be diagnosed since expanded newborn screening, this condition has been addressed in the medical literature in a variety of ways: to advocate for its inclusion in newborn screening (Wilson et al. 2007); to report on the success of this inclusion (which one presumes is necessary for continued funding) (Kennedy et al. 2010; Wilson et al. 2016); and to add to the nuances known about the condition and what makes or does not make a positive diagnosis (Grob 2006, 2011; Raspberry and Skinner 2007). As MCADD is easily managed, from a medical perspective, with a normal healthy diet, it hovers in a liminal state. So long as a child is eating and is well, they are seemingly at no more risk than any other child. The social consequences of MCADD are mentioned in the work Mara Buchbinder and Stephen Timmermans have contributed on newborn screening (Timmermans and Buchbinder 2013a, 2013b): the interpretive work and diagnostic uncertainty involved in establishing a diagnosis of “classic” MCADD (Timmermans and Buchbinder 2010); and parental anxiety around the threat of disease (Buchbinder and Timmermans 2011). The social impact of diagnosis is addressed mainly in terms of false positives or negatives and the effect on families (Grob 2006, 2011; Raspberry and Skinner 2007) but there appears to be a dearth of ethnographic
data on the lived experience of MCADD post newborn screening, an experience that starts with the diagnostic letter.

The black letters on the white page enfold nuances of grey that hide the concern medical specialists have with phrasing and tone, their fervent wish to ‘do no harm’ as they give advice on preventative strategies for a condition that could have no obvious impact on a child or could result in sudden death. Medical specialists also consider the potential harm a diagnosis could have in the form of potential anxieties and behavioural issues around eating, or a prolonged impact on family life.

The fact remains that the diagnosis does save lives. Without screening, approximately 25 percent of MCADD cases die from the disorder during the first clinical presentation, which usually occurs in the first three years of life (Kennedy et al. 2010; Wilson et al. 2007, 5). The aim of screening is to detect newborns with this (and other) disorders and treat them before symptoms develop. In the case of MCADD, this includes providing parents with guidance on appropriate feeding management and treatment. Specifically, the necessary enzyme required to break down medium chain fats to create energy is either missing or damaged. Practically this means that not eating for more than a few hours in those first precarious few months of life could lead to what is termed a metabolic crisis, leading to life-threatening complications and/or death (Ministry of Health 2010a, 5; Wilson et al. 2007). For the rest of these children’s lives, the implications for daily living are that they should not go for more than 12 hours without food. This simple-sounding rule however is complicated by their health; it is predicated upon an absence of fever, gastroenteritis, or anything that might interfere with their appetite or energy consumption. These then, are children at-risk.

Molecular genetics are shaping and mutating the very concept of personhood, creating new subjects and “re-shap[ing] the ways in which we are governed, and the ways in which we govern ourselves” (Novas and Rose 2000, 486). Novas and Rose specifically include people
identified as at-risk, maintaining that these genetic forms of personhood alter individuals’ health identities to those that “construct the subject as autonomous, prudent, responsible and self-actualizing” (Novas and Rose 2000, 507). Once identified post-screening as at risk for a particular genetic disorder, individuals are expected to manage that risk, not only for their own health but for the burden ill health could bear on family and the health system at large. Children identified as more than at-risk, born with confirmed genetic disorders, must also manage this risk as their condition is normalised and framed according to a new perception of normal.

From the moment of birth (and sometimes prior), children diagnosed with MCADD are constructed at a molecular level; from birth their health identity and daily practice is linked to their genetic diagnosis. The enhanced newborn screening test, otherwise known as the heel prick test or Guthrie Test, comes at the end of a raft of technologies encountered by the new life, including anatomy screens, blood and urine tests and potentially chorionic villus sampling (CVS) or amniocentesis. The Guthrie Test has been conducted in New Zealand since 1969, and currently screens for 28 metabolic disorders (www.nsu.govt.nz/health-professionals/1012.aspx), including Phenylketonuria (PKU), one of 14 amino acid disorders screened; and cystic fibrosis (CF). Inborn genetic metabolic disorders currently affect approximately 700 families in New Zealand. Only in 2006 was screening extended to the group of nine fatty acid oxidation disorders (FODs), which includes MCADD and have an incidence rate of approximately 1 in 12,000 (National Screening Unit 2017). As outlined by scholars (Buchbinder and Timmermans 2011; Grob 2006, 2008; Landsman 1998, 2009), we live in an age where after this barrage of technological intervention, parents expect the birth of a ‘normal’ or ‘perfect’ child. Instead, some receive a letter with the results from a test they may have already forgotten during the first exciting weeks of caring for a newborn who presents such time-consuming, all-encompassing rewards and challenges. Many of the plans
parents may have made for their expected child are now viewed and modified through the lens of disorder.

A positive result re-identifies a child according to her genetic result; and is a shock for parents who are confronted with a changeling, the ‘Other’ in the place of their ‘perfect’ child. This impact has been well documented in earlier studies (Buchbinder and Timmermans 2011; Fitzgerald 2008; Grob 2006, 2008; Landsman 1998; Layne 1996). Parents cope with a remaking of their own identity, and their no longer perfect child's identity through a variety of strategies, one of which is the recreation and control of the experience through stories (Frank 1997, 2009; Kleinman 1988; Mattingly and Garro 2000). These stories are then abridged and narrated to the children to explain their condition and ensure they comply with medical instructions. However these stories do not necessarily strive for authenticity; parents will tell their children they must eat for multiple reasons, but most do not openly reveal that if they do not, they could die.

Anthropologists have examined the social impact of genetic metabolic disorders on the parents of children diagnosed with PKU and cystic fibrosis; what resources they harness to manage this impact; and the lived experience of adults living with disease (Ablon 1984, 1998; Fitzgerald 2008; Frank, Fitzgerald and Legge 2007; Legge and Fitzgerald 2007; Nagy and Ungerer 1990; Raspberry and Skinner 2007). Bluebond-Langner (1978) was a pioneer in her child-centred research with children suffering from cancer (Bluebond-Langner, Perkel, and Goertzel 1991; Bluebond-Langner and Korbin 2007) and with the well siblings of children diagnosed with cystic fibrosis (Bluebond-Langner 1996; Bluebond-Langner, Lask, and Angst 2001). These post-diagnostic ethnographies that I have cited have mostly examined the daily lived experience of metabolic conditions in different institutional settings through the gazes of medical specialists, parents and siblings. This study includes these gazes
but also incorporates the lived experience of the young participant, the child. But what is meant by ‘the child’?

1.2 The framing of the child in relation to chronic illness

Within the parameters of ‘childhood’, the term child can be used to express the varying theories and models of childhood and can be used to signify a foetus, a newborn, an infant or baby, toddler, 'child' and teenager. Depending on cultural frameworks, these categories are delineated by age, physical development like puberty (Hardman 1973), milestones such as walking and talking, and social events such as a naming ritual or achievement of personhood. Gottlieb writes about the “dominant secular [age-focused] Western model”.

This 'rounding up' is not a biological certainty but a cultural convention premised on the Western calendar. The pinpointing of two years as the end of ‘infancy’ is also premised on a cultural assumption that life stage ought to be defined by reference to absolute time spans rather than say, to shifting activities. (Gottlieb 2000, 123)

As this research is based in New Zealand and relies to some extent on hospital and clinic data it makes sense to draw upon accepted norms. Organisations, such as Plunket, which focuses on child wellbeing before the age of five, directly relate to how ‘children’ are categorised. Established age categories are vital to understand in terms of hospital services and the transition to later 'adult' services. The World Health Organisation's categorisation of children and adolescents is also influential. For the purposes of this research ‘infants’ and ‘young children’ are those up to the age of two whose parents share their role as patient. ‘Children’ are split into two research groups aged two to five (the period before entering primary school) and five to 10 (primary school).² As expanded screening was only initiated in 2006, participants were within these age groups at the start of the study.
The research data shows that the explanatory models that these children use are primarily embodied sensory and emotional models relating to the consumption of food and drink (daily preventative) and the experience of childhood illnesses that result in hospital admissions (escalated preventative). Table 1.1 illustrates the treatment or preventative measures that are taken depending on the child’s health that feed into these models.

<table>
<thead>
<tr>
<th>HEALTH</th>
<th>PREVENTATIVE MEASURE</th>
<th>FREQUENCY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well</td>
<td>Regular meals as part of a ‘normal, healthy’ diet; do not fast for more than 12 hours (over 1 year of age)</td>
<td>Daily</td>
</tr>
<tr>
<td>Unwell</td>
<td>Polycal Emergency Regimen drinks at home until eating and drinking normally</td>
<td>Every 15 minutes or 2 hourly</td>
</tr>
<tr>
<td>Persistent vomiting and diarrhoea, lethargy</td>
<td>Low threshold for hospitalisation: • nasal gastric tube • intravenous of dextrose until eating and drinking normally</td>
<td>Continual. IV line replaced within an hour if it comes out</td>
</tr>
</tbody>
</table>

Table 1.1 Progression of preventative measures to stop MCADD from presenting

Jutel (2011, 65) labels diagnosis the “fulcrum of the medical narrative” and the narratives and preventative measures described above derive from this diagnosis. As Armstrong (1995, 402) states: “The screening of surveillance medicine extends the diagnostic power to a space before disease. The risk factors are ‘pointers to a potential, yet unformed, eventuality’” however in the case of MCADD the space exists between disease and risk. The unformed eventuality is that the symptoms of the disease cause organ damage or death, this is a potential but by no means a certainty, particularly if management is followed.3

The first confirmed case of MCADD picked up after the expansion of the newborn screening programme in 2006 was in May 2007 (Wilson, personal correspondence 2017). By the time this research started in 2013 there were 34 children in New Zealand who had been identified. The majority of these had been picked up by screening, with four older siblings discovered after a newborn’s diagnosis. Two had moved here from another country. By 2017, there were “54 children and four adults with MCADD, one being diagnosed this week, one or
two you could argue if it’s MCADD or not” (Wilson, personal correspondence, March 2017), living in New Zealand under the care of the Metabolic Services Team.

What has emerged as these numbers increase is the shifting, fluid nature of diagnosis and the construction of disease as medical professionals globally discover more about MCADD. Black (2000) cautions against unnecessary screening or overdiagnosis, however in this study, specialists were highly conscious of the potential for both and factored this in to their diagnoses. If, as Jutel (2011) maintains, diagnosis is a result of the merging and juxtaposition of doctor and patient narratives, then in the case of MCADD, there is a breach in the expected order of the biomedical encounter that causes uncertainty and frustration. Unless an infant is already showing signs of deterioration, there is no initial patient narrative to weave with that of the clinician to create a diagnosis. Diagnosis is presented, post screening, as an uncertain genetic certainty; the child has MCADD but to what extent this will impact on the child and her family’s daily lived experience is unknown. The story that is woven is the story of risk, and to what extent a child’s life may be at stake as specialists seek to reassure and assess childhood illnesses as normal and parents seek to explain, based on their own observations and personal experience of illness in their children, how the abnormalities in the presentation of these illnesses could be an indication of the disease.

Parent-patients believe in the power of diagnosis, they have internalised a belief in the power of medical authority based on previous interactions and socialisation within the health system and then are jarred, unsettled, when told to ignore it so long as management is followed. The normal order of things, where illness narratives form the starting point for a diagnosis negotiated between patient and doctor, is overturned. Illness as the personal experience of sickness is kept separate from the biological disease: compartmentalised. As shown by the hospital discharge letter, MCADD as disease is not permitted to cause illness; the personal experience of sickness is attributed to other, unidentified causes such as viruses.
The second breach in the expected order of the biomedical encounter is the experience of the clinic. Rather than exploring narratives to come to a diagnosis, the assumption is that the link between signifier and disease is known; the aim is to prevent symptoms. A common criticism of biomedicines made by medical anthropologists is that doctors seek to treat the disease not the patient but this ethnography shows specialists are trying to ensure the patient is looked after by transferring responsibility to both the parent and patient, a New Zealand practice (Trnka 2017b). However, as my research revealed, the structures in place do not entirely support them in this endeavour.

Pertinent to this understanding is an analysis of how disorders and embodied difference are framed and what this contributes to the discussion on bioethics and the ‘new’ ethics of life for which the Bourdieusian concept of habitus could be useful. Disability studies have sought to theorise the normal/abnormal dichotomy and look at impairment and difference as “one form of variation among humans” (Scully 2008a, 3. See also Ablon 1984, 1988; Battles and Manderson 2008; Ingstad and Whyte 1995, 1997; Shuttleworth and Kasnitz 2004). It is useful to consider and apply some of the theoretical frameworks and questions asked within these studies, starting with the unavoidable negativity of the prefix dis-order and how this could lead to an examination of identity.

As Scully asks:

Bioethics has… failed to address… crucial questions about the ontological and moral character of bodily variation. Can this form of embodiment be considered an identity, a way of being? Can it be a desirable way of being… when and how [does] variation become[s] impairment or disabling, and why [does] it matter[?] (2008a, 4)

Personhood5 is a social creation, denoted by signs and symbols, and tied to historical and social forces (Comaroff and Comaroff 2012). The molecular vision of life has led to a debate about selfhood becoming increasingly somatic, while acknowledging that genetic identity is only one aspect of personhood; personhood cannot be reduced to genetic identity (Lock et al.
2007; Lock and Nguyen 2010; Novas and Rose 2000; Rose 2001, 20). As Novas and Rose describe this:

The birth of the individual ‘genetically at risk’ has to be understood as one dimension of a wider mutation in personhood that we term ‘somatic individuality’ - in which new and direct relations are established between body and self. (Novas and Rose 2000, 487)

This debate and others about the relationship between the social and the biological child diagnosed with a genetic disorder (i.e. viewed through a molecular lens) fall under a discussion about what constitutes the “new ethics of life” (Novas and Rose, 2000) or “vital politics” (Rose 2001, 20). To negotiate between the two frameworks of biological or genetic reductionism and a postmodernist “self as constructed in the course of social interactions that inscribe identities on bodies” (Scully 2008a, 6) I will be drawing on Bourdieu’s theory of habitus to argue that how children diagnosed with MCADD see themselves develops within the constraints of habitus, daily behaviour radiating around food practices shaped by the genetic diagnosis.

The ways that diagnosed children and their families respond to the diagnosis reveal the unintended consequences of the expansion of newborn screening, adding to broader discussions about the role diagnosis plays in preventative medicine. These include the potential for the medicalisation of food and increased anxiety around breast feeding. As newborn screening affects infants, studies have examined how families make and remake their social worlds when disrupted by potential illness but few have accessed the child’s point of view. This study makes a contribution to the literature on childhood chronic illness, and shows that growing up with an existing diagnosis of chronic illness sets up a primary habitus aimed at preventing serious consequences from the condition, which in the case of MCADD is rapid progression to encephalopathy, seizures, coma or death after fasting (Gartner,
McGuire, and Lee (2015). This habitus has life saving attributes but has the potential to create anxiety around eating and fear of common childhood illness such as gastroenteritis.

While MCADD is chronic, patients tend to experience acute episodes of gastroenteritis and other illnesses that bring the metabolic condition to prominence. From the patient perspective, MCADD is the reason for hospitalisation; from the biomedical perspective (as seen in the example discharge letter), a suspected virus is the reason. Smith-Morris credits Estroff (1981, 1995) with challenging medical anthropologists to move from a biomedical understanding of chronic disease to one defined more by the identity of the sufferer, where “chronic disease becomes chronicity” (2010, 24).

Chronicity is a process through which almost any patient may pass, regardless of the diagnostic label they carry. It is the process of identification with one's disease — the movement from having a disease to being a person inhabited by that disease. (Smith-Morris 2010, 25)

What are the implications of being “inhabited” by MCADD? If, as Frank (1997), Kaufman (1988, 1994), Mattingly (1994, 1998) and Smith-Morris (2010) maintain, that the return to continuity after the disruption of disease occurs not from healing or remission but from the creation of a new social identity, how does a child develop their personhood in the context of diagnosis?

Identification of this genetic disorder is life preserving but also creates a status of “patients-in-waiting inhabit(ing) a liminal state between sickness and health, or more specifically, between pathology and a state of normaley” (Timmermans and Buchbinder 2010, 409). Frank (1997) uses the term “remission society” to describe a similar state in cancer patients while Jutel (2011, 126) refers to the “person-as-well… whose wellness is refuted by objective findings”. The situation is further complicated as while some children are fairly quickly diagnosed as ‘classic MCADD’, others are borderline ‘at-risk’ yet are treated as if they have classic MCADD as a precaution. Thresholds as to what levels constitute a
diagnosis of ‘MCADD’ also change and each potential new diagnosis is carefully discussed and mediated before confirmation. My study extends the term “patients-in-waiting” from newborns waiting for a potential positive or negative diagnosis to those diagnosed with a fatty oxidation disorder (FOD). These children will always occupy a liminal state. They will always have the diagnosis and be taking measures not to present with a metabolic crisis due to another illness. They will always have to guard against a ‘shadow illness’ only visible using the tools of biomedical technology. The letters are therefore also a reference to medical uncertainty. Neither specialists nor parents know categorically how MCADD is affecting the diagnosed child, they can only take precautionary measures against the disorder clinically presenting by ensuring the child always has stores on board.

![Figure 1.3. The impact of the lack of the enzyme medium chain acyl-CoA dehydrogenase on the body](image)

If these infants are not fed regularly, they *could* die as illustrated in Figure 1.3. However, no one can say for certain that they *would* die if they fasted and since the newborn screening programme was extended to include MCADD in 2006, there has been a 100 percent survival rate (Wilson et al 2010; 2016). Child mortality is a sensitive topic in New
Zealand. The death of a child from illness is perceived to be particularly tragic and triggers a strong emotional response from not only those directly involved with the child but also wider society. However, medical professionals are trained to be objective, and to deal with tragic, very human events in a detached and objective way, through encasing the patient. This does not mean that they do not share in these human, emotive responses but that they have been taught to deal with them in particular ways (Foucault 1994). Parents, particularly mothers, respond to the responsibility of caring for a child with a chronic illness in different, socially mediated ways, and children too, apply their own meanings and understandings to a diagnosis. Trnka explains that:

One could argue that young children represent the outer limits of individualized, personal responsibility, as they simply cannot take care of themselves and thus represent the inherent need for collective interdependence…. The figure of the suffering child thus provides a powerful, emotive focal point for debates over the obligations of the state. (Trnka 2017b, 74)

How best to represent the intertwined, shifting concerns of these sometimes conflicting agendas? In the following section I argue for a multimodal form of ethnography that represents multiple viewpoints with greater accuracy.

1.3 Whose story? Ethnographic representation in a visual age

Increasingly anthropologists are acknowledging that it does not make intellectual sense to divorce affective considerations from our analyses when they are a key component of the experiences that form the bedrock of our understanding. (Gottlieb 2016, 101)

Anthropologists have long debated the politics of ethnographic representation, historical claims to objectivity and the validity of knowledge (Clifford and Marcus 1986, Vargas-Cetina 2013; Zenker and Kumoll 2010). In order to explore the layered narratives that make up this
ethnography and in an attempt to amplify the voice of participants, I have presented my argument in three parts, covering biomedical perspectives, the parents’ perspectives (whom I refer to as the ‘parent-patients’) and a move towards the perspectives of the child. These three components also incorporate time: the time that passes between meals, the temporal construction of biomedicine that moves through stages from diagnosis to treatment, and children’s development over time. The sensory experiences gained at each of these points in time is situational. The ensuing ‘stories of illness’ are about similar experiences but told from different viewpoints. Embodied meaning and narrative are created from the intersection of place and time. The body of a clinician during a hospitalisation is experiencing something quite different from the patient, or the worried parent watching over that patient. How to represent this in ethnography?

Each part is prefaced with a short vignette taken from my research notes which is intended to represent the voice and primary focus of the participant, and illustrate the socially constructed nature of illness. These vignettes are themselves constructs. I employ a technique used by other medical anthropologists (Bluebond-Langner 1978) to create composite characters from my case studies in order to protect the identity of my young participants, clinicians and the families involved. Part I, prefaced with clinical letters, develops the background of the argument; the history of the disorder, the New Zealand health system it is situated in, the literature that links to this, the expectations of parents prior to birth, and an overview of what is to come. I argue that although relatively infrequent when compared to daily treatment⁶, that hospitalisation is the end point which families paradoxically fear and appreciate.

Part II illustrates this with an excerpt from a mother’s diary that highlights the visceral experience and emotional toll of caring for a sick child: the sleepless nights leading up to hospitalisation, forcing a child to eat through various mechanisms, the worry, the call in the
early hours of the morning, the relationship stresses, and then, the admission. This comes with the feeling that the nurses are not really paying attention and being left for hours due to another emergency. It culminates in relief when you are finally able to go home coupled with worry that you could end up there the next night. Wolf (1992, 59–60) cautions against prioritising form over content and is concerned that the blurring of boundaries between fiction and ethnography could blur “the ethical assumptions of our craft, [leaving] our audience… to wonder whether we have in any particular instance sacrificed a set of observations in order to preserve a mood or enhance the plot”.

Much like others who advanced this discussion post-Wolf, I argue that preserving the mood, the sensory aspects of the ethnographic encounter is vital to presenting an authentic, self-reflexive picture of the encounter and that this can be used to enhance the nuances of analysis. As Csordas (1993), Narayan (2012) and Pink (2009) have all observed: we experience the research locale with our bodies and senses and this must be brought to our analysis and imparted to readers.

The early years of childhood thus form the focus as parents learn to navigate the care of a child with a metabolic disorder; a drama that is played out mostly within the home, in the small daily battles of lived experience and family learning as parents try to make the best moral decisions for their child’s future while coping with the trials of infancy. The diagnosis means they must learn a new language of biomedical terms, and to navigate the health care system and hospital geography. Sobo describes parents’ life courses when parenting children with special healthcare needs as “redirected… spatially dislocated… They seek to reconstitute themselves within the new landscape, and to equip themselves as best as they can to travel around it” (Sobo 2010, 228–229).

Part III is introduced by a graphic narrative, a comic, and has been modelled on the scripts my young participants developed during the research as well as participant observation
and in depth conversations. It analyses this question from the child’s point of view, looking at health identity and personhood and the visceral sensory and emotional experience of foodways, illness and hospitalisation. This is graphic anthropology, more than a “one-to-one translation of ethnographic field notes [but] a method for seeing and communicating relationships in the field” (McMullin 2018). The comic has been derived from participant observation with the children in this study, the stories they have created and the observations they have made. It touches on the key themes that the children brought up in discussions about MCADD and highlights the ambiguities inherent in discussing an invisible condition that even clinicians do not fully understand. The script was developed after extensive analysis and coding of field notes, and annotated with detailed art notes to enable an illustrator to draw the images.  

There is a small but growing body of multidisciplinary work around the genre of graphic medicine and its ability to analyse and communicate issues in illness, medicine, and disability and add to our understanding of “health.” Al-Jawad (2015, 372–373) argues (in graphic form) that comics can be used as a research method due to their ability to “unlock emotional responses to data,” promote reflective practice and “offer a resistance to the medical mainstream, an alternative ‘regard’”. McMullin (2016, 150) examines cancer autobiographical graphic narratives and situates these “as part of a medical imaginary (DelVecchio Good 2007) in the era of biomedicalization (Clarke et al. 2010)”. As she states, graphic narratives illustrate the everyday and although she is talking about cancer, the method can still be applied.

The illness experience is bound in the ordinary relations between objects (biomedical technologies) and people in the chronicity of interacting with health professionals, [metabolic specialists], and institutions who preserve life, and the… experience of… treatment. These relations become the illustrated aspect of the medical imaginary, generating assemblages of meaning and value. (McMullin 2016, 151)
Together, the three creative narratives further the anthropological endeavour; making sense of what makes us human. Parenting is a visceral, emotional experience; parenting a child with a life-threatening condition even more so. The daily experience of living with this condition for families is felt and sensed, strongly. There are no watercolour emotions when it comes to children or illness. The creative pieces are a way to bridge the gap between participant and reader, to short-circuit academic jargon and form a sensory link, emotion to emotion. This is not to say that theoretical considerations have been discarded. Far from it, this is intended as a critique on anthropological ways of writing culture, a critique spearheaded by Clifford and Marcus’ text (1986) that has been developed by writers such as Abu-Lughod (1993, 1999), Behar (1996), Dawson, Hockey, and Dawson (1997), Stoller (1989) and Van Maanen (2011). The vignettes are also intended to show how these perspectives are linked in a network, all with the same aim, to ensure the child has a healthy, full life. The vignettes illustrate that this particular disease is constructed and presented differently depending on the social context and the primary receiver of the narrative. Illness and foodways are culturally framed; both are necessary for the construction of MCADD and it is this that makes analysis so rich.

1.4 Thesis structure

The thesis is bookended by the biomedical, by the diagnostic construction of illness in Part I and the maintenance of this health identity in Part III. Part I of the thesis can be seen in much the same light as the diagnostic letter that prefaces it as it outlines the condition, introduces my research thesis and aims and provides a background pertinent to understanding the ethnographic narratives presented in Part II and III.

To discover how children with genetic disorders develop their personhood, and how they are shaping new ways of embodying diagnoses through their stories, the following
chapter examines ways in which the body has been constructed and debated within medical anthropology. I engage with four subfields of anthropology, the first of which is an examination of what sensory anthropology brings to an embodied ethnography of illness. The second highlights the usefulness of illness narratives as a theoretical framework to establish what the stories these children tell to describe and cope with their disorder, tells us about the development of their identity and sense of personhood. Third, I consider how genetic disorders, and the technology used in diagnosing and managing this disorder in particular, relates to identity formation in children. Fourth, I examine how childhood has been negotiated historically and as an anthropological concept. Chapter 3 introduces the site of this nationwide study, New Zealand, reflexively examines what it means to have a dual role as insider and outsider in a broad constructed community, and discusses methodology pertinent to this study.

Part II builds on this groundwork to show how the first year of life post diagnosis constructs MCADD in a relationship with two main themes: food and drink; and its association with illness. It describes the daily lived experience of food as experienced by families; how the child is being culturally positioned through food and eating, and how this positioning is foregrounded by the idea of risk.

Part III argues that this medicalised body is further pathologised and in Chapter 6 and 7, I argue that the habitus set up around foodways, the ‘place signals’ cast by the clinic and hospital and the sensory experience of hospitalisation construct MCADD as illness even while master narratives seek to normalise the child’s life.

Conclusions

At some point in every person’s life, they will have dealt with illness of varying degrees of severity, from a cold to cancer. Life is disrupted, they recover and continue, with
the memory of illness shaping how they will deal with a similar experience in the future, perhaps by resting more, or seeing a doctor sooner. Increasingly, people are also having to come to terms with long-term, ongoing chronic illness that besets them or a loved one. In some cases, diagnosis is a relief, an answer to suffering made worse by disbelief on the part of peers or medical professionals; in other cases, a source of confusion and concern as they rationalise the potential consequences of a currently asymptomatic condition. Now imagine being diagnosed with a chronic illness in the first few weeks of life, a disorder that will not affect you in any way so long as you always take your medicine. If you don’t, you could die. Your life will be exactly the same as any other person without a chronic illness, however the question “what will happen if…” will in all likelihood haunt you and there will be occasions when you don’t take your medicine and that question still lingers as you are treated in hospital.

MCADD is that chronic condition. Since 2006 it has been diagnosed early in children’s lives and it could be argued this has resulted in no MCADD-related infant deaths in New Zealand post-screening. Diagnosis not only shapes and remakes parent identities, it also changes the perception of a newborn from ‘perfect’ to dis-ordered. It is not fixed. Liminality and temporality are fluid concepts with medical professionals and parents alike renegotiating what constitutes or defines a diagnosis of MCADD and how to manage common childhood illness through the lens of MCADD.

Treatment, the regular intake of food, is biomedically simple yet socially complex, and further complicated during any unrelated illness episode. The changing nature of the disease status, of what MCADD means in different contexts, and during a child’s development, changes social parameters. The experience of New Zealand childhood illnesses is brought into sharp relief by the diagnosis of MCADD. In the next chapter I analyse where this body of research sits within four areas of scholarship: sensory anthropology, illness
narratives, science and technology studies and the anthropology of childhood and use this to highlight taken for granted social assumptions about ‘normal’ experiences of and management of, illness.
Chapter 2
Sensing illness – locating MCADD

2.1 The source of the shadow: sensory anthropology

In this thesis I argue that the construction of MCADD in the children’s lives is linked to their experience of MCADD in different spaces, specifically the home, school and the hospital. Much like Trnka, Dureau, and Park (2013, 1), who look at the “interplay between our embedded sensing of the world and our emotional and conceptual means of ‘making sense’ of it”, I examine how children's lived experience of MCADD, their sensory experiences of the disorder, are embodied (Csordas 1990; 1994) and thus subject to their perception, particularly in the case of food-ways (Trnka, Dureau, and Park 2013, 2) and hospitalisation.

I show how feeding becomes medicalised in the context where taking in food and keeping it within the body is the key to vitality and I explore the effects of this process on the emotional responses of children and parents to daily life. Here I refer to emotion as Lutz and Abu-Lughod (1990, 2) do: “as about social life rather than internal states, and its exploration of the close involvement of emotion talk with issues of sociability and power - in short, with the politics of everyday life”.

As previously explained, once diagnosed, MCADD is easily managed with the regular intake of food as part of a low-fat diet and thus the relationship between the growing child's sense of agency, food and identity is linked to the disorder. The body of the child and related food practices become a contested space. Breastfeeding is the first point of contestation (Keenan and Stapleton 2009; Portnoi et al. 1999) where the parent, particularly the mother, is under pressure to feed the infant every few hours, which the baby may resist or physical constraints may restrict. Similarly family mealtimes and food practices become fraught with
tension as toddlers and young children engage in 'normal' independent behaviour and choose not to eat (Cook, 2009; James, Curtis and Ellis, 2009).

How do these early embodied, sensory experiences affect these children? Do they recall them as they grow older and the condition becomes easier to manage? How does this become linked to later broader understandings of foodways? In an extensive review on the anthropology of food, the senses and memory, Holtzman (2006, 365) states: “Giard (1998 with De Certeau) construes the everyday practice of eating as making ‘concrete one of the specific modes of relation between a person and the world, thus forming one of the fundamental landmarks in space-time’ (1998, 183).” He defines memory as “the notion of experience or meaning in reference to the past” (Holtzman 2006, 363), and food as a cultural construct, one that is often biased towards Euro-American experience (Holtzman 2006, 364). If eating is framed around a particular set of actions set to prevent ill health, surely each meal is an affirmation of the diagnosis of MCADD? These include how infant feeding is managed, changing advice related to weaning$^9$ and how parents handle children’s actions like spitting out food.

It could be argued that if “one meal is understood in reference to previous meals” (Holtzman 2006, 365) then MCADD creates a breach in taste and social foodways for those diagnosed. As Holtzman states:

The experience of food evokes recollection, which is not simply cognitive but also emotional and physical, paralleling notions such as Bourdieu’s (1977) habitus, Connerton’s (1989) notion of bodily memory, and Stoller’s (1995) emphasis on embodied memories. (Holtzman 2006, 365).

Lupton (1994, 1996) explores how the structure of eating habits is connected to emotional embodied memories and similarly Batsell et al. (2002) report “flashbulb memories” from participants in the United States who recall childhood experiences of being forced to finish food.
Not eating or vomiting may also be evocative. The consequence of fasting (not eating) for any length of time is hospitalisation (Wilson et al. 2007). At this point, MCADD can no longer be managed at home and care is transferred to the hospital. It can be argued that from a clinical perspective management is still easy as the low threshold for hospital admission is intended to prevent MCADD from presenting. Thus MCADD is not being treated, treatment is still preventative and provided in the form of nutrition/energy in the form of an IV of dextrose (Wilson et al. 2007).

Mol and Mesman refer to intravenous food given to a child in hospital as having multiple meanings depending on the relations in which it is enmeshed; a series of numbers, a glucose solution, a weight, and an infusion (Mol and Mesman 1996, 430). Each of these represent an extended foodway with its own set of sensory experiences specific to a ward environment. Studies that investigate children’s hospitalisations show that these experiences include the smells and sounds of the hospital when confined and tethered to an IV (particularly in the case of active toddlers) (Rice 2003), the pain of luers being inserted (along with sometimes multiple attempts to find a vein), and the distress caused by the visual appearance of blood.

As Desjarlais reiterates:

1) The senses matter in people’s lives; 2) sensate modalities of engaging in the world tie into so many aspects of sociality and human forms of life; 3) ideas of citizenship and belonging, inclusion and exclusion, and their blunt effects and realities in the world, jolt through time so often through sensory means”. (In Trnka, Dureau, and Park 2013, 266)

If children’s embodied experiences in spaces like hospitals, clinics and the home are sensory, these experiences create biosocial networks of belonging; to their family group, to a health system and to a particular condition.
2.2 Narratives of illness, narratives of health

Disease has been described as a “loss of predictability”, with “the question of control suggest[ing] that the body is lived along a continuum from… predictability to contingency. Contingency is the body's condition of being subject to forces that cannot be controlled” (Frank 2013 [1995], 30-31). For Arthur Frank, identity is tied to how well people's bodies can be brought under control.

Children with MCADD have a condition that on one hand means their body has lost its capacity for control. The body affected by MCADD sits squarely in the realm of the contingent. As a ‘genetic inborn metabolic error’ MCADD will not go into remission nor disappear, it is always there with the potential to cause harm. However as a disorder that ‘presents’ mainly when the child has another illness that affects their appetite, ability to eat, or ability to keep food in their bodies, it can also be seen as shifting along Frank's continuum, from predictability, when they are well, to contingency, when an otherwise minor illness could have a devastating result due to the hidden MCADD and the potential for harm decreases as the age of a child increases.

This thesis draws on the foundations laid by Kleinman (1988) and Frank (2013 [1995]) to discover how narratives about MCADD are constructed and changed before delivery to the child-as-patient; how the child then reconstructs this; and what implications different forms of the narrative have for the child's developing personhood (Bury 2001; Mattingly and Garro 2000). The use of illness narratives as a way of shaping and making sense of experience has been well documented.

Landsman (2009, 10) “examines the process of remaking stories as mothers interact with reproductive technologies, medical personnel, their own children and the society that often devalues them,” and Petersen (2005) explores the narratives of adults with genetic conditions. Pertinent to this research is how the nature of this disorder is related to parents by
metabolic specialists as this can vary quite dramatically between hospitals and countries; in the United States parents are given quite a strict emergency regime to follow while New Zealand is comparatively relaxed. Parents are proactive in seeking information about MCADD and confusion arises from the mismatch between online information often derived from the American experience and that conveyed by their New Zealand doctors.

Parents share information with their children about a genetic disorder in different ways (Gallo et al. 2005). Bluebond-Langner (1996) found that some parents chose to shield their children, withholding details about the severity of their CF and preventing them from access to films about the disorder. During this project, narratives told about, to and by these children about their disorder were recorded and analysed to build up a composite picture about how different children understand and articulate MCADD, how this changes over time, and how their sense of personhood may differ as a result. This thesis adds to the literature by examining how constructed narratives told to children change over time, across the child’s life course, and in relation to place.

This study charting the development of children affected by MCADD from birth should contribute substantially to debates about diagnosis and screening for genetic disorders in all people and how this is impacting on and changing the cultural and medical landscape of the future. In the following section I examine how new technologies have shaped the molecularised body, and explore how different relational definitions of social personhood can be understood within this context.

2.3 New technologies, new bodies, new persons

Since the 1950s health and “life itself” have been viewed through a molecularised lens (Lock and Nguyen 2010, 306) and subsequently, medical anthropology has been concerned with the social impact of ‘geneticization’, genomics (Lock and Nguyen 2010, 310, 331) and
the science and technology that makes the viewing of the molecularised body possible (Hess 1992; Lock and Nguyen 2010; Novas and Rose 2000). Screening technologies have been criticised as leaving some families in a diagnostic limbo, living with the discovery of a genetic disorder that relegates an infant to a life-long liminality on the border of pathology and health (Ginsburg and Rapp 1995; Grob 2006, 2008, 2011; Rapp 1988, 1999; Timmermans and Buchbinder 2011).

While studies address the experience of parenting these infants (Fitzgerald 2008; Grob 2006, 2008; Nagy and Ungerer 1990), the change to the parents' identity (Landsman 2009; Nagy and Ungerer 1990), adults' lived experience of both chronic and terminal genetic disorders (Frank, Fitzgerald and Legge 2007), disability (Ablon 1984, 1988; Ingstad and Whyte 1995, 1997), and risk and moral reasoning (Lock and Nguyen 2010; Novas and Rose 2000); how the diagnosis of a genetic disorder is understood and accommodated by children has not attracted comparable attention.

This ethnographic research included children of different ages who have been diagnosed with MCADD and provides an account of how the condition is constructed and experienced at different life stages. Like other researchers I found that the infants' identity changed from ‘perfect’ to ‘disordered’ (Buchbinder and Timmermans, 2011; Fitzgerald, 2008; Grob, 2006, 2008; Landsman, 1998, 2009; Layne, 1996). This ethnography moves beyond infancy to examine how these children and their families negotiate ‘ordinary’ childhood illness and mealtimes through the lens of the geneticised identity established by medical technology shortly after birth.

Social anthropology has long been concerned with the development and expression of identity and how individuals relate to their social environment. Children are identified as belonging to a broad community of children sharing the common experience of childhood (James 1993, 28), however childhood experiences are acknowledged as cross-culturally
diverse (Hewlett 2012; LeVine and New 2008), and within the same culture no two individual experiences are identical.

James (1993, 31) states “children's individual identities are transformed and homogenised through their categorisation as children, with their individuality, their Selfhood, often made secondary to their status as children”. The child who is sick or unwell experiences a double marginalisation, with their “social personhood subject to further qualification” (James 1993, 82). Social personhood, much like selfhood and identity, is relational, children’s personhood exists in context with other people, social settings and environments and shifts and changes accordingly. What personhood is has been debated extensively in anthropological literature, and I have been guided by Degnen’s nuanced definition:

Personhood is not identity. Personhood is not always equivalent to being a human. But personhood does entail a capacity for action in the world of social relations, and it also arguably extends a moral value to persons that non-persons are excluded from. (Degnen 2018, 7)

If personhood is linked, as Appell-Warren (2014) states, to an individual gaining physiological, psychological and social competence, a process marked by culturally accepted markers, then how does the diagnosis of a condition in infancy impact on this personhood? Personhood is not neatly delineated, the factors that make someone a ‘person’ differ between cultures (Gottlieb 1998) and even within groups. Degnen (2013) proposes that personhood is connected to various phases of the life course, more secure at some points and less than at others and in a later study, moves towards examining the relationship between personhood and the life course (2018). As the lived experience of MCADD also shifts according to the life course, more prominent at some points and less so at others, how does the relationship between the two converge; is there a correlation between the points at which MCADD is constructed as disease, and a diminished or enhanced personhood for the diagnosed child? Answers to these questions contribute to studies on the anthropology of personhood through
the dual lens of chronicity and preventative medicine. Degnen (2018, 17) examines “the life course via a focus on how people build relations with the world and each other at various crucial points across their lives”. In Part II and Part III, I examine at which points the diagnosis of MCADD impacts on children’s lives, and how relations are consequently formed or disrupted.

Buchbinder (2011, 459) uses the term personhood to “highlight how diagnosis serves as a technique to categorise people, identities, and selves-in-the-making”. As noted by Manderson et al. (2010), long-term chronic illness is punctuated by acute episodes in an otherwise normalised lived experience; it can be argued that a concealable chronic illness is thus not a preventative to a healthy body, nor to the attainment of social personhood but that potentially frequent hospitalisation in early childhood could be.

Studies working with children's health have investigated the impact of chronic illness such as asthma and diabetes on children's identity (Dell Clark 2003; James 1993) but have not included genetic metabolic disorders where the prognosis is positive. Terminal disorders such as leukaemia and genetic metabolic disorders such as cystic fibrosis have been examined under the dual lens of medical anthropology and anthropology of childhood (Bluebond-Langner 1996; Bluebond-Langner, Lask, and Angst 2001) but again, not those chronic genetic disorders where the child is likely to live to full adulthood but under the shadow of a secret, hidden disorder that holds fatal potential. Frank, Fitzgerald, and Legge (2007) also studied a genetic disorder treated by diet (phenylketonuria) and found that the dietary requirements created many demands on social relationships and lifestyle. Although MCADD requires no such special diet, living with it also has multiple social dimensions.

If, as Degnen (2018) maintains, personhood is closely interlinked with infant feeding and social practices of eating, would a child whose eating was medicalised feel excluded from “normative society”? How to frame the demands of an invisible condition in socially
acceptable terms when the treatment is such a taken for granted part of social life that norms are unconsciously followed and rarely debated. With older children and young adults learning to self-manage their disorder, autonomy comes into play. An understanding of the growing child's perception of the disease is vital. Some young people diagnosed with disorders like CF, asthma, allergies, haemophilia and diabetes experience stigmatisation in the playground, ignore medical advice as the disorder can be asymptomatic, have eating disorders, don’t believe there is anything wrong with them, believe they are flawed in some way, or abuse alcohol (Bluebond-Langner 1996, Buchbinder 2009; James 1993; Park 2000).

This research aims to add to this body of knowledge by asking how children with MCADD frame their ‘special’, yet when looked at against other disorders, ‘easily managed’ condition and how their personhood and their relationship with food is consequently structured. Interwoven, is that in the majority of cases, the disorder for the younger children has been diagnosed shortly after birth, through newborn screening introduced in 2006.

These children are not just diagnosed; they embody their diagnosis (Lock et al. 2007; Scully 2008a). It is told to them and recreated in the telling. However, they then create their own narratives which differ from the ‘official’ telling. These narratives are widely diverse from their multiple sources (like specialists, parents, teachers, etc) and reveal a complex layering of multiple medical understandings. Observing that little is written on the narrativising of patient's families, Layne refers to “…the process by which technoscientific knowledge is made (or remade) by others,” (1996, 625), a phenomenon increasingly under investigation by medical anthropologists (Downey, Dumit, and Traweek 1995; Hess 1992; 1993; Layne 1996; Trnka 2017a).

Petersen (2005, 485) makes the case that genetic explanations are appealing as they resonate with broader “discourses on self and society. The notion that genetics defines one's identity and one's destiny is deeply rooted in the dominant western cultures, in discourses of
individuality and individual responsibility…”. However studies with adults have shown that patients prescribed a “technoscientic identity”, defined as “a type of illness identity that involves applying biomedical information and characteristics to a person’s sense of self in the face of illness” (Sulik 2011) do not necessarily subscribe to this identification, due to the lived experience of illness (Sulik 2009, 2011). In the case of the child diagnosed with MCADD, the already contested and medicalised body of the child (Christensen 2000; James 1993; Prout 2000) is pushed through the system by other actors, all united in the common goal of ensuring they don't ‘present’ with a metabolic crisis and if they do, that the condition is managed to keep them alive and well.

2.4 Childhood in Anthropology

This research situates itself within the current child-focused approach to anthropological work with children (Bluebond-Langner and Korbin 2007; Buchbinder 2008; Caputo 1995; Christensen 2000; Christensen and James 2000a; Christensen and Prout 2005; Spray 2018), which advocates for children’s active participation in the research process. The anthropology of childhood has been a growing subfield of anthropology since the 1970s (James 2007; Schwartzman 2001).

The concept of ‘childhood’ has developed from children being viewed as tiny, deficient adults in the middle ages (Christensen and Prout 2005, 44) to modern childhood, precipitated by the nuclear family unit, with children separate from adults (Christensen and Prout 2005, 45). An age-based or developmental approach is seen to be the basis of anthropological and sociological thought about childhood linked to the ideas of 'naturalness', 'universalness' and 'rationality' (Christensen and Prout 2005, 48). This model assumed children were natural rather than social phenomena and that they would develop competence as they matured towards adulthood (James, Jenk and Prout 1998, 19). Theories of
socialisation and children as ‘becoming social’ came about in the 1950s but it was only in the 1970s that a child-focused approach began to be considered with anthropology viewing children as agentive social actors.

It has been argued that children have been the objects of research as opposed to meaning-makers with valid insights equal to that of adults (James, Jenks and Prout 1998), despite early and much critiqued ground-breaking work on childhood (Goodman 1970; Mead 1928, 1930; Opie and Opie 1959; Schwartzman 1976). Hardman (1973, 503) in particular criticised anthropology for not viewing the culture of childhood as a valid area for critical enquiry, stating “none of these approaches… revealed the beginnings of an anthropology of children, concerned with beliefs, values, or interpretation of their viewpoint, their meaning of the world”. This is an argument that continues to be debated, with some advocating a more child-focused approach to anthropological work (James, 2007) and others arguing that ethnographies of childhood have always had a presence in anthropology (Lancy 2008; LeVine 2007; Waterson and Kumar Behera 2011).

Drawing on a century of articles from American Anthropologist Schwartzman argues that these studies have moved from a focus on children as specimens for examination or as a tool, during the rise of culture and personality studies, to analysing familiar relationships between child-training practices and adult personality development. Often they have focused upon specific socialisation contexts and ‘agents’ and have assumed that developmental change occurs in a linear and progressive direction. She suggests that it is only those articles from the 1990s that are more child focused and concludes by saying:

We can begin this new century by developing an anthropology of children that takes children seriously and in this way finally asks the questions all good ethnographers [should] ask about children's views, experiences and behavior. (Schwartzman 2001, 29)
Many texts have appeared that deliver insights into the anthropology of childhood (Lancy 2008; LeVine and New 2008; Waldren and Kaminski 2012) and while these cover a relevant cross-cultural reading of childhood, not all speak with the voice of the child. Thus Caputo's reference to children as members of a “double-muted” group, patients with no voice, is still relevant, “forc(ing) one to question the kinds of power structures that are intertwined with the production of anthropological knowledge” (1995, 23). It is pertinent that the same critique has been levelled at medical patients and this thesis aims to address this in Part III, where children’s silences and actions during clinic narratives and hospital encounters are analysed, showing that children are communicating even if they are not vocalising.

Once childhood was established as an area of research, scholars such as Alma Gottlieb queried an apparent lack of an anthropology of infants (1998, 2000). In more recent years, the anthropology of childhood has grown to include both the study of infants, children, adolescents and young adults, with current approaches advocating for a child-centred approach to research such as Christensen's work with Danish children (1999), Bluebond-Langner's work with cancer patients (1978, 1991) and Buchbinder's work with adolescent personhood and the expression of pain (2011).

Conclusions

This chapter has shown how this research fits into larger issues about the impact of newborn screening on society, taking into account existing studies on narratives of illness and biomedicine; and sensory anthropology, and highlights the contribution this study will make. It also raised the point that although MCADD may not require adherence to a specific diet, the fact that treatment is dietary creates demands on social relationships and lifestyle. In addition, while a concealable chronic illness does not necessarily prevent the attainment of social personhood, potentially frequent hospitalisation in early childhood could disrupt this process. If sensing the world as a child contributes to our personhood then what contribution does a medicalised identity make to the formation of this personhood? Are feelings, taste, and experiences altered by the diagnosis? Finding the answers to these questions requires a robust research design, and in order to do this thoroughly I needed to ask more questions. How would I assess the impact (if any) of an invisible condition in young children, one that is so slippery that even medical specialists are constantly debating what does and does not reach the criteria for disease? How to obtain robust data amongst a range of ages? What are the key points where it is likely a crisis point will reveal more information? How to manage the logistics of researching a community dispersed across an entire country? The following chapter will outline how I attempted to answer these questions and how this eventually played out in the field.
Chapter 3

‘Stranger danger’ and other misadventures – the fieldwork encounter

3.1 Clean, green New Zealand as a field site

These key questions about the invisibility of the condition, ethically communicating with young participants, and the range of my field kept me company on the scenic 200km drive to reach my very first young research participant, aged five at the time. I had what I felt was a robust research design that had stood up in a pilot study but how would that play out in the field, a field characterised by geographical and demographic diversity?

In the 15 years I’ve called New Zealand home, the greenness — the lush rainforests with giant ferns that fringe the roads in between major cities or spring up on suburb edges — still manages to instill a sense of wonder. These pockets of nature can be found in sprawling cities like Auckland, small suburbs, and along roads. It was no different on this trip. The landscape wears a mythological, arcadian aura, driven in part by film landscapes like the Lord of the Rings (Jackson, Osborne, and Walsh 2003) and The Piano (Chapman and Campion 1993), its pioneering goldrush history, its 100% Pure marketing campaign (Tourism New Zealand 2009) and attraction as an adventure sport mecca.

New Zealand is a small country; approximately the same size as the United Kingdom but with an estimated 4.844 million inhabitants (Statistics New Zealand 2018) versus the UK’s 65.65 million, spacious. This makes New Zealand an ideal site for a medical study on the first generation of children included under the expanded newborn screening programme; the population is small enough to enable a nationwide study, it has a well-developed infrastructure and technology; and there is a single national Starship Paediatric Metabolic Service, based in Auckland. Specialists also visit their patients at clinics held around the
country, a country that is not only geographically diverse but also features a broad population diversity.

How to include methods that will incorporate children who live in different locations and therefore attend different schools and have different social networks? What methods are flexible enough to cater for differences in ages, linguistic capability, and family demographics? How would I manage the different perceptions of participants, and my multiple roles as ‘fellow mother with MCADD child,’ and researcher? How would I approach working with the children? What role would I take? As I soon found out, I had less control over some of these questions than others.

Stranger danger

Sarah and her 9-year old sibling, who does not have MCADD, enthusiastically greeted me. After spending some time with the family, I sat down to go through the assent form process (see Appendix A) with both siblings. I initially intended to get assent only from Sarah, however realised that Susan felt left out so included her. This inclusion of young siblings proved to generate some of the most valuable information throughout the study. The assent process proceeded well until until we reached the first set of permissions:

Pauline: If it’s ok with you I’d like to spend time with you at home, like we’re doing now.
Sarah: No [her mother laughs]
Pauline: [laughing, as this is something I hadn’t anticipated]. Ok. Would you like me to leave? [I was a bit bemused as Sarah had jumped on me, showed me all her toys and seemed very comfortable with my presence].
Sarah: No.
Pauline: Ok. If it’s ok, could you tell me why you don’t want me to spend time with you here at home.
Sarah: [quite proudly proclaims] Stranger danger!
Nancy (Sarah’s mum): Oh, she was just doing that at school. Sarah honey, this isn’t quite the same. We do know Pauline and I’m here as well.

Pauline: But only if you’re happy with it. You don’t have to agree to anything you don’t want to.

Sarah: Oh, ok then [climbs into my lap to investigate the rest of the form].

In any research project questions arise about power relations and gatekeeping, usually in an attempt to protect children and young people (MacArthur and McKenzie 2013), for example, what if a child wants to take part but their guardian disapproves or vice versa? As MacArthur and McKenzie (2013, 81) outline, “the power of an adult does not dissolve away in a research context” and these power differentials exist in both age and time (Skelton 2008). This was my first introduction to some of these issues in practice. I was keen to address some of the methodological and ethical issues raised by MacArthur and McKenzie (2013): assumptions about children’s vulnerability, an insensitivity to children’s participation rights, adult agendas favoured, and an emphasis on children as subjects rather than persons. Children therefore had the same recourse to opt out of the study as adult participants and this was negotiated at each visit. I wanted the children to trust me, but I also felt a responsibility not to interfere with the families’ already difficult jobs of managing MCADD on a daily basis. What the experience above highlighted was that the fieldwork encounter is fluid, constantly changing and that one’s research design needed to be flexible enough to accommodate this but also empower children to negotiate their own participation.

Persendt (2014) has argued that the granting of pseudonyms disempowers the participant and I considered asking participants to choose their own pseudonyms or their own names if they wished. However, on reflection I was concerned that as the study dealt with multiple family members and their relations with and to each other, that a greater sensitivity would be afforded with blanket anonymity. This was especially as four of the families in the
study had separated or reported marital challenges, with participants reporting they felt this was largely due to the pressures put on the family by the diagnosis of MCADD.\textsuperscript{12}

In the following pages I outline how I conducted the research; and give an overview of how I was both researcher and a part of the research community. To achieve this I will focus on three areas; first the research design that was influenced by the field site and dispersed community described in the previous pages; second, a reflexive examination of the extended community I worked with, that included parents, children, medical, and educational professionals and third, the multiple methods I used to gather data and the reasons I chose these methods. Finally, I reflect on ways in which the data collection, analysis choices and my personal involvement has shaped the research results.

As mentioned in the introduction, this research was multi-sited with families based in multiple locations, from as far South as Invercargill, up to the North Island’s Auckland.\textsuperscript{13} Over 50 percent of New Zealand’s residents live in the urban centres of Auckland, Hamilton, Wellington and Christchurch (Statistics New Zealand 2010) and accordingly, the majority of participants were based in and around these centres. Houses were located in suburbs, and on farms (lifestyle and rural), all with three bedrooms or more, most owned by the participants, with the exception of three rentals, and two families in state housing. There were no apartment dwellers. With the exception of four, households shared several characteristics: middle-class, well-educated,\textsuperscript{14} homeowners.

The ‘country’, an aspiration for a bucolic lifestyle, was seemingly everywhere with suburban gardens filled with song from tui and fantails. One family told me about a rare bee ball that landed on the strip of lawn they use for backyard cricket and kicking the rugby ball around. It drove them inside their freshly painted house in a newly created suburb. There were hedgehogs and pet kunekune pigs and mice, even a pony or two. Chickens. Some dogs
and cats. It felt indicative of an idealised world of children, tiny naturalists exploring their world, where things that jump and crawl and sing are of interest.

However, as Freeman and Higgins (2013) point out, while growing up in Aotearoa New Zealand can occur in a beautiful environment, with opportunities to take part in a multitude of activities from swimming to kapa haka and robotics, New Zealand children also live in an environment with pollution, respiratory disease due to poor housing, and poverty. They state:

Children in Aotearoa New Zealand live in a variety of whanau or family structures. There is no universal Aotearoa New Zealand childhood, but a multiplicity of childhoods that reflect the many ways that the country provides or fails to provide for its children. (Freeman and Higgins 2013, 14)

This multiplicity of childhoods is also reflected in space, in a shrinking of external environment (Freeman 2013); the blurring between town and country, of rural and not-rural, where one short road will merge the two. In 20 minutes I drove from one family in their suburban home in Wellington to another’s semi-rural lifestyle block, complete with sheep and pony. A further 45 minutes and I was bumping down the gravel entry road to a ‘proper’ working farm. Sometimes, this took an hour or more, getting lost, due to poor signposting and country roads. There were also homes in state housing where children shared a snug room with their siblings, only five minutes drive from affluent, middle class homes. Others were in small towns two hours drive or more from the nearest hospital, no fresh paint here, with a single or no income to support the families.

The earthquakes changed the urban landscape too, with road works changing access to homes, rerouting the way to Christchurch Hospital. Entire suburbs were relocated due to slips. Sensory experience shifted with new sights: shipping containers holding emergency supplies at the bottom of farms and new sounds: the constant din of roadworks. Families migrated suburbs, cities and even countries, sometimes due to the stress of these South Island
quakes, other times due to work, landlords moving them on or new housing opportunities. All of these revealed that manageable disorders become less manageable during crisis or change and that stress, known to trigger changes in eating patterns (Macht 2008), adds to this.

Ongoing participant observation was conducted at Auckland-based clinics, and during daily to weekly contact with core Auckland based families over the space of two years. I demarcated the country into six broad geographical regions (See Figure 3.1).

Figure 3.1 Map of the Territorial Authorities of New Zealand overlaid with Regional Council areas, including the Chatham Islands in an inset. Territorial Authorities, Regional Councils and text labels are in three separate layers. Map created with GIS data from StatsNZ [1] (Retrieved March 2017). Date: 10 March 2017. Author: Korakys
The first included Northland and Auckland (six children), the second, the Bay of Plenty, Waikato and Gisborne (four children); and the third the lower third of the North Island, Hawke’s Bay, Taranaki and Wellington (11 children). In the South Island, the fourth band incorporated Tasman and Marlborough (no participants), the fifth, the West Coast and Canterbury (eight children) and sixth, Otago and Southland (two children). It is interesting to note that despite at least four children affected in the fourth band, no families chose to take part in the study, a possible area of enquiry for future studies.

I visited each of these areas for a period of up to two weeks, a minimum of three times over the space of a year and a half, timed to coincide with outpatient clinics from the Auckland-based team and significant milestones in each child’s life, such as starting primary school. In addition, much like other relationships, I maintained contact with families (mainly mothers) via text, phone calls and social media (Horst and Miller 2012; Madianou and Miller 2012). Research was conducted in four primary locations: school, clinic, hospital, and the home. During fieldwork I discovered that these different locations were crucial to the multiple constructions of MCADD.

To paraphrase Paul Stoller (1989), my long-term immersion in this project yielded the most results. The field was constructed through the personal relationships and networks I made with these families, and while the official fieldwork period lasted two years, it is the ongoing contact with the friends made in the field that has made certain research insights stand out with startling relief, and the new members that join the Facebook group15 that have reaffirmed previous discoveries.

3.2 Part of the family: the participants and I

My approach to this ethnography is child focused, it theoretically grounds itself in the concept of empowering the child's sense of agency (Christensen and Prout 2005; James, Jenks
and Prout 1998). As MacArthur and McKenzie (2013, 79) state: “Researchers can be guided by the principle that if the research matters for children and young people, there is a mandate to consider how children and young people can be involved”. This thesis is polyvocal. As the parent shares the role of patient with the infant and very young child, and the narratives told to the parents and then relayed to the child are of central import to this thesis, it is important to include parents' and other social actors' views on and about the child. Childhood is broadly deemed to represent a period between birth and adulthood, including infancy and adolescence. A total of 31 children and young adults participated in the study, along with their immediate families, representing 72 percent of all children diagnosed with MCADD in New Zealand at the time fieldwork was conducted (Starship Personal Correspondence 2013-2015).

The majority of the research participants were identified and invited to join the study via Starship Metabolic Services, who sent out letters on my behalf. One family joined the study from Parent to Parent New Zealand16 and two others from an international Facebook support group. The children and young adults ranged in age from newborn through to 19, with the majority from age three to seven. James, Jenks and Prout (1998, 177) refer to “childhood’s middle years” as being from ages four to ten. They find it significant that sociological, and I would argue, child-focused anthropological research has looked “backwards towards infancy and forwards to adolescence”, with a dearth of literature in the period between infancy and adolescence; a phenomenon they attribute to a lack of linguistic capability. I have addressed this apparent lack with a multiple-methods approach that enabled each child to express their views in a medium they were comfortable with. This has been detailed extensively in the section below on methods.
The skew of participants towards these middle years mirrors that of all children currently diagnosed in New Zealand due to the relatively recent date that MCADD was included in the expanded Newborn Screening Programme; 2006. As can be seen in Figure 3.2, children from this programme are aged 10 and under at the time of writing. Those older were discovered when a younger sibling tested positive for MCADD or due to infant death from the symptoms of MCADD.

The research design places the young patients at the heart of the study, with immediate caregivers and siblings around them, followed by medical professionals and then other adults who at varying times take responsibility for their care, such as educational professionals and extended family and close family friends. While children are the focus of this study my work engages with the progressive broader groups involved in their experience of MCADD (Figure 3.3): parents, medical professionals, teachers and other education professionals.
The first group of research participants included the parents of the children diagnosed with MCADD. A range of experiences presented within this group: two mothers became pregnant and gave birth to their second child during the research period, one with and one without MCADD; and three had IVF babies for fertility reasons. Practical considerations to take into account included the linguistic capabilities of very young children in particular and that building a relationship with a child is done under the overarching umbrella of the family. Interviewing parents before working with their children had multiple benefits. As the main body of research dealt extensively with these children, this enabled me to build a relationship and platform of trust with the parents and children, who were often present at the parent interviews, prior to working with them. It also provided the families with a two-fold opportunity to take part in the study. Those parents who did not wish their child to take part could still opt to be involved in the interviews about their experiences as a parent of a child with MCADD, adding value to insights about the change in identity from the ‘perfect newborn’ to ‘other’.
As the condition is managed with food, the first two years in particular are fraught. This is when an infant is learning to feed, transition to solids, join the family meals, and often experiences their first hospitalisations. These parents share and embody their child’s condition, from the mothers physically imparting breast milk (whether by breast or bottle), to the genetics that have caused it. I use the term ‘parent-patients’ to describe this embodied experience in the early years of the child’s life and incorporate in my examination the experiences of the parents sharing the patient role, the impact of newborn screening, infancy and the toddler phase.

As the parent of a child with MCADD myself, I have an "insider view" (Gottlieb 1995; James 1993; Landsman 1998; Layne 1996), which allowed me greater knowledge of some of the issues and sensitivities affecting these participants in the early, tentative stages of fieldwork engaging parents, while remaining cautious about making assumptions (James, 1993).

**Constructing the field: a reflexive network of relations**

In August 2011, I was abruptly initiated into the dual fields of motherhood and disability. Like Landsman (1998), Layne (1996), Gottlieb (1995) and Rapp (1999), for the first time I considered the role of the anthropologist as mother, and how motherhood is constructed and reconstructed “in an age in which infants are commodified and technology seems to hold put the promise of ‘perfect’ babies” (Landsman 1998, 3).

Landsman continues:

For the mother of a child recently diagnosed with an impairment, the 'Other' is neither hypothetical nor located in an exotic, distant land to be written about…; the Other is… a member of the family. And like an anthropologist…such a mother becomes engaged in a meaning-making, interpretive process, seeking to find, and often to advocate for the personhood of a child whose life is routinely devalued, and… once might have been devalued by the mother herself. (1998, 3)
I had recently postponed plans to conduct PhD research on a different genetic condition and by early 2012 I was sufficiently intrigued by these questions and others regarding the construction of genetic identities to consider formally researching them. By February 2013, I was registered for a PhD. As the mother of a child diagnosed with MCADD, one who was unaware of the child's disorder until approximately day six of life, I share an emic view with parent-patients and am a member of the research field. I am a part of this MCADD network, part of New Zealand society, deal with the same healthcare system and in many cases share the gratitudes and frustrations of any other citizen of a social welfare system. This offers valuable reflexive anthropological insights as well as significant challenges.

My fieldwork has been conducted both ‘at home’ and ‘away’, necessitating a heightened awareness of the potential autobiographical nature of field site choices (Knowles 2000). Thus while there is no denying my personal involvement in the research community, the fieldwork conducted with other parent-patients as well as with the affected children themselves marks a separation between the self and the other, while simultaneously highlighting a dialogue with the self and casting light on personal experience (Knowles 2000, 61). “Understanding the relationship between home and field requires a reflexivity about what we do and why we do it: an exercise which places the social investigator back into the research frame” (Knowles 2000, 56). When I was in Starship with my son it was near impossible to disconnect myself from personal concern as a mother and fatigue after the days and nights spent trying to keep him out of hospital; when he was sleeping I had to consider if that time would be best spent catching up on sleep myself or use the opportunity to update my journal about our lived experience. Likewise as I shared the dual role of anthropologist and parent-patient, what are the ethical considerations inherent in jotting down observations, comments from nurses and doctors, and frustrations as a parent?
In addition conducting research at “home” versus “traditional fieldwork as an archetype” (i.e. “away”) can present a number of challenges, including a “fieldworker persona… [that] abruptly shifted according to changes in context,” an expectation to maintain and be active in academic and social networks, an inability to never be completely in nor out of the field, and the logistics of carrying out research with young participants in a dynamic urban environment who also had time and social networking constraints (Caputo 2000, 27-28). Almost two decades have passed since Caputo's observations and broader anthropological discourse has embraced the shifting boundaries of culture and citizenship (Gupta and Ferguson 1992), with childhood and biological citizenship (Fitzgerald 2008) of particular relevance to this thesis. As Caputo (2000, 26) notes, “in fact, the difficulties were an important part of the research itself” and the field, one in which “I am at once 'at home' and 'away'… not mutually exclusive terms” (Caputo 2000, 29).

As Hadolt (1998, 312) maintains, labelling research as ‘at home’ can be problematic. He defines “medical anthropology at home as a metaphorical shorthand which refers to research being done by Western medical anthropologists in Western research settings”. What is ‘at home’ for me? I am a citizen of New Zealand, live here and am raising my children here, however I was born in South Africa, have retained dual citizenship and still find alien many aspects of New Zealand society taken for granted by others, such as the schooling and medical systems. I found this tension a useful foil when analysing the data in the field.

Reis (1998, 295) explores ‘being at home’ in affective terms; “referring to shared experiences and processes of identification,” and “the idea that one’s emotional response may alert to socio-cultural issues”. My family's lived experience of genetic disorder has influenced both theoretical and ethnographic components of the research and I have taken care to adhere to ethical considerations and sensitivity with regards to the medical professionals involved in personal consultations, as well as my family. However, my child's treatment in all likelihood
informed my thinking about and development of the research question and methodology and how I approached my young participants.

The second group of participants included the children and young people\textsuperscript{17} who had been diagnosed with MCADD. With fewer than five young adults diagnosed, and under the care of the Paediatric Metabolic Services team at the time of writing, the identity of the young adults would be easy to ascertain and all but impossible to make anonymous. This study therefore focuses on patients under the age of 10 at the time the study started. It also includes their siblings, who took part in the same research activities. It examines the lived experience of children affected by MCADD at key transition points relating to their participation in social and particularly educational institutions. These include: their transition from the critically dangerous period of infancy to the time when they are able to go without food for longer periods of time; the attendance of day care or social interaction with other children and playgroups and thus having their condition explained to others outside of family and medical caregivers; primary school entrance where they interact with peers who may be aware of their condition; and likewise the social markers of intermediate school. It is at these points that the narrative the child is told about her condition dynamically shifts to accommodate the new environment, along with her lived experience and the recreation of that narrative.

This deliberate strategy aligns with the “age stratification of the school” (James, Jenks and Prout 1998, 176), as this is probably the first time these children have to decide how they are going to negotiate their ‘otherness’ and ‘disability’ with peers and teachers, if they choose to disguise or ignore it and, if not, how they articulate and frame their understanding of their illness. The upper age limit of this group is of particular interest for future research as they grapple with autonomy, as framed against the management of their diagnosis and more specifically experiences around alcohol, the ‘big OE’, competitive sport, body image and related challenges.
The third group of participants included medical professionals who came into contact with the child and her family. Fieldwork primarily consisted of participant observation with the Starship Metabolic Team’s metabolic specialists, nurses and dieticians during clinics, as well as in depth interviews with each consenting member of the team. I also interviewed local doctors who conducted bi-annual clinics with families in between the Auckland team’s visits, and family GPs, nurses and midwives about their experiences with MCADD before and since meeting the family.

How to anonymise these individuals, particularly pertinent in the case of the metabolic services team that every single family dealt with? There were two specialists at the time of writing, one male and one female, with more training in the wings and a small number of metabolic nurses and dieticians that fluctuated slightly depending on leave, and when new staff were hired. The metabolic services team generously included me in clinics, helped me get in touch with participants, and gave up time for interviews so I could understand more about how the team and its services worked, and some of the challenges they faced on a daily basis.

I decided to follow the example of Bluebond-Langner who created composite characters. As Wolf (1992) and Narayan (2012) caution this can be a fraught exercise, with the writer needing to adhere to a true reflection of the social complexities while still refraining from identifying key attributes that could identify the participant. I combined the specialists into a single character and attributed any comments and clinical narratives to this single character. I also gave them the opportunity to see verbatim comments within context in the event that this compromised their working relationships with their patients.

Other adults I interviewed included educational professionals; the principals or heads of the schools, kindergartens and preschools the children were attending as well as the children’s main or class teacher. I obtained permission from the families prior to interviewing
this group and made it clear to both parties that interviews were confidential and anonymous. In addition, incidental information was provided from conversations with extended family such as grandparents, aunts, uncles and close family friends who were treated as and referred to as ‘family’. These interview participants often evolved organically as part of participant observation.

3.3 “Where’s the coloured paper?” Participant observation in action

A solution to my question on how to work with a diverse range of people of varying ages was to use multiple methods, particularly when working with the children. Participant observation, “the systematic description of events, behaviors, and artifacts in the social setting chosen for study” (Marshall and Rossman 1989, 79), formed the basis of the qualitative research and took place in participants’ homes, regular clinics held at regional hospitals, schools and during hospital admissions when a child was unwell. I have also observed and been a part of families' communication networks when a child is unwell; texts, Facebook posts and telephone conversations when in hospital. The multiple methods used during this observation period are outlined in Table 3.1 below.

<table>
<thead>
<tr>
<th>Method</th>
<th>Quantity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Semi structured interviews</td>
<td>524</td>
</tr>
<tr>
<td>Body mapping</td>
<td>12</td>
</tr>
<tr>
<td>Drawing</td>
<td>5</td>
</tr>
<tr>
<td>Metaphor Sort Technique (MST)</td>
<td>14 children (2 non MCADD, 1 entire family)</td>
</tr>
<tr>
<td>Photo voice and child led interviews</td>
<td>5</td>
</tr>
<tr>
<td>Facebook support group</td>
<td>17</td>
</tr>
<tr>
<td>Storyboarding</td>
<td>7 comics, 1 story, 2 role plays</td>
</tr>
<tr>
<td>Medical records</td>
<td>8 families</td>
</tr>
</tbody>
</table>

Table 3.1 Research methods
I aimed to mirror the success of other researchers by conducting participant observation during routine clinic visits (Landsman 1998; Rapp 1988; Timmermans and Buchbinder 2010), following these up with detailed open-ended interviews in the home (Landsman 1998). I recorded, filmed and transcribed sessions to enable me to compare the clinic conversation with the parents' reconstruction of the experience of finding out about their child's disorder and analyse the children’s participation in the clinic. I also gathered copies of all hospital notes and records the families had kept in their personal files for analysis and comparative purposes with their narratives.

Documents used in this study were copied with permission from families. Davies (2008, 204) cautions the “continuing relevance of reflexivity” when using documents in ethnographic research. These documents were given to me by parents from the family medical files. In some cases, a jumbled pile of papers included the mother’s prenatal history, diagnosis and clinic letters, other siblings’ medical histories and hospital admissions (once located from a pile of other paperwork in the home). In another a few loose pages were handed over with an apology that the paperwork was culled in a recent move or tidy up; and then there were those who chose to create a tidy folder that had been edited to include only the documents pertaining to MCADD, not the entire medical history of the child.

In order to address how these children constructed their identity and personhood in relation to MCADD, it was necessary to examine how the unborn foetus was initially viewed, described and thought of prior to and after reproductive technologies such as prenatal anatomy scans, blood tests, chorionic villus sampling, amniocentesis and IVF. Prior to starting participant observation I contacted each set of parents who had returned the consent forms, usually in the first instance the mother, and conducted multiple open-ended interviews on the phone and Skype. This approach aimed to “construct an understanding of informants’ perceptions of particular life experiences” (Davies 2008, 210) paying attention to how they
reshaped their narratives to accommodate a genetic diagnosis into the experience of having a child (Davies 2008, 210). Initially these interviews generated an emotional response, often with tears, or anger; in subsequent meetings there was more reflective analysis, and as the child grew older, the parents appeared to be more relaxed.

I told parents that I myself was the mother of a child with MCADD, who at that point was two years old, and gave them the opportunity to ask further questions about the project and its aims. Topics covered in these initial interviews included: personal reflections on diagnosis; decisions around infant feeding and health; reactions from social networks; choices in relation to childcare and schooling; personal reproductive choices after the discovery of being an MCADD carrier; mealtimes and feeding; the management of the child's health when unwell and personal experiences during a hospital admission. These interviews varied in length from forty-five minutes to three hours and topics were abandoned and picked up organically during participant observation periods as parents had new insights and observations about their and their children’s experiences. The interviews were recorded and transcribed to enable me to compare the parents' reconstruction of and narrating of the experience of finding out about their child's disorder with later conversations and clinic observations.

I found the phone interviews had multiple benefits. As Bernard (2011, 211) describes, they are inexpensive, convenient, “have the impersonal quality of self-administered questionnaires and the personal quality of face-to-face interviews” and are safe, especially where children are concerned. The parents got to know and build an initial rapport with me based on the common ground of parenting, specifically, parenting a child with MCADD.18 It was something that could be done intimately, at any time parents found convenient, often in the car waiting to pick up a child from school or after drop off. Parents reported that they could talk without distraction, that there was a level of intimacy afforded by the initial
telephone conversation and that many had never had the opportunity to talk about their experience with the condition with someone who shared that experience. The last point was often reiterated during my initial participant observation period. The physical distance afforded by communication technology was a gentle introduction to both parties without the social anxiety often felt when a stranger is welcomed into the home (Pridemore, Damphousse and Moore 2005). As Bernard says:

> The anonymity of telephone surveys lets the interviewer as well as the respondent off the hook. You can ask people things you might be squeamish about if the interview were face to face, and respondents feel that they can divulge very personal matters to disembodied voices on the phone. Bernard (2011, 229)

Similar to McCoyd and Kerson (2006), I found initial telephone interviews to be a good way to build rapport with the participant prior to visiting. Entering their home to talk about illness and document how they feed their children and parent/mother is a daunting prospect for many in a society where mothering can be harshly judged. The telephone was a way of answering a set of questions with an easy, socially acceptable way of ending the conversation, e.g. an interruption like a child. Similarly, it could be done at ‘in between times’, and fitted into mothers’ daily schedules ferrying children from activity to activity.

**Facebook**

When I started the study, there were no specific New Zealand or Australian based MCADD support groups. I set the group up in May 2014 after I discovered two New Zealand participants on an international MCADD support group. The New Zealand support group is clearly identified as being part of the research project and as a result Facebook has become both a site of enquiry and a research method (Pink 2011). While some members found out about the Facebook group from their participation in the larger project, others were directed to it by the Paediatric Metabolic Services team based at Starship Hospital in
Auckland, searches on Facebook and word of mouth. Support group members who were willing to take part in the research had to explicitly give permission, even if they were already participants in the overarching research project and equally, existing participants could choose not to take part in the Facebook component. This thesis includes findings from 17 New Zealand families who are both participants in the study as well as members of the group, totalling 17 mothers and two fathers. I mostly use the terms mothers and parents interchangeably in my discussions in order to conserve the anonymity of the fathers on the group.

Many of the topics raised in the initial telephone interviews were spontaneously referred to on the Facebook group, with members continuing to contribute to a vibrant, dynamic community that waxes and wanes as MCADD features more or less prominently in their lives. Anonymity on Facebook is hard to achieve, however by making the group private, non-members of the group are unable to browse through the comments, and these conversations do not appear on the participants' personal feeds. As advised by Boellstorff et al. (2012), I have also refrained from copying statements verbatim to prevent search engines from finding them, and have used pseudonyms. Like Boellstorff in Coming of Age in Second Life (2008) I was an active member of these groups, although I tended to post my observations after the rest of the research community.

The hand of the child

To capture the voice of the child I needed to capture ‘the hand’ of the child. Children ‘do’ voice, they give their opinion through physical activities, not necessarily through verbalising. As previously mentioned, a crucial aspect of this project was that the child’s voice was included. Spyrou proposes that:

Instead of taking an uncritical positioning of children as agents, children’s particularities as a social group should be continually considered. Despite the
currently widespread interest in childhood studies, children probably never initiate research projects, let alone consume the knowledge produced in the same way as adults would. (Spyrou 2011, 161)

To achieve this, while reflexively acknowledging the “mess[y]… multi-layered of nature of meaning in ‘stories’ that research produces” (Spyrou 2011, 162), multiple, time consuming methods were required, especially as many of the participants were so young. Much as O’Connell (2013) found, due to the broad age range of the participants, different techniques worked best with different ages. I chose techniques and tools particularly suited to an ethnography of children using artistic and sensory cues (Christensen and James 2000a). In addition to the participant observation described in the first part of this chapter, that took place over a period of two years, I also undertook several tasks/ projects with the children, in sequential visits. The first of these included the assent form and familiarisation with the digital camera, a Canon IXUS. The second was body mapping and drawing. This was then followed by a combination of photo voice and photo-elicited, child-led interviews; where participants were asked to take photographs about various aspects of their lives and these photos used in the interview process (Hughes 2012, 40). The final two stages, once the children and I had established a relationship, were use of the Metaphor Sort Technique (Dell-Clark 2004) and storyboarding, using comic scripts, toys and images. While this was the planned trajectory, it did not always play out according to plan; unexpected hospitalisations, children not wanting to participate on a certain day or other activities would change this and I followed the fluidity of daily life and activities.

I used graphics to explain what I was doing,21 including who I was, and what I was trying to learn. I phrased this in terms of finding out how children feel about being well and unwell, as opposed to MCADD for two reasons. One, I wanted to assess what the child’s understanding and knowledge of MCADD was and two, in some cases the parents had not
specifically told their children they had MCADD for a variety of reasons and I wanted to leave this open for the families to choose to what extent they wanted to discuss it. The fact that I was doing the study obviously alerted attention to this but I left it to the parents to decide. I specifically asked if it was ok to:

A) spend time with you at home
B) be with you when you have clinic visits
C) visit you at school
D) visit you in the hospital.

I also explained that I would be taking photos and video, talking to teachers, parents and doctors; that nothing in the study would hurt them or cost any money, and that I wanted to draw, tell stories and play games. I checked that the child understood each point and made notes about their answers. I also explained what my recorder was and how it worked and in several cases the children would eagerly bring me the recorder and help me set up the activities.

While some children were very distracted during the assent process, wanting to play with the equipment, open the camera box or do something else (another challenge) the majority took a keen interest in the proceedings, asking questions and in the case of one boy, Jake, age nine, being very specific about what permissions I did and didn’t have:

Jake: If it’s ok with you, I’d rather you didn’t come to my school.
Pauline: Even if no-one knows who I am or that I’m there observing you?
Jake: Yes. I don’t want any of my friends knowing. MCADD is a family thing. It’s private.

Jake’s brother George, age seven did not share his older brother’s reticence and was apparently indifferent about whether I came to his school or not.

Children chose their crayon colours very carefully and coloured in the assent ‘smiley’ and those that could, wrote their name. Many embellished these with extra emoticons or
pictures and chose different colours; there was no time limit on this exercise. Those four years old and upwards each received their own camera and I gave them the box to open and gave them a lesson on how it worked. At the end of this dual assent form/ camera process, which didn’t always happen simultaneously and often took several hours, the children and I had established an initial rapport.

I initially had not intended to include young siblings in the participant activities, but it quickly became clear that siblings already felt they received less attention because of their siblings’ health. I made sure that each child in the family had a small box of crayons to keep for themselves after the body mapping and drawing exercises and extended the camera use to siblings, under the proviso that they kept track of who had taken which photos. The children were very proprietary about their photos and proud to show them off, although this enthusiasm waned over the volume of images.

As James, Jenks and Prout (1998) note, children are often more adept at expressing themselves through drawing and stories, as opposed to a formalised interview process. Dell-Clark explains:

Such tactics build on an expectation that an interview is, in part, about an exchange (“inter”) of looking (“view”). Incorporating visual approaches can extend the modalities through which a researcher attempts to connect and see eye-to-eye with a child. (Dell-Clark 2011, 138)

Thus, in addition to participant observation, story telling and gathering sound, photographs and the children's drawings as data, I also used these drawings and photographs as visual and sensory tools for the children to participate in discussions about what they represented (Dell Clark 1999, 2004, 2011; Dryden et al. 2009; O’Connell 2012).

The task set was as follows: Draw an outline around your body. This was done by siblings, a parent or myself according to the child’s wishes, in a crayon colour of choice. They helped me set up the equipment, roll out the sheet of paper, measure and cut it. I then
asked them to draw anything on the picture that could tell me it was them. Some wrote their
name and drew clothes. I gave them about 20 minutes to do this before moving on to the next
task but kept the timing loose — if they really wanted to keep going, they could. I then asked
them to add anything that would tell me that their paper identity was happy and well; a smiley
face, a football. They were asked to add their favourite food and show me what they thought
happened to the food when they ate it. We kept up a running dialogue as they did this, with
the children telling me where they thought it went and what it did. Finally I asked them to
change the picture to show me what would happen to it if it was unwell. Some children
readily added a ‘vomit bucket’, thermometer, hospital cross or teddy bear. Others appeared
unsure what to do. Still others baulked completely and wanted to do so on another body on
the other side of the paper, which I readily complied with.

As Mitchell (2006) notes, “the central methodological problem is that the inside-out
view of the body is an adult and scientific one.” However, many of the children handled this
confidently, in one case drawing tubes in the belly region to show where the food goes, or in
another, a detailed map of the female reproductive system. The first gained this knowledge
from school biology lessons, the second from a children’s library book. Others approached
the activity with some anxiety, as if it was a test, even though their mothers told me they had
done a similar activity at school.

Children also drew pictures, some spontaneous, like a portrait of me wearing a
ballooning, black dress, others I requested, for example, a picture of their lunch box. I both
filmed and audio recorded these activities, letting the child explain what they were drawing as
they went, paying particular attention not only to what they drew and said about the drawing
but how they went about doing so in order to mitigate an adult perspective or interpretation
on what the images could mean (Harrison 2002, 864).
Cindy Dell Clark argues that “visual, metaphor-derived modes of interaction… can be instrumental” in interviewing minors (Dell Clark 2004, 172). She builds on established play therapy theory (O’Connor, Schaefer, and Braverman, 2016; Schaefer and Cangelosi 1993; Singer 1993) to outline a discourse where children show as well as tell what they want the researcher or therapist to understand. I was interested in the Metaphor Sort Technique (MST) that Dell Clark used “to directly make use of visual metaphor as a means of engaging the child through a hands-on, interactive activity” (Dell Clark 2004, 174). She used the MST in a study with a group of children with asthma and diabetes and I wanted to see how children with MCADD would respond to a similar technique.

I asked the children to set up two black boxes that are folded together. They could choose which box represented MCADD and which box represented everyday life. I tried not to prompt them as to whether it was associated with illness or food. The child then had to pick from 14, A5 numbered photo cards that were laid face down. I asked them to describe what they saw, tell me how it made them feel and to then sort them into one of the boxes.

The images were chosen to cover a range of positively and negatively associated stimuli and included images suggestive of things I knew impacted on the children’s lives, in particular, food, time between meals, activity and the location of Starship. Pictures included: 1) an orca in a glass bottle, set in a desert wasteland with a dead tree; 2) a picnic table in long grass and foliage; 3) a child hanging on to the arms of a life size alarm clock; 4) a close-up of melted chocolate; 5) Auckland’s skyline as seen from the ocean; 6) the head of a yellow and black snake glimpsed through grass; 7) a ground level view of yellow and red tulips against a blue sky; 8) an arc of fire created by a mine worker; 9) a colourful, empty playground; 10) the swirling purple interior of a sea anemone; 11) a cottage in an autumnal forest; 12) a coastline silhouetted by an orange sunset; 13) three miniature ponies; and 14) snow capped mountains and sea ice. A selection of these can be seen in Figure 3.4 overleaf.
Figure 3.4 A selection of images included in the Metaphor Sort Technique (MST) toolbox
Children took the activity very seriously and were very consistent with their interpretations, even if it was contrary to what I anticipated. For example, one girl, aged five put everything she viewed as dangerous or frightening into the non-MCADD box and all pictures she said made her happy into the MCADD box. Her older brother did the opposite. Sometimes adult family members would try to intervene, to ‘correct’ the child’s understanding, as did siblings and I gently reiterated that each person would have an opportunity to report their observations on the image.

I tried to ensure each child (siblings included) had a private space to play the ‘game’ and after the activity, redid it with siblings and sometimes adult family members, which stimulated quite deep discussion about the impact of the condition on daily life. While it generated quite different responses to Dell-Clark’s study, whose participants were very clear about their conditions and its management, the MST was the most successful method in revealing the children’s feelings towards MCADD, the ambiguity of this ‘shadow’ in their bodies and lives and the difficulty not only for them in understanding it, but that of adults as well.

The majority of children who participated in the MST were over the age of four. Some children did not participate as they did not have the verbal skills to articulate this or as this activity was not conducted with them. There were three distinct patterns of choice when it came to which box to place an image into. The first linked MCADD with ‘happy’ feelings. This was the ‘good’ box. These participants consistently put every image they identified as happy or good in the MCADD box.

This included for example the family of ponies and chocolate. The second pattern appeared to be inconsistent. For these participants it didn’t seem to matter which box they put the image in, what was important was the sentiment expressed during the action, e.g: “this is scary” went into both the MCADD and non-MCADD box, as did “happy”. The third choice
(made mostly by siblings and older children), linked MCADD to “survival” and images that were described as “scary”.

Only a small proportion of participants put images into the box I had assumed they would associate MCADD with, and these were mostly older siblings who shared the task with parents of ensuring their younger siblings were fed regularly, and older children who had experienced multiple hospitalisations or ‘scares’ in infancy that they had been told about.

Some of the limitations with this method were that the children were prompted to think of MCADD, as opposed to generic health questions. They also had to know how to articulate their feelings (however, the school curriculum that the children were enrolled in seemed to equip them with the skills to do so). The metaphor sort technique did work well as a tangible way for the children to emotionally and visually represent what they think through metaphor.

**Storyboarding**

Three sets of siblings participated in a storyboarding exercise using an app called *Comic Strip Pro* (Roundwood Studios 2014). Out of the six children, five with MCADD participated. Each child had the opportunity to create a storyboard with me on their own and then each set created a joint storyboard. This was the final activity in the set of methods I used and was introduced once the children had familiarity with me. I wanted to specifically explore the children’s understandings of MCADD so set a loose script for them to follow. The main character could be anything or anyone they wanted but that character had to have MCADD. I did not explain or expand on what MCADD was. I introduced an inciting incident; the character might miss breakfast and left it to the children to explore why and what the character was going to do about it. We used my tablet as a camera to photograph images such as Lego pieces chosen as avatars, a house and a toy. The exercise was supposed to be ‘quick and dirty’, able to be completed quickly and effectively. The shortest storyboards
had four frames, the longest eight. We also sourced images on a laptop and photographed these for inclusion. Children were creative with their choices, laying Lego pieces against the image of a bed on the laptop to show them sleeping and using props found in the house like a kitchen bowl. The children picked their own fonts and colours from the selection available.

As will be discussed in detail in Part III, the stories revealed the social fabric of these children’s worlds. Kate’s story of a boy with MCADD showed an ordinary school day, with no other reference to MCADD (Appendix C). Her concerns were about school work and fears of going to “the naughty corner”. Jake’s character picked up some chocolate donuts from the dairy in response to “missing breakfast” and then proceeded to his main interest, rugby. In contrast Kate’s sister, who has had more hospital admissions than Kate, crafted a story about her Bear’s visit to hospital, where she leaves him to go skiing (Appendix B). She was very particular about finding an exact picture of the hospital she had been admitted to for use in the story.

**Analysis**

Interviews have been transcribed verbatim with qualitative analytic coding carried out in two phases, line-by-line open coding followed by focused coding on items of particular interest (Emerson, Fretz and Shaw 1995, 143). I initially searched for broad themes guided by my research aims, objectives and the literature already discussed. Drawings, film, photographs and any other research outcomes have been similarly coded and analysed. I used NVivo software to do so (http://www.qsrinternational.com).

NVivo is software designed to be used for the storage, analysis and visualisation of qualitative data. It is ideally suited to a multi-sited, mixed methods project as it allowed me to import data from multiple sources such as text, audio, video and social media content and then code, visualise and map the data in a central location (Richards 1999). While this was
not the sole means of coding data, it was a useful way in which to manage the large volume of data generated by the multiple methods falling under the umbrella of participant-observation, data that began with a single diagnosis.

**Reflections**

One of the aims of this thesis was to experiment to discover what methods are most effective in empowering children to communicate their understandings of abstract medical concepts. Multi-sited, mixed methods proved to be an appropriate way to gather data from different participants with different viewpoints of living with MCADD, or a family member with MCADD, with visual methods proving to be a particularly useful tool when working with young children and those who were not as verbally confident as their peers. These elicited finely nuanced narratives that showed what was important in the social world of these children. Conducting research as an anthropologist ‘at home’ in New Zealand, and as an ‘insider’ forced me to reflect on the role of affect in my research, and led me to further consideration of what sensory anthropology could contribute to the study.

**Conclusions: Part I**

In this thesis I set out to discover whether individual personhood changes in relation to the lived experience of a potential, future illness diagnosed at the beginning of a child’s life; how this diagnosis shapes children’s health identities; the impact on family expectations prior to diagnosis and how children understand and shape this diagnosis. I have outlined how medical anthropologists are moving towards understanding chronic disease as chronicity – in relation to a process of identification with a disease and that diagnosis disrupts the idea of the ‘perfect child’.
I have argued in Part I that the diagnosis of MCADD creates new subjects (Rose 2001), that of the ‘disordered child’ - a geneticised subject - and her parents. Parents are carriers of the disorder and thus genetically responsible for their child’s condition, as well as responsible for ensuring that symptoms do not develop by ensuring children are fed.

Part I has also examined how the diagnosis of a genetic disorder like MCADD contributes to an ongoing discussion about the molecularisation of personhood and what this could mean for a child. It has situated MCADD and the participants affected by the diagnosis in a nationwide field and discussed the challenges that this has brought to the study. In short, Part I has laid out the terms of this thesis in brief, much as the initial diagnostic letter lays out the treatment and potential ramifications of MCADD.

It is therefore fitting that this work starts with the letter that marks the diagnosis, and the ongoing relationship that the patient and her family will have with the New Zealand health care system. It is the first of many clinic letters that the children will receive, stored in hospital databases, copied to GPs and filed at home, with school records and taxes. These letters chart and create a web of social meaning in relation to the child’s health identity and will become part of the ongoing politics of everyday life — the minutiae of which I chart in the following section.

Part II examines how the diagnosis creates a medicalised body, and what the daily lived experience of this body entails. In the following chapter I will explore how parents take on responsibility for the care of their infant and grapple with the diagnostic uncertainty that preventative medicine is composed of. I discuss how infant feeding is medicalised and how, when that fails, treatment is escalated to a hospital admission.
PART II:

“I’LL NEVER, EVER EAT AGAIN” —

THE CONSTRUCTION OF MCADD IN

THE CONTEXT OF DAILY LIFE
Children’s Hospital — Day 4: Wednesday 14 January

I’m looking out the window at the cityscape. It’s not often that I get to look out, I’m usually focused in, into the sealed room, into the bed, into the IV, into my child’s eyes as I soothe her and tangle her hair, into my heart and soul as I think why? I’m so tired. I’m tired of the flu making its way through my family, picking us all off one by one, leaving Lola till last so we think we’re home free. I never thought I’d be so stressed about the flu. I’m coming to my journal far too late. I’ve repeated myself to every doctor and every nurse at every shift change, every family member, every concerned friend.

This is night five. It’s a small area to inhabit and I walk the same pilgrimage daily — from my seat to the bed, to the en suite bathroom (lucky), to the kitchen to make her a sandwich to tempt her. Peanut butter, cut in triangles and a piece of marmite toast. Occasionally, when she’s sleeping, a cup of tea for myself. I always make too much food as I know the one time I don’t will be the time she’s on a roll and by the time I get back with more the moment will have passed.

I reread this and laugh. It sounds so melodramatic, like she’s dying. I know we’ll be out of here as soon as the bug, if that’s what it is, has passed. That’s more than I can say for a lot of the kids in here. But it’s hard to remember that and I’m tired. Tired of having to be stoic when every meal rumbles with potential battle. Tired of having to wonder what’s going on in that tiny body...

It’s 21:00 and the helicopter is flying in and I wonder who it holds and why. I want to cry. The drip creaks its dextrose into the bloodstream. It sounds like it gives a stealthy squeeze. The last lemon and strawberry twirls of summer light have popped. I can’t put the lights on so instead I reflect. I document 62 ‘events’ over 24 hours. I know I’ve left some out because they happen so often I can’t scribble down what happened before the next one. This is my day...

5:00. Lola wakes up crying, my three-year old, a ‘big girl’ now. The fever soaked her bedding. The IV’s ‘gone bad’ in her hand. New nurse Lisa takes it out. We like Lisa. She’s wearing a cute cartoon shirt and gold nurse watch. They’ve all got different ones — the kids seem to like them. “Leave the IV off,” Lisa says. “She should have enough fluid. The doctor will be fine”. I say: “unless the specialists have specifically authorised that, the IV stays in.” I hate having to do that but she’s ok about it. I worry for kids whose parents don’t speak out. I worry for Lisa. It must be so hard to deal with dying kids and then us marked with invisible disease, just in for a cold or the flu, parents of both looking after their own. They put the numbing cream on her ‘old’ hand and both arms and again I find myself explaining: “her skin reacted to it last time”.

My little girl’s skin, raw and paper thin, resisting.

6:40. I’m dressed and ready. I text Mike to say still no luer. I forget to tell him I love him.

7:00. Nurse Lisa takes us to the Treatment Room, away from Lola’s ‘safe space’ (Room 5). I carry her. We discuss the site. Lola’s left hand and arm are swollen and tender. Lola is screaming. “I’m hungry, I’m tired. Stop doing this to me, take it out”. She thinks if she just eats something, they’ll stop. She thinks it’s her fault. Lola’s sitting on my lap, arms looped under
mine to restrain her. House doctor James says, “Here’s a scratch” and then again, which makes me think he had to try another vein. I wish they wouldn’t. It’s not a scratch and she now freaks out if we so much as mention a scratched knee. What’s taking so long? I tell her she’s very brave. Lola says: “I’m not brave, I’m scared.” I say it’s ok to be scared. They wrap her hand, I remind them again to leave the thumb out. Nurse Lisa is lovely, all smiles. Lola likes her.

Over the next four hours, there are nine interventions: Pamol for her fever, a play specialist — twice with Mr Potato Head and the Monkey Barrel (Lola’s not impressed), then playdough — general obs, the metabolic dietician Christine and...

9.45: Maria, the metabolic nurse. She tells me they’re expecting another metabolic on the ward tomorrow and another on Friday, not MCADD though. That means it’s pretty serious. If you’re going to have a metabolic disorder and had to pick one, you’d pick MCADD. I hope those kids are going to be ok. She leaves.

10.00: Peta, metabolic specialist arrives. Yesterday she told me we’d be at home treating this if Lola would take her Pamol. Today she says we’ll definitely be in overnight. It’s a blur.

Three more interventions... obs and someone bustling in and then out.

10.30: The dietician returns, asks: Is there anything she can do to make it easier, like some juice? Yes please. She says she’ll send it up, either on the lunch tray or they’ll be in the kitchen. I find out later it’s the locked staff one. I miss my friend Anna. She’s been there when Lola starts vomiting and we’re not sure if we’re going to have to go in, calling relatives for Sammy, packing a bag, driving the distance. As if she knows what I’m thinking, Anna arrives, with a hot choc. for me and coffee for Anna. Hot choc. is the best thing I’ve tasted, like sweet humanity in a paper cup. We chat cycles: illness, her upcoming cycling trip, pregnancy and the work loop. I don’t know how I’m going to get work done. I don’t even care but Auckland mortgages don’t pay themselves, we need two jobs for one home. Through all of these visits Lola just watches TV although I think she pretends to and listens to us all talk about her and over her. I didn’t get lunch yesterday and neither did Lola. I reheat some leftover chicken for lunch.

11.30: I check Lola. She’s slumped and feels warm so I press the call bell.

Three more interventions... Change nurse, Beth, for her temp: 38.3 and more ‘PR’ Pamol. Again to do obs; pressure and heart rate (‘bear hug’ and ‘glow worm’). I’m proud of Lola. She’s not freaking out.

11:55: Finally, peace and quiet. I’m suddenly drained. I should nap when she does.
12:00: I have to hold a crying Lola down, forehead and arms, so house officer Nicole can check her throat. Lola’s decided that the stick the doctor used in ED on our admission (seems like a lifetime ago) made her tongue sore and she is now scared of throat checks. Red tonsils. Antibiotics.

12:40: I text child minder Nell about Sammy. I’ve abandoned my other sick child. Nell texts us a pic of Sammy looking cute but pale. Guilt; I should be there. I’m needed here. Lola gets to ‘talk’ to Sammy. The sisters breathe down the phone at each other.


13:50. The plaster from Lola’s IV flaps. “Should I take off your plaster?” “No, it’s sore under here”. I hope the IV hasn’t gone bad again. I just found out dextrose is really hard on the veins but I don’t want the NG. Once was enough for us. The play specialist stops by with a medicine contract for Lola, where she agrees to take her medicine (she doesn’t). My kid adds 1001 clauses. I try to work, sending zombie emails from the apocalypse.

Interventions/interruptions x 4: temp. 37.8, obs, play specialist, preschool phonecall

14:30. It’s just us and Lola’s looking really tired so I put the TV on and hope she’ll drift off. All the rules are out the window, along with my patience. I seem to have lost it in the night.

15:00. Lola finally falls asleep. I’m so relieved, I just want her to get better.

15:05. Typical. The IV starts beeping. Message ‘VTBI done’

Interventions/interruptions x 5: My friend with a bag, obs x 2, metabolic nurse x 2.

16:00. I keep my eyes shut. I feel like two in one — a small, warm, feathered bird rolled up with a scratchy hedgehog; so grateful for the care my daughter is receiving, feeling undeserving; scratchy with tiredness, with fear, for feeling undeserving. Keep telling myself how worse off others are. Remind myself how lucky we are. Ignore the shuffling feet coming in and out.

16:25. Wakes up with a fright. Cries. Lovely Sharon brings her a peanut butter sandwich, Lola asked for it but now doesn’t want it. That small act looms large. I know how much Sharon has to do: machine maintenance, one of her many small bodies.


17:50. Peta pokes her head in. Asks if temp. I know that temp = problem, energy out. But Lola has IV = energy in, which balances it all out. I appreciate Peta checking in.
17:56. VTBI stopped. Sharon reset it for another 2 hours. The earlier rate was taken down from 80 to 50% (down to ‘maintenance’ – is she a car?) to encourage her to eat and drink. Poor kid. It’s back on her. You’ve got to eat. You’ve got to drink. Even if she feels ill.


19:00. Sharon came in, took trays, and food log: 1/2 bowl chips, 125ml juice. Lola helps: “My daddy buy hot chips. For me and him and mummy to share. My family.”


19:40. Lisa arrives for obs. “Lady, I like that one. I know how to do it”. Lola happily lets Lisa take her temperature (38.3), ‘bear hug’, then the glow worm. “It’s sore on my skin, on the other side” she shows me evidence, an ulcer in her mouth – she says it’s from the medicine.

20:20. When did blue sky purple to black? Another hospital night. Despite my whingeing I know Lola’s safe now, better than at home with us setting a two-hourly alarm, firmly instructing, then pleading, begging, threatening for her to drink then hoping she keeps it down. 125ml, roughly half a cup of sweet syrup, or 3 shot glasses – it never seemed so much to me until now.

Interruptions/interventions x 5: IV bag change, bedding change, Lola toilet, teeth brush, obs

22:50. Cuddle her to sleep. Anticipate midnight wake up for obs and Pamol. That gives me an hour’s sleep. I raid the hall linen closet for a blanket. Note to self, need slippers and a headband.

Interruptions/interventions x 5?, x 10?: hand and pump check, obs, temp: 37 something, drip occluded x 2. I half register through milky night vision.

6:00. Light flicks my lashes open. I’m under the window, a natural target. Lola’s awake, half. Crying a bit. I climb into the bed with her until she settles then go back to bed.

7:00. Shift change. Mike calls. I’m awake, fully dressed. I remember the ‘love you’ this time. The helicopter clatters outside, like a big bat trying to get in out of the light. I’m desperate for fresh air. Lola moans in her sleep.

We finally leave two days later and my records changes. I now monitor two sick children at the weakly wagging tail end of the flu, pale, wan, unhappy. They fight over me like a mouldy, beloved teddy. I write down what meds they have and when the next is due as I’m so tired I won’t remember. I note what miniscule amounts Lola eats and how much polycol she is having in between so her body rides this out until she is better.

The discharge letter arrives in the post. A single sheet.

The cause of it all? Not MCADD.

“Suspected viral infection”.
Chapter 4: “How much is enough and when should we hospitalise?”

Newborn screening, MCADD and the medicalisation of infant feeding

The creative diary on the previous pages represents the end point of medical uncertainty, where the child has been hospitalised. It is represented in a font that resembles handwriting to remind the reader that this is a montage of the personal; the interior, subjective world, not an emotionally objective encasement of a patient (Foucault 1994; Kirmayer 1988). The diary itself has been constructed from participant diaries and handwritten notes during children’s illnesses, hospital observation, and personal experience as an alternate writing of ethnography, a way of enmeshing reader and participant in the emotionally dense, fleshy, sensory world of parenting a child with chronic illness. As a result, it is truncated, repetitive, at times, boring. Mothers (and it is usually mothers) write notes to soothe themselves and chart their child’s progress, and as a tool to answer specific queries. Time blurs and interruptions are seemingly incessant. It is sprinkled with the liberal use of acronyms: NG, IV, ‘obs’ and others. They are by now a part of this world.

The diary compresses the intense emotional range of learning to become part of this world of caring for a child with chronic illness. This chapter examines the processes that have led to this point of hospitalisation. It explores how these processes construct MCADD as disease and how this leads to the medicalisation of food during infancy, setting up future ingrained habits around feeding in later childhood. This is a journey that parents expressed by way of four key themes: i) that their baby will always be an ‘MCADD child’; ii) the shock of having to contend with the diagnosis and everything that comes with it; iii) that feeding their baby either by breast or bottle becomes extremely stressful; and iv) a sense that any non-specialist such as a GP, midwife or registrar will not know what it is, how to treat it, or how severe it is (with several mothers stating that medical staff do not read or ignore the notes
stating the child has MCADD). These themes, the focus of this chapter, chart a parallel journey of ‘rites of passage’, that starts with the diagnosis and ends with the first hospitalisation, usually in the first year of life. The period in between is interspersed with learning how to manage the condition, the small trials of daily parenting — much of which revolves around feeding a child, and negotiating their child’s shifting health identity. How do parents construct MCADD on a daily basis? How are children’s health identities post-diagnosis constructed and enmeshed with an existing medicalisation of infancy and a tendency to objectify child bodies as needing to subscribe to age and developmental related standards (James and Hockey 2007, 137).

The creation of patients, both infant and otherwise, begins at the initial diagnostic clinic. In addition to creating the genetically ‘disordered’ subjects discussed in the introductory chapters, I argue that MCADD is socially constructed as disorder and disease through its management in the first fraught year of life and by the physical spaces where this management takes place. I discuss the role of the clinic in this process and how the medicalisation and measurement of infant feeding, already prevalent within middle class New Zealand (Anderson 2015), is exacerbated by the diagnosis.

In the following section I examine the ‘parent-patient’ experience and how this idea of an ‘MCADD child’ sets up a framework within which family social life will be conducted. This brings about a moral dimension linked to the discourse of the ‘good mother’ that will be also be further discussed.

4.1 The creation of the parent-patient

Parent-patient is a term I use to describe the parents of infants with chronic illness; the parent shares the role of patient. Mothers in particular embody the patient experience. They often wear their children for extended periods of time, and in many cases, it is their
breastmilk that nourishes the infant, whether by bottle or breast. They take the part of the patient in clinics with children, ‘speaking’ for the infant, interpreting their non-verbal cues and providing context for medical professionals. Trnka observed similar behaviour with asthma patients:

Mary shifted between describing her son’s condition and her own, often melding the two together. Other mothers who don’t have asthma themselves similarly cast themselves — both discursively and sometimes physically — into the position of their children in order to respond to their conditions. (Trnka 2017a, 61)

Scholars have written about the patient-expert (Dumit 2006; Epstein 1995). Trnka and McLauchlan (2012) extend this concept to that of the parent-expert, exploring how parents control children’s asthma with pharmaceuticals and engage in familial care experiments to preserve childhood normality (Trnka 2017a, 56). I further extend this concept to talk about the parent-patient who shares and embodies the sick role played by an infant patient.

This management is necessary due in part to the vulnerability of all infants in the early stage of life and to the ambiguity of the condition and its effects on young patients. This ambiguity derives from the construction of MCADD as both normalised and manageable, yet potentially acutely life-threatening. The management of other chronic illness in New Zealand shares a similar ambiguity. Trnka (2017a, 73) describes “how ‘asthma’ gets constructed as something that can be dismissed and normalised and yet simultaneously requires constant surveillance and at times the use of quite intensive medical intervention”. Park reports a similar, normalising approach with young haemophilia patients in New Zealand, where children are able to live ‘normal’ lives only through adherence to regular treatment (2000; Park et. al., 1995).

The diagnosis of MCADD leads to medical uncertainty which further exacerbates the ambiguity linked with the condition. Because of this ambiguity, parents have to make moral choices about which actions will best contribute to the well being of their child. The idea of
being a ‘good’ mother (Anderson 2015) underpins their decision-making, turning feeding into a site of moral decision-making. This then sets up the parenting habitus explored in the following chapter where parents adopt a set of learned dispositions around feeding their children aimed at preventing MCADD from presenting. Spatially this ‘illness habitus’ links to home and temporally, to approximately the first 12 months of life.

Already a space where morality, science, tradition and social practice intersect, feeding becomes a medical solution that staves off serious complications as long as it is done every few hours. An example of the building tension can be seen in the following conflicting advice aimed at expectant mothers.

It is important to make sure the baby has a good milk intake. A term baby should be fed every three to four hours from birth…. There is a particular risk of problems in the first 72 hours in breast-fed babies, since the supply of breast milk is often poor at this stage. These babies may well need top-ups of formula milk. Because it is hard to know how much breast milk is being taken, there is a strong case for giving top-ups routinely for the first few days until a good milk supply is established. (Starship Metabolic Services 2011)

Breast milk is the only food babies need in the first 6 months. We recommend that you continue to breastfeed baby until they are at least 1 year or older, and that you start introducing solid food around 6 months. (Plunket 2015)

The above messages are starkly different. The first is taken from the New Zealand newborn emergency protocol for a newborn with an older sibling with MCADD and thus potentially also a baby who will test positive for the condition (Starship Metabolic Services 2011). The second is from Plunket, New Zealand’s “…largest provider of free support services for the development, health and wellbeing of children under five in New Zealand” (Plunket 2015). They contrast the difference between the socio-cultural expectations placed on mothers of infants both before and after birth, with that of newborns who are diagnosed with MCADD. Contrary to health education messages in most countries, many new mothers experience
difficulties with breastfeeding in the first few weeks (Anderson 2015; Maher 1992; Murphy 1999; Wall 2001). But whereas most new mothers of newborns without medical conditions are assured by health professionals that baby and mother will learn to breastfeed together with no ill effects on the infant, mothers of babies diagnosed with MCADD are told the child cannot go to sleep without a full stomach. I argue that the precautionary nature of the treatment of this disorder, and the inability to quantify how much milk each individual child requires, coupled with the socio-cultural importance that food holds within families, leads to a state of uncertainty about the best course of action to ensure good health outcomes and that this uncertainty is derived in part from the shifting nature of preventative medicine. This is illustrated in the letter sent out to the parents of patients that states:

MCAD deficiency is an inherited disorder of fat breakdown and one of the commonest inborn errors of metabolism. *Most of the time patients are healthy and do not require a special diet. Infections, fasting or vomiting can lead to serious illness with encephalopathy (drowsiness, seizures etc) and a risk of sudden death.* (Clinic letter from Paediatric Metabolic Service, Levi, August 2013, own emphasis)

The diagnosis thus creates anxiety for the parent, particularly during infancy and when the child is unwell. As in other studies (Raspberry and Skinner 2007; Timmermans and Buchbinder 2010), I found that additional stresses include first, the diagnostic uncertainty of the disorder as neither specialists nor parents know if the disorder will become symptomatic and second, the contradictory messages parents receive as medical teams try to relay the potential severity of the disorder in a manner that does not cause undue panic in parents. These stressors are examined further in the following section through a consideration of what internal (Ryan, Bissell and Alexander 2010) and external (Murphy 1999) moral work mothers undertake to understand and frame their new sense of self through the experience and expression of feeding their infant in the first year.
4.2 Diagnosis: An uncertain certainty

The historical development of the medical specialisms of paediatrics… within western medicine can be seen as the outcome of medicine’s attempts to engage with the very instability of human embodiment. (James and Hockey 2007, 138)

In 2014 a storm raged across the country. I remember this because I was talking to my first research participant, Michelle, on the phone and at times the dual cacophony made it hard to hear her. She lived on the southern tip of New Zealand’s North Island and had a two-year old diagnosed with MCADD. I was almost 700 kms away, north of Auckland, with my own two-year old and a six-month old baby. We swapped notes over the phone, lamented sleepless nights, two-year-old tantrums and compared tips and strategies. It was similar to my conversations with friends of young children without MCADD; most of the conversation revolved around food and eating; what to feed them, when to feed them, how to feed them and the biggest conundrum, how to get them to eat when they don’t want to.

I asked Michelle if she thought the diagnosis had changed her life.

“Yes” she said and laughed.

“I’m always grumpy at dinner time, having to smile and say ‘well done’ even though he’s only eaten a tiny bite and it’s taken 20 minutes to do even that. So yes, it’s made me slightly more uptight about eating and food, especially as I’m a rubbish eater. I’m really picky and I don’t want him to be like that”.

After a pause she continued, “We were just lucky that he was so small when he was born that I was already feeding him three hourly so when the midwife told us [about the MCADD] it didn’t really change my schedule that much”.

Diagnosis is commonly a “tangible sign of ‘real’ illness and ‘genuine’ claims to particular types of behaviours” (Townsend 2011, 97). In patients suffering from unspecified symptoms, a diagnosis can bring closure, a set of actions to follow and access to help. Townsend draws on Bourdieu to explain:
As such, the GP consultation provides economic capital (sick or disability pay) and symbolic capital (validates illness and benefits claims) but also has the capacity to act as symbolic violence (in accordance with dominant values about appropriate illness behaviours and making authentic claims to a ‘sick role’). (Townsend 2011, 97)

In the case of MCADD, the diagnosis is also nullified by the claim that the child is fine so long as they are well and eating.

As Fitzgerald (2008), Park (1995) and Trnka (2017a) have shown, New Zealand parents are “structurally encouraged… to take up more active roles in determining their child’s health needs” (Trnka and McLauchlan 2012, 4). This is especially true in the case of MCADD, which is viewed medically as easily managed at home with food. The conversation with Michelle turned from food to her current pregnancy. The due date was looming and she had been scheduled in for several scans as this baby, like his older brother, didn’t appear to be growing although it was still classified as a routine normal pregnancy. Despite the multiple technoscientific interventions Michelle told me about, the scans and blood tests, she never considered amniocentesis or chorionic villi sampling (CVS) to find out whether the foetus had MCADD. Gender scans, yes. Genetic disorders, no. Why?

She told me “I didn’t think about any wider responsibility, we probably should have, but we didn’t. We knew there was some kind of genetic testing you could do but we didn’t consider that either. And then [the specialist] said, you don’t really need to do that so I don’t really know what they would do or what testing they would do.”

I mention this example to foreground the wider notion of risk and responsibility already inherent in pregnancy and around motherhood. Families’ reproductive decisions after diagnosis give us a holistic view of the impact of this information and how it remained an ‘uncertain certainty’ in their lives. “Luck. Hope. Chance.” These were all words that featured regularly in conversations about reproductive choices — almost as if there was no choice and fate was completely in charge. While Michelle and others wished their children did not have
the condition, they chose to frame this in positive terms; the majority expressing a sense of relief or 'luck' that their children have MCADD as opposed to any of the other disorders in the expanded Newborn Screening Programme. However due to the ambiguous, asymptomatic nature of the disorder they also expressed a sense of guilt and anxiety in using public health resources when there are as Michelle put it, “others out there who are far worse off”. As Ginsburg and Rapp (1995, 4) observe “biomedical technologies aimed at the control of reproduction… have deeply unsettled notions of what is ‘natural’” and as I will show, are ambiguous and fluid. Michelle and Mark were following the ‘At risk MCADD newborn protocol’.

Suddenly Michelle cut the conversation short. Mark was away and one of the ewes on their lifestyle block needed help. Over the next few days I tried to touch base, with visions of everything that could go wrong when a heavily pregnant woman was alone out in a storm birthing a lamb. Finally, I received a text four days after Michael was born: “Mark was 3 yesterday so had his birthday at the hospital... Michael is doing well but his levels are up and down. But... no MCADD! Yay yay yay!”

Some of the questions prompted by the introductory case study and others include an analysis of the language of risk. The pregnant body was seen at risk, as was the foetus, assailed by unseen forces. Despite the apparent routinisation of amniocentesis, growth scans and blood tests, of the ten mothers who had an older child with MCADD and were carrying a second child, not one chose to seek genetic counselling or undergo testing for MCADD. Reasons varied from “we didn’t really think about it,” to specialist advice that cautioned against testing^{26}. Additionally, none of the parents in the study felt dissuaded from having another child due to MCADD, despite the self-reported trauma and mostly maternal sacrifice required in the early years. In order to answer these questions I needed to examine these families’ experiences and decision-making processes around reproduction.
I flew down to Wellington a few months later with my own baby and spent time with Michelle and Mark who told me more about Michael’s dramatic birth — a sudden induction due to fears Michelle’s womb had turned into a ‘hostile environment’, and one that resulted in the baby having an initial blood sugar reading of 1.9 and a secondary reading ten minutes later of 1.1. The lowest normal blood sugar level for a newborn baby is above 2.6mmol/L (Auckland District Health Board 2013).

Michelle reflected on the “overcautiousness” of staff who had all been prepped about the potential of a newborn with MCADD, something she was grateful for. She described the experience as we sat in her lounge with coffee, after the children had gone to bed.

They took him straight to neonates and I thought: “Ok, awesome, it’s started already”. Once we’d been in neonates a couple of days, we found out he’d had a really traumatic birth. They needed to get him out quite quickly and they think he just wasn’t prepared for everything and his little body was a bit shocked by the whole thing. They did a blood test and he was producing ketones, you can’t produce ketones when you’ve got MCADD, and so the doctor was saying: ‘He’s producing ketones so your 25% chance has gone down to a 5% chance’. So this was before the Guthrie result tests had come back. I thought “That’s awesome but I’m not going to get excited about it yet.” Then they didn’t tell me properly; it was weird. Everyday I’d ask them, “Have the results come in?” The nurse came in and she was chatting away to his doctor about his notes while I was feeding. She said: “Oh yeah the Guthrie results have come back with nothing on them”. And I’m like: “Hello, what was that? Pardon?” She said, “It’s all come back normal.” And I’m like, “Are you sure, can you retest it, and double check?” “No, no, no,” she said. “It’s all come back ok.” … I phoned another friend and said, “Uh, can you tell me how to look after a normal baby? I don’t know what to do.” So that was quite nice and they all relaxed a bit more after that.

This vignette reveals that by the birth of her second child, Michelle’s parenting is steeped in a habitus geared towards risk management. Her wry comment: “Ok, awesome, it’s started already,” reveals a familiarity with the processes that lead to hospitalisation:
starvation, low blood sugars and the procedures that play out once in hospital. She is hesitant to believe the results of the Guthrie that she overhears by chance saying, “are you sure, can you retest it?” and then phones a friend to find out how to look after a “normal baby”.

Later Mark told me: “They took his blood sugar every two hours, the poor little guy must have had no blood in his feet… I don’t think we want more [children] but it’s not because of the MCADD. It wasn’t something we even discussed. I don’t feel our experience has been that bad when I compare it our friends who have kids with eczema, or allergies. It doesn’t seem to affect us as much on a daily basis, and the treatment, while it can be frustrating is relatively simple, effectively the medicine is a glass of milk. [The specialist] explained in very simple terms the genetics and the maths from a statistics perspective, more around the chances of a second child having MCADD so that was a worrying time when Michelle gave birth to Michael – the odds were in our favour but still not massive”.

The notion of risk as being ‘one in four’ featured regularly in discussions with parents as they interpreted recessive genes as a Russian roulette of fate, with some literally interpreting it as one child in four in each family. For example, another participant Annie, the mother of four children, two of whom had MCADD, was in tears as she blamed herself for “inflicting this disease” on her children. “I thought I’d had the one,” she told me, “what are the odds?”

Not all families consciously considered whether or not future children may have MCADD. While I was speaking to Michelle and Mark about their newborn, on the opposite side of the city Lanie was two weeks away from having a long awaited second child after IVF and was also having regular sizing scans and glucose intolerance tests due to carrying an excess of amniotic fluid. She was fairly optimistic, saying:

I’m not too concerned about his health… I don’t know if anyone has a straightforward pregnancy, I don’t know, again I’m a pretty positive person and I feel reasonably well in myself and I sort of go on that as a good sign you know. And I deal with whatever we need to deal with at the time we’re told. I feel that my midwife has
handled things appropriately and I trust her and what she is asking me to do so we just did the tests and things and people don’t seem to be too concerned.

The text she sent me when her son was born flew in the face of that optimism: “MCADD. Not great”.

What this section highlights is that it is not just people acting as agents in shaping their own reproductive lives (Ginsburg and Rapp 1995, 9), there are power relations at play that would imply some reproductive futures are valued while others are not. Browner and Press (1995) argue that the main rationale for genetic screening for ‘disability’ is to provide pregnant women with the information to decide whether to terminate a pregnancy. Prenatal testing information available to New Zealand women seems to corroborate this as it states:

> If your results reveal an abnormality you will be told what the problem means for the child and if treatment is available. You and your partner can then decide whether you wish to continue the pregnancy. (Auckland District Health Board 2016, 7–8)

However, as I have shown, MCADD does not seem to meet the cultural criteria for ‘disability’ and all participants were horrified at the notion of termination due to a diagnosis of MCADD. Unlike some conditions that are considered to present considerable hardship for families, MCADD is invisible and despite the families in this study reporting an impact on their lives, neither families nor specialists advocated prescreening. It is viewed as, and indeed is, manageable with a good prognosis once detected. A prenatal test would not change their pregnancy care in any way, other than to suggest they pump stores of colostrum.

*The ‘rebirth’ of the clinic: renegotiating diagnosis*

While clinics and hospital admissions create social signals that mark MCADD as serious and life-threatening, what *MCADD is*, is continually being negotiated, particularly in the space between illness at home and hospital admission. This disjunct between the potential
MCADD holds to cause harm, and the lived experience of MCADD if managed well, adds to the ambiguity of the diagnosis for all concerned and is most visible through clinical narratives and during hospital admissions. Since being included in expanded newborn screening programmes around the world, MCADD has been found to not only occur more commonly than was suspected prior to screening but to also differ from what was suspected from symptomatic patients (Iafolla, Thompson and Roe 1994; Smith et al. 2010), leading Timmermans and Buchbinder (2012, 208) to declare “that any prior understanding of disease is found to be insufficient once population screening is instituted” and that diseases inevitably change with the practices they become linked to (Timmermans and Buchbinder 2010; see Mol 2002).

This has led to the “rebirthing” of the clinic as a site of knowledge production (Latimer et al. 2006; Rabeharisoa and Bourret 2009) where the diagnosis provided by molecular technologies is debated and finessed. This process, which Timmermans and Buchbinder (2012) refer to as “bridging work”, is conducted in the clinic. The clinical gaze now focuses on the relationship between the “observed body and the dispersed images of pathology” (Latimer et. al. 2006, 604), with this relationship being negotiated between, in the New Zealand case, metabolic specialists and the Lab. These discussions determine which images from a deck of bloodwork, DNA analysis and urine analysis — molecularised images not accessible to the untrained eye — do and do not determine the diagnosis of disease. There is no cookie cutter, the definition of what readings constitute a particular disease can and do continue to shift. The observed body is that of the patient: the child.

I argue that the clinical experience frames and foregrounds every experience the patient has about and around MCADD, however, it is not the only site of knowledge production; the experiences of illness at home and in hospital add to the different forms MCADD takes as it is socially and sensorially constructed in relation to individuals. If illness
is history “written on the body” (Mattingly 2010, 80) then, as the next chapter will show, genetic conditions such as MCADD scribe in invisible ink, made manifest in toddler food wars. There are no visible scars, shortness of breath or paleness, just the (mostly) unspoken threat that if children do not eat, especially when they are unwell, that something could go wrong.

It was clear from all of the participants that despite their hopes and dreams for their children being altered, sometimes radically after the diagnosis of MCADD, they still did not perceive the risk of MCADD to be worth risking the life of their unborn child with invasive procedures such as amniocentesis and CVS. Additionally, it would appear that health professionals subtly discouraged genetic counselling by not actively promoting it. Risk implies uncertainty, however these parents have learned from experience with their first child with MCADD that they will have uncertainty well after the birth of the child; is she eating enough, is she presenting, does she need to go to the hospital, is she tired and sore because of normal childhood activity or because she is deteriorating? Parents routinely report how ‘lucky’ they are, that in comparison to other visible ‘dis’abilities and chronic illness they have no cause to complain. Finally, without a confirmed diagnosis, there is always hope that they will be the ‘three in four’ and that this child won’t have MCADD. And even if it does, again experience has taught them that ‘it gets easier’, an oft repeated refrain, with every year.

In some cases, usually those where a newborn had gone straight to a neonatal intensive care unit (NICU) after birth, mothers were unaware their child had MCADD and after diagnosis expressed a need to be proactive due to, in their view, the failure of healthcare professionals to identify and respond appropriately to the problem.

Lily's story of how she found out about her three-year old son's disorder shares similarities with many of the mothers interviewed:

We had a very complicated birth with Michael and it got to an emergency scenario and eventually when he did get delivered, with assisted delivery, he was quite poorly.
They didn't know what was wrong with him. He was taken straight to NICU\textsuperscript{10} and I was really poorly as well. They fed him and warmed him and brought him back up when he was better. They told me to just put him to sleep and get some rest and something made me wake up and I reached over and he was still and cold. So he was rushed back to NICU. And for quite a few weeks we didn't know what was wrong with him. And eventually he got diagnosed with MCADD but by the time he was diagnosed we were already home. The Guthrie\textsuperscript{31} was actually postponed until day eight, not on purpose but because other things seemed to be more important... we got the results when he was two and a half weeks old.

We'd been in and out of hospital twice and just started thinking things were settling down when we got a phone call one evening from someone, “Oh hi, we've had some tests back from Michael”. Which I'd completely forgotten about with the other things going on, and “it looks like he's got this thing called MCADD. Don't panic but he's got to come in and we've got to do some more tests and talk about it. In the meantime don't look on the internet as it'll say lots of scary things like he may die, so in the meantime until we see you if he does get poorly phone us and come straight to the hospital. Make sure you feed him regularly. If for some reason he's not taking his normal feeds, come to hospital.”

They broke it down very simply, he can't store fat so needs to be topped up. Being a new mum, being very poorly myself, as I was quite sick, trying to contend with that and dealing with this new thing I'd never heard of with my lovely newborn baby who'd already been critically ill — was quite difficult.

Later she told me how it made her “quite cross” that specialists were so focused on trying to reassure her that she felt they downplayed the severity of it, and it was only when she met another mother with a baby diagnosed with MCADD who had died that the realisation hit home. In comparison, Lynn found out about the diagnosis within days of the Guthrie, from a very supportive midwife who visited them at home to relay the news and their son’s clinic with the metabolic team was scheduled within a few days. She described the short time frame leading up to the clinic:

Well we didn’t know if... we didn’t know anything. We didn’t know if our daughter was going to survive a year old or anything like that, I think at that stage. We just didn’t know what to expect. It meant nothing to us other than our kid — there’s
something wrong with our kid. Our family is a fairly healthy family so it was just so unusual to have something wrong.

Specialists work with families to negotiate the social positioning of the body. They too, through the medical uncertainty MCADD presents, negotiate the body as that of diseased but well. James and Hockey (2007, 158) write that “Much writing shows biomedical technology as bounding a body” however I argue that the ‘MCADD body’ “is the product of embodied engagement with health technologies”. This engagement starts with the initial clinic, which takes place after the family has been told their child’s Guthrie test has been returned positive for MCADD and that they need to feed the child accordingly until further tests can be done. This message is usually relayed by the midwife over the phone or in person. The family is scheduled in for a clinic, usually the following week if the family live within driving distance of Starship Children’s Hospital or whenever outpatient clinics are being held in their region.

James and Hockey (2007, 138) link the process of social identification to a body’s medical framings and age, stating that: “Across the life course, the body as object is achieved through the intertwining of social, economic and medical framings. Together, these render the body’s chronological age a central feature of social identity”. The infant clinics encapsulate this; the age and vulnerability of the infant is intertwined with their medical needs. These initial diagnostic clinics can take up to an hour, compared to the 15-minute check-up clinics described in Part III. They include blood and urine samples, and a physical examination which includes palpation of the liver. Infant clinics, which take place during the child’s first year where the parent shares the role of patient, tend to be longer than the clinics of older children. They are scheduled every three to six months and take a mostly educational format, where the consulting specialist checks how the infant is feeding and delivers monologues that reinforce key messages about infant feeding, normality, and positive long-
term prognosis, and seeks to minimise parents’ fears and answer developmental questions. These questions are usually related to feeding, developmental milestones, weaning, vaccinations and the introduction of solids.

These lengthier clinics highlight risk more so than later clinics, and over the short period that this research has been conducted, these heightened messages of danger have softened as MCADD becomes one of the more common metabolic disorders. The clinics are aimed at mitigating risk in three ways: physically sighting the child to check they are well, educating the parent about care of their infant in relation to MCADD, and attempting to mitigate dietary and psychological stress for the child if anxious parents over-medicalise daily life due to fears about the diagnosis. I argue that the first clinic sets up the parameters for the construction of MCADD as disease, necessary for the young patients to have a low admission threshold to hospital if needed.

Joralemon neatly summarises a clinic from the perspective of medical anthropology: …the clinic is the site where a complex of social forces intersect. In the encounters between medical specialists and patients, it is possible to see encoded the power and authority of biomedical knowledge. Also evident are the variety of alternative cultural constructions of disease held by patients from different class, educational and ethnic backgrounds. The specialized social systems of hospitals have prestige structures and political tensions that can alternatively reinforce and clash with the hierarchies and economic divisions of the wider society.

(Joralemon, 2017: 19)

A diagnosis is necessary for MCADD to be ‘easily managed’ and it is mostly due to New Zealand’s centralised and largely free public health care system that this is possible. In a country where health care for children is not free, health insurance is required for basic care or where public health is inaccessible, MCADD could easily result in sudden death. However, because of the health care facilities, as long as a child is admitted in a timely fashion, once diagnosed, this is unlikely to occur. The caveat is that this comes with the assumption that
people can easily access healthcare and this is not always the case. Some of the challenges a few participants faced included financial constraints, lack of transport, and the distance between their home and health care facilities.

The New Zealand health system is made up of 20 District Health Boards. Longmuir (2016) has shown how this has resulted in disparate care for some patients, specifically those with Duchenne Muscular Dystrophy (DMD) and I will show in section 4.4 that the low threshold for admission does not always follow protocol, especially away from Auckland and other main centres. Sobo (2010, 214–215) examines parent acculturation to the healthcare system after a diagnosis of a child with special healthcare needs and argues that classification “has important implications for which children can receive what interventions or care, where, when, from whom, for how long — and who will pay for that care or intervention”. It is with the New Zealand health system structure in mind that we turn to how parents acculturate to the hospital system, starting with the first clinic. This is a process that socially signals that a child has a medical condition requiring escalated intervention, even if specialists are careful to emphasise the child’s wellness and the precautionary nature of the health care.

*Initial orientation to the clinic*

Children’s outpatient clinics take up a curious space, folded within the walls of a hospital. The outpatient clinic starts with a challenge, a maze, especially on the first encounter. There is parking to consider, different from the parking parents will encounter when rushing there in the middle of the night (because as most parents agree, the ‘bugs’ that children end up in hospital for, always strike at night). That lack of parking space has to be factored in. In smaller towns, parking can be free but you have to find it first, hunt your park in time to make it through the maze to get to the appointment in time. And you have to pay for parking as well but you have your child disability allowance to help with this cost so it is
not too bad. And of course, all healthcare is free for children under the age of 13, not just in the hospital and clinic, but also in General Practices (Ministry of Health 2017). Once you find the park, you traipse up stairs and down stairs, in lifts, through corridors, following paw prints and lions or arrows and broken red or blue lines, depending which hospital you are at, in which town. Everyone has to do this, parents, children, specialists, nurses and of course, researchers.

Finally, with one or more children in tow, you are at reception. Here you give your name to a woman behind a long desk, silhouetted by the whiteboard behind her, or tucked in a hole in the wall. She is always well defended, defences in front of her and behind her; always a woman. Sometimes the usual outpatient rooms are full and you need to meet elsewhere, adding to the confusion.

Once this is all done there is the wait. There are toys and a TV. Brightly coloured decals stuck on the wall, fish swimming their way towards the ceiling, never quite making it. Children are weighed and measured, always prior to the clinic. This is the mark that discussion will rest on, and it will seesaw accordingly.

This is the setting for the first clinic, where a parent finds out how a rare metabolic disorder will affect the lives of their families and where children grow to understand there is something different about them that requires regular outpatient clinics.

Rodman (1992, 647) argues that:

a single physical landscape can be multifocal in the sense that it shapes and expresses polysemic meanings of place for different users. This is more accurately a multivocal dimension of place, but multi locality conveys the idea that a single place may be experienced quite differently.

Thus the outpatient clinic is a place where clinicians can check that a child is indeed healthy, as a precautionary measure; it is a place where families, parents in particular, move from believing their child could die at any moment to “it gets easier the older they get”; and it is a
place of sensory experience and embodied learning for a child about MCADD. In this place, the child has MCADD and is checked for its potential impact, she embodies a risky body and fluid personhood, constantly negotiated by the child and others depending on age, developmental milestones and health.

As Lily told me, “my mother told me that he can live a normal life (I hate having to use that word, ‘normal’) and I said, no, he can’t. No matter how much I want it, Jamie (his sister) is going to be able to do things he won’t”. Some might argue that this is not true, that he is ‘normal like any other child’ however what is important is her perception of what her child can or cannot do in the future. He will not be able to do an overseas experience (OE) in Thailand or surfing in Bali (with less developed countries bearing a greater risk of gastroenteritis coupled with limited access to health facilities equipped to deal with this condition).

The initial clinic meeting thus constructs MCADD as a condition with life threatening potential that needs to be managed particularly carefully in the early phases of a child’s life course but that ultimately has a good long-term prognosis. It also introduces the idea of an uncertain temporality as specialist teams can offer advice but not fixed absolutes in terms of windows between feeding times, quantity of food required or if the child will or will not start to deteriorate after fasting for an extended period of time. What is certain, is that children with MCADD must eat.

Parents are faced with the physical and geographical reinforcement that their child has a disorder yet grapple with the knowledge that the hospitalisation is a precautionary measure; they are here in order to feed their child intravenously or via a nasal gastric tube (NGT) to avoid MCADD presenting. They worry that they are unnecessarily using resources that a ‘sicker’ child could benefit from and simultaneously worry that their child could die from a common childhood illness. There are no absolutes. How much food is ‘enough’ and when to
hospitalise if not enough is consumed, or too much is expelled are the primary concerns of parents of infants with MCADD. All three are difficult to quantify. Avoiding the potential effects of MCADD guides the feeding of infants and children. In the next section I show that mothers experience enhanced medicalisation of infant feeding via the targeted advice given to prevent the emergence of symptoms of MCADD; this is in tension with the broader socio-cultural health messages around infant care and breastfeeding.

4.3 “I’d set an alarm to be safe”: Risk mitigation and medicalised feeding

Lynn: We didn’t know she had MCADD until she was about five days old, when we got the results back. And at that stage I still tried to breast feed her but basically once we found out about MCADD (I still tried for a day or two), I went no. I was so stressed out. I was sore and raw, so the bottle. And Demi screamed a lot, she wouldn’t feed very well. She didn’t latch on properly so as you can imagine that was very painful and you don’t realise it until it’s painful two or three days later and it’s so hard then to get them to latch on properly. Once I knew about MCADD I just thought no, I can’t risk it. I think when Demi was two weeks old she actually had an episode where her blood sugar levels dropped dangerously low at night.

Pauline: Oh no, how did you know?

Lynn: That’s right, with breast feeding we couldn’t measure how much she’d drunk. As you know I had to feed her every three hours to four hourly and I couldn’t guarantee that she’d had a decent drink from me. Yeah, that was another reason for going to the bottle. I did express for probably a month with her.

In the conversation above, Lynn explained her reasons for switching to bottle feeding. This is not an isolated example. As I will show, mothers expressed the perceived risks of MCADD as a factor in choosing how to feed their child. This perception, in combination with social pressures around being a ‘good’ mother, contested feeding advice, and an historical
background of medicalised feeding contributed towards an uncertainty as to which is the best feeding approach for the health of their child.

All 24 mothers who took part in the study expressed that, prior to diagnosis, they had an interest in breastfeeding. At least half recalled an intention to ‘give it a go’, driven largely by health education messages such as “breastmilk is the perfect food for your baby,” from Plunket, midwives and antenatal classes. However, only one of the participants exclusively breastfed, following an intensive mothering model that saw her breastfeed her child until the age of three. The rest breast-fed in addition to bottled feeds with expressed breastmilk or formula. Reasons for supplementary feeding included being able to quantify how much the baby had drunk, other people being able to feed the baby if necessary, risk mitigation, pain, and stress.

Ryan, Bissell and Alexander (2010) and Anderson (2015) discuss the moral work women undertake when talking about breastfeeding. The women in this study are having to contend with their preferred identity as breastfeeding mothers being supplanted by that of the mother of a child with a ‘life threatening’ rare genetic disorder. There is a constant tension between what was imagined as best for their child prior to diagnosis and post-diagnosis.

Mia, a mother of four said:

I wanted to breastfeed my baby exclusively but what if something happened to me? I needed Chloe to be able to drink from the bottle or breast, in case I was sick. I pumped and stored milk in the freezer and also got her used to formula by mixing it with breastmilk. Plunket and the midwives didn't want this as they said it would change the bacteria in her gut.

In comparison, Rhonda was concerned about monitoring how much milk her son consumed:

I struggled to breastfeed and even when I expressed milk I'd barely get 40ml out. I never knew how much he was getting so even though I wanted to breastfeed him for the immunity, so he wouldn't get sick and have to go to hospital, we decided to go with formula. That way I always knew, you know?
For many mothers, two contradictory key considerations guiding their decisions around infant feeding are that it is difficult to gauge how much breast milk a baby drinks as compared to when bottle feeding (other than by weighing them), and that breast milk offers immunity against childhood illnesses that could otherwise prevent the child from feeding.

In a recent study of “white, middle class women” in Auckland, Anderson (2015, 13) reported that “New Zealand is a country with a highly centralised healthcare system, and one that places a large amount of focus on infant feeding”. It is in this context that I examine the medicalisation of infant feeding to prevent a metabolic crisis from occurring. “Medicalization is the process by which aspects of human existence are assigned to the realm of medicine, to be defined and managed by medicine’s authority” (Jutel 2011, 9). Apple (1994), Beasley and Trlin (1998) and Van Esterik (1989, 112) have convincingly argued that infant feeding is already medicalised. Further, Wall (2001, 596) noted in her analysis of Canadian health education material that “there is much moral authority inherent in the cultural construct of nature, authority that often goes unquestioned and unchallenged”. However Anderson (2015, 79) critiques this stance, noting that in New Zealand, the biomedical impact of infant feeding has become diffused. As she explains, “women have become agents of this new medicalisation; they will self-police and self-pathologise their own infant feeding practices”.

Blum (1999) and Carter (1995) discuss the dual maternal and medical models of breastfeeding in Western culture both of which highlight the benefits of the mother's milk. Rather than being valued solely for the 'natural' and immunity building properties of breastmilk, however, it is the quantity about which women in my study are concerned, the raw calorific energy that stands, in their mind, between the well, ‘perfect’ infant they anticipated prior to diagnosis and one who will not ever wake up from a nap. The mother is the source of this wellspring of health but the majority were unable to overlook the severity of what could go wrong to truly enjoy feeding their baby. None of the women in this study
expressed breastfeeding in terms of attachment or bonding; these were secondary to its health benefits, findings which mirror Anderson (2015).

As previously explained, once diagnosed, MCADD is managed with the regular intake of food as part of a low-fat diet and thus the relationship between the growing child's sense of agency, food, and the parents’ duties of care towards the child, is linked to the disorder. Family mealtimes and food practices become fraught with tension as toddlers and young children engage in ‘normal’ independent behaviour and choose not to eat (Cook 2009; James, Curtis, and Ellis 2009). Specialists are very sensitive to this and go to great lengths not to medicalise eating, and to highlight that a) the condition becomes more manageable as the child gets older and b) that meals and eating should be normalised when the child is well.

As Anderson (2015) and others have shown (see Beasley and Trlin 1998), the medicalisation of breastfeeding and a cessation of breastfeeding in favour of bottle feeding are already prevalent; how does a diagnosis of MCADD shape feeding behaviour? I found that the majority of women felt MCADD was a legitimate reason to stop and pursue other means of feeding; they did not want to endanger their child just for the ‘sake of appearances’.

Many experiences — from whether to breastfeed, attend playgroup, or be around other babies with colds — were mediated through the lens of MCADD, with mothers particularly feeling anxious and judged by their peers. As Mia said: “Plunket keep telling me he shouldn't have a bottle during the night. Seriously? I think keeping him alive is more important.” If children did not want to drink milk or eat, parents felt criticised by extended family and friends for being hypervigilant. Added pressure came from trying to deal with what can be seen as ‘normal’ infant behaviour (spitting up milk) versus vomiting as a cause for concern, as demonstrated by this plea for help:

Hi everyone – my son was born a week ago and diagnosed with MCADD. So far we are doing good but struggling with nursing and formula. I try to pump but my supply varies. I really wish I can nurse him but it’s so sore we both get frustrated and it ends
up taking over an hour. So I pump here and there and try formula but he just gags/chokes on his bottles and spits it up. I’m at a loss. Any advice? (Sophie, message posted on a Facebook support group for MCADD).

These mothers felt a grave responsibility for the well-being of their children and weighed up many parenting decisions based on prioritising getting food into them, often forfeiting their own needs (Wall 2001, 605). Lily reported feeling heightened seclusion: “I never left the house with Michael. I was always pumping or feeding or cleaning and sterilising bottles,” whereas Mia still remembers her sleep deprivation and feelings of guilt at having to wake a “happy, sleeping baby”:

I'd set an alarm every three hours just to be safe. I could leave him for four but sometimes I couldn't get him awake to feed. I was so tired and felt so bad for waking him. I'd feed him on one side and then change his nappy to wake him up and feed him on the other side. Sometimes I'd resort to a damp cloth to wake him up and make him feed.

In both Lily and Mia’s example above, time was a limited resource and they reported that this constricted their choices. Other studies have reported on the stress, fatigue and loss of identity that comes with feeding an infant (Maclean 1990, 123–124). In addition to this, these mothers could not let the baby sleep and catch up on sleep themselves and would panic if they slept through an alarm. Decisions about sleep training, bottles before naps, and weaning were all negotiated through the lens of MCADD. As Rowan explains:

We did set alarms. I would probably say that from that point on alarms were a regular occurrence [laughs]… I mean most newborns are asking for food every few hours anyway so you know we got in quite a good routine from very, very early on. He had slept for almost eight hours before we found out so that all went out the window. Again being a nanny I knew all about sleep pattern training and getting them into all those things and I thought well that’s not going to be me for quite some time now [laughs].
Others, such as Nina, felt that MCADD promoted a child-led, as opposed to an adult-led parenting style.

I followed Babywise with my first child, Bronwyn. It was very structured, Bronwyn was sleeping through, she was a dream baby really. With Eve it was different, I really felt that it was child led, not adult led. If Eve woke up before the four hours alarm, then I’d just feed her anyway and set the alarm again. I would never have done that with Bronwyn.

Women held the perception that their peer group judged them negatively and did not understand the pressures they were under, despite illness being a socially accepted reason for diverging from ‘breast is best’. During periods when the child was well and asymptomatic, the parents, usually the mother, were in sole charge of actively managing the child's disorder as parent-experts (Trnka and McLauchlan 2012). While the day to day management of feeding the child brought challenges, an additional constraint was when the child became ill. At this point parents needed to decide whether to escalate and contact the hospital or manage this at home, a strategy partly structurally motivated by the New Zealand health care system where patients are encouraged to take responsibility for their own healthcare (Fitzgerald 2004). As in other New Zealand studies (Fitzgerald 2008; Park 2009; Trnka 2017a), parents also felt that they carried more knowledge about their child's rare disorder and how it should be managed than the majority of health professionals (with the exception of their specialists). While some parents were frustrated by the insistence of their health care team that parents needed to make the decision to bring their child in to hospital, others, such as Lily, found the New Zealand system accessible and reassuring as compared to their paternalistic experiences of health-care in the UK.

The criteria for being a ‘good mother’ for self-policing mothers of infants with MCADD include ensuring the baby is fed frequently, however as has already been discussed, the volume of food and timing between these feeds is variable and inconsistent. This is by no
means easy as parents' sense of responsibility about their infant eating healthily is overshadowed by the shadow of the MCAD deficiency. The aim therefore broadens; to manage the disorder well enough to prevent a precautionary hospital admission. However, as I will show, the multiple responsibilities of the new parent-patient shift along a continuum from predictability to contingency in tandem with the body of the child (Frank 2013), with the responsibilities mounting as the child becomes unwell, until finally the decision is made to go to hospital.

4.4 “You’ve brought him in nice and early”: Negotiating biomedical healthcare

Medicalization encompasses more than just diagnosis. For example, infant feeding and child rearing have been — and continue to be — medicalized as part of scientific motherhood. The privileging of medical authority over other forms of knowledge (even where there is no diagnosis or pathological condition) is notably present in parenting, where the mother or father may seek medical advice for matters of infant health using medical endorsement for child nutrition and educational products, and reading doctor-authored columns or books on childrearing. (Jutel 2011, 9)

The first hospital admission is a major rite of passage for families. It is the second of the two tools they have to prevent MCADD from presenting. It is at this point that parents are confronted with the reality that their child has a life-threatening condition, despite all attempts to normalise it. Mothers in particular report struggling with the perception that they have somehow failed in their moral duty to feed their child enough to prevent a hospital admission. It is here too that many parents experience mounting frustration as they have to take responsibility for getting the correct health care for children, often acting as a kind of surrogate specialist in a non-specialist environment where triage staff may downgrade their admission based on the appearance of a relatively healthy child. As Rhonda said:

We come through ED [laughs] first, they put a line in and worked out what they were meant to be doing [laughs]. We're the only ones in rural Central North Island with it and
they're not familiar with it and the doctor that was on yesterday was a different doctor
to what was on last time and last time they put a nasal gastric tube in and fed him
through that and then he wouldn't breastfeed as he was filled up with Polycal. It was
the first time we'd been in and I didn't know what was meant to be happening... later I
spoke to the specialist who said they were supposed to stick a line of dextrose in
which is what they did yesterday.

Many parents express frustration that on admission to hospital they are reassured the
child's blood sugar levels are “normal” or that “you've brought him in nice and early for
gastro” (Field journal, Levi, July 2014) when protocol specifically states “hypoglycaemia
also occurs, but only at a relatively late stage so it is not safe to base the management on
monitoring of blood glucose” (Starship Metabolic Services 2011). While blood sugar tests
may be part of a suite of routine data collected on any child admitted, parents take this as an
indication that they are not being taken seriously, partly due to their clinic education and
partly due to their often-reluctant advocacy as experts on their child’s condition. Parents also
express frustration at the wait before an IV line is put in. Through specialists' advice, and
meticulous note taking of times when food is ingested and expelled (usually in a dedicated
book), parents gauge when they need to take their child to hospital and factor in the timing so
it is urgent but not an emergency. Busy hospital staff are presented with a child that has
normal blood sugar levels, and looks relatively well.

The following clinic conversation highlights the difficulties for both the specialist care
team and parents when children outside the Auckland region are taken to hospital after
vomiting and the emergency protocol is not followed.

Peta: And that was managed okay in the hospital? They did a drip?
Nia: They didn’t actually put the drip in that last time.
Peta: They didn’t need to?
Nia: I’m not sure what happened. All the times before that they’ve always put the drip in but the last time I was there they didn’t and they just kept checking his blood sugars like they do every three hours.

Peta: The thing about the blood sugars, as we’ve talked about before, he shouldn’t ever become hypoglycaemic. Is he eating and drinking?

Nia: Oh at the hospital?

Emma: Yeah.

Nia: Not for a little bit, that’s why I took him there because he wasn’t eating. He was vomiting everything up and I did ask them if they were going to put a drip in and they said that they didn’t need to.

Peta: I’ll send another copy of the emergency plan and say can they put this at the front of the notes. Sometimes parents do have to advocate for their kids in that situation. Actually, you don’t want him to become hypoglycaemic.

Nia: Yeah, I got a bit scared because they didn’t put the drip in and he hadn’t had food for...

Peta: For so long.

Nia: And they just kept checking his blood sugars and stuff, and they wouldn’t listen to me.

Peta: If you are ever in that situation you can always call us.

Nia: Yeah, I had no reception in the hospital. I don’t have any reception in Rivers Hospital.

Peta: Or get them to call us, just say can you call the metabolic person because this seems quite different from the usual management and...

Nia: I think it was because they didn’t have many beds and they were just, I don’t know, they were really, really full that night.

Peta: Okay. Maybe it was just a one-off thing.

Nia: Yeah.

This incident was by no means isolated as other families in areas outside of Auckland reported being told to go home with an infant with gastroenteritis, that there was a long delay in ED because of a shortage of beds or had blood sugars monitored continually (in one case the child now has tiny scars in her heels from her hospitalisation in infancy) but no IV or
NGT inserted. However, there were also cases where the protocol has been followed appropriately:

Peta had given us a letter and in their note saying if [our daughter] presents with any symptoms to instantly do the blood sugar test and to get a drip going, I think there was a letter that already informed the hospital and it was instant. We got looked after really well. Because it was all new to them.

It was not only hospital staff that relied on blood glucose monitors. Despite specialist advice against using blood glucose monitors, eight of the families had been provided with blood glucose monitors through their GP or local paediatrician assigned to the child’s care. Like a sonogram (Taylor 2008), the blood glucose monitor acted as part of a technological network that tied them to the hospital — quasi-magical — used to predict a potential future hospitalisation when in reality it was reporting the past.

For those families who had experienced a hospitalisation and were expecting a second child, there was a sense of urgency around the birth. Again decisions such as whether to opt for a caesarean or natural birth, and how to deal with the newborn, were all based around the potential disorder. The baby was treated from birth as if it had MCADD and given formula top-ups in addition to breast milk. Unlike many mother's experiences with their first child, where they were discouraged from formula top-ups through a variety of strategies, parents and hospital staff worked as a team to ensure the baby was fed every few hours and had additional formula. Whereas previously the mother may have been discharged early, now she waited in hospital until the Guthrie was taken.

Although theoretically the foetus can be tested for the disorder, in this study the majority of parents did not do this and instead relied on staff to follow the ‘at risk MCADD newborn protocol’, which begins: “Please read this carefully as there is the risk of death and serious complications in the newborn period... It is helpful to establish promptly whether the baby is affected since, if they are not, it allows everyone to relax”.

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Lily told me that being in hospital always makes her feel emotional and guilty. She feels it is her and her husband’s fault when Michael is sick: “It’s our genes and I know that’s not right, that it’s just a genetic lottery but it’s still so unfair.” (10 Sept 2015, field journal 4). Mothers such as Lily, whose first child was diagnosed with MCADD, typically found the experience overwhelming. In addition to learning how to mother their child, they had to contend with seemingly constant feeding of their child day and night, expressing milk and freezing it so a back-up supply was on hand, familiarising themselves with the emergency protocol and trying to figure out when the child needed to be admitted to hospital. They experienced significant uncertainty around the medical management of their child’s condition, amplified by the lack of clear medical markers around risk of serious illness.

He just wasn’t feeding. He wasn’t vomiting or anything but he was so snotty he wouldn’t feed. I kept waking him to try get him to have more and I was so stressed and my husband just didn’t understand. He thought I was overreacting. So here we are, at the hospital with what looks like a smiley, happy baby with a cold. I don’t think the staff are taking it seriously but he just won’t take anything in. It breaks my heart. (Rowan: mother of boy with MCADD, 4 months old)

Parents’ sense of responsibility about their children’s healthy eating is amplified by the shadow of the MCAD deficiency. As parents of children with MCADD incorporate precautionary measures into the daily family routine to keep the disorder asymptomatic, there is growing tension between the medical certainty of the diagnosis and the ongoing uncertainty of the disorder’s management via feeding, response to emerging symptoms and illness, and inconsistent medical practice, messages and treatment upon hospital admission.37 Thus initial diagnostic and infant clinics frame feeding as one of two tools that parents have to manage MCADD; the other being hospitalisation.
The relationship between food and technology on a ward

As the opening diary extract illustrates, while this hospitalisation may be seen as “high drama” (Mattingly 2000, 181) on the part of the parent, in biomedical terms, the reality is mundane. It is a small, precautionary drama punctuated with routine observations where fortunately in most cases, ‘nothing’ happens. Hospitalisation is a food practice. It is a way of getting food/ energy into a child when they are unable to do so themselves because of illness. The food however, as Mol and Mesman (1996) point out, takes a different form. The food that parents have so lovingly given their children, this gift of love, as well as a gift of life, is no longer being accepted and they worry about their child's life. Their gift is now supplanted by medical technology, by bags of dextrose intravenously given to their child. It is the nurse that gives this gift, monitored by the doctor. But in these cases, the parent is still trying to give their child food (in some cases, to coax them) while others are 'letting their tummy rest'. The overarching message from hospital staff is to try to get them to eat, and the focus is on this, as they would not be here otherwise. The illness infants have (such as gastroenteritis or flu) is secondary to the reason they are here — which is to stop MCADD from presenting.

Parents and hospital staff wait for the illness to pass, for food to stay down, so home management can resume. For the child however, the experience is anything but mundane; it is sensorially overwhelming. This sensory experience is largely due to the invasive nature of an IV or NGT and while these details will be explored in depth in Part III, it is worth considering the substance being delivered to the child via these technologies. As Mol and Mesman (1996, 431) state: “Where food is valued as an element of the relation between people, a gift, a reflection of care and love, infusions are horrendous”.

They use symbolic interactionism and semiotics to explore food in a neonatal ward, describing symbolic interactionism as “the way in which different groups of people make sense of the world,” and semiotics as “explor[ing] and expos[ing] the orderings we currently
live” (Mol and Mesman 1996, 434). The medicalised feeding of a baby in a ward is very different to the medicalised feeding of a baby at home. It lacks intimacy. For Mol and Mesman (1996, 430), food becomes a series of numbers, then a ward calculation, an instruction to the dispensary to act, then fluid, then lipid or glucose, then weight, then an infusion. This is a different medicalisation of infant feeding from that described by Anderson (2015) or Apple (1994). Food becomes a mostly unconscious registering of a series of numbers, how much the baby has consumed, versus how much time has passed between feeds. A set of behaviours is formed around reinforcing an acceptable ratio between consumption and time passed. When an infant is sick, blurring time, these quantities and time measurements are often written down. They are written on a piece of paper or formalised into a book, that can be referenced when sleep is short, or to tell the many doctors and nurses that they encounter in a clinical or hospital setting. These scraps of paper are given to co-parents (like fathers) to take to clinics, and used for reassurance, although this is not always the case. A paradox of medicalisation of food is that mothers try to document illness episodes as a means of control, however each individual’s biology means that this is more complex and not really quantifiable. This action creates distress, an impression that they are not living up to their own moral demands of providing for their children’s health. At other times these calculations are mental and instinctive. No, she has not had ‘enough’.

Degnen (2018, 58) highlights “the subtle ways in which technology shapes debates over personhood. So for instance, in cultural settings that are highly reliant on biomedicalised birthing practices, medical technologies themselves can become tightly bound up in demarcating personhood”. She also argues that personhood is created through a relation to food and illustrates the centrality of food and feeding “in childhood for ensuring the formation of person and kin” (Degnen 2018, 58). In the examples above, technology both frames the diagnosis of MCADD and the delivery of preventative treatment in the form of
IVs and NGTs once hospitalised. Clinics set up a habitus of eating that is very subtle and slippery, mixed in with ‘ordinary’ survival of children and vitamins and minerals. This eating is preventative, as all involved in the care of an infant do not want a metabolic crisis to occur. But the physical sign of this prevention is not the eating (that is done anyway), it is when ordinary childhood illness occurs. That is the trigger for active prevention.

**Conclusions**

The diagnosis of MCADD shortly after birth creates a set of tensions for the mothers of these newborns. They have to deal with becoming the parent of a ‘disordered’ child, recreated as new subjects, genetic citizens, parent-patients and parent-experts with all of the enhanced responsibilities that these roles bring. In addition to the normal responsibilities and duties of care that parenthood brings, the medicalisation of newborn feeding adds layers of uncertainty around managing risk of what otherwise could be considered easily managed once diagnosis has been confirmed. Pressures reported elsewhere as common among new mothers, such as sleep deprivation, are nested within a round-the-clock feeding regime that medicalises the milk (both breastmilk and/or formula) that the infant receives.

The mothers thus have to negotiate how to feed their new baby; navigate the social pressures around feeding already embedded in their social and kinship networks; and overcome their own feelings of inadequacy when they ‘fail’ and their baby has to be hospitalised. Although they are reassured after a year the child will be safe overnight, these mothers find it difficult to relax after the rigours of the first year of infant feeding and this colours their experience with their child and the management and medicalisation of food in the future. As parents of children with MCADD incorporate precautionary measures that keep the disorder asymptomatic into the daily family routine, there is growing tension between the medical certainty of the diagnosis and the ongoing uncertainty of the disorder’s management.
via feeding, response to emerging symptoms and illness, and inconsistent medical practice, messages and treatment upon hospital admission.

Mothers find feeding most challenging in the first two years and whenever the child is unwell. In between these points, the mother tries to ‘normalise’ feeding and activities as much as possible, weighing up and prioritising the bottles, night time feeding battles, and fevers through the medicalised lens of MCADD. Thus parents chart a fraught course, shedding some responsibilities and prioritising others towards the goal of preventing the metabolic disorder from presenting. It is only when the child is unwell and they are deciding whether or not to take them to hospital that they consult specialist advice, both for guidance and to gain access to an IV.

As this chapter demonstrates, the diagnosis of MCADD, while life-saving, brings with it an abundance of medical uncertainty that parents, doctors and extended family must continually navigate and which leads to a low threshold for hospital admission in times of potential crisis. There is persistent uncertainty about how much food the infant is receiving, whether milk ‘spills’ are ‘normal’ or could be defined as vomiting and thus a cause for concern, how quickly the infant is using up the energy she has from the last feed and in the case of illness, whether or not to hospitalise.

While MCADD represents a diagnostic certainty as an outcome of inheriting faulty genes from both parents, the lived experience of managing the medical needs of a newborn with MCADD is one of significant uncertainty; it is this terrain that so often veers into medical contingency that mothers navigate. This medicalisation of feeding, coupled with the first and subsequent hospitalisations, sets up a set of learned dispositions on the part of parent-patients, oriented towards preventing first, the child from going to hospital and second, MCADD from presenting. Both feeding and hospitalisations are characterised by heightened emotion, fear, fatigue and stress (Herbst 2015), reinforcing existing risk-prevention strategies.
This reveals constant tension between what was imagined as best for their child prior to diagnosis — e.g., exclusive breast-feeding — and post-diagnosis, through the lens of ‘disorder’ (Scully 2008a).

I have also drawn on Degnen (2018) to show how medical technologies, through the diagnosis and hospital experience; and food, through medicalised feeding at home and in hospital, are entwined with the demarcation of personhood. The prominence of some of the themes that have been discussed in this chapter wanes by the time the children are in primary school with families experiencing fewer hospitalisations. However, as the following chapter will show, this habit of ‘how much is enough’ continues once the infant is weaned, stitched into the social fabric of mealtimes.
Chapter 5: Food as love, food as medicine — the shadow habitus revealed

Negotiating “…between the two frameworks of biological or genetic reductionism and a postmodernist “self as constructed in the course of social interactions that inscribe identities on bodies”. (Scully 2008a:6)

One fresh winter afternoon, nine-year old George, his older brother Jake, and I sat down to storyboard a way to visually illustrate MCADD to someone who has no idea what it is. In trying to understand what MCADD was, George had worked through genetics (blue eyes) and kinship (why don’t mum and dad have MCADD?) and finally, in frustration, turned to me to ask “What is it?” rapidly answering his own question with the “food and drink” response: “It’s food and drink, right? It’s food and drink!” This was after afternoon tea, where in a scene repeated in similar homes across the country, the boys had voraciously eaten through several large packets of biscuits at the kitchen bench while I drank coffee with their parents. It was also before dinner, which we ate at the snug round table in the corner of the room. The kitchen bench was the hub of this world and we, the food and conversation were its spokes. We seated ourselves on one side on tall stools, or stood, leaning against it. Dinner was usually eaten at the bench, I was later told, except when I was there. There was nothing overt to suggest either of the boys had a metabolic condition.

The storyboarding exercise started with the following discussion.

Jake: Well with MCADD I don’t know how to start it [the exercise] to be honest.
Pauline: Ok
Jake: I must admit, I’m not good with that stuff.
George: [very loudly] Well with MCADD, you start with MCADD, you have to have food, like everyone has to have food. Everyone has to have a drink. [He is very earnest and hyper focused on the project]
Jake: No, no, no, MCADD has nothing to do with drinks.
James, Kjørholt and Tingstad (2009, 4) note that the:

Ways in which small children are already engaging with ideas of food moralities and self-worth... raises potential implications for young people's sense of self and identity in relation to current moralising about food and eating practices.

Indications of these moralities at work in everyday settings can be seen in ‘no sugar’ or ‘no lollies’ policies at schools, and signs at the mobile dentist showing how many packets of sugar there are in juice. These children are encouraged to drink juice (with additional sugar) when unwell. How do these conflicting messages impact on them? Especially when they are well aware of what is seen as healthy and ‘good’ for you. This was illustrated when Sarah drew me her favourite lunchbox, complete with apple and brown bread sandwich. Her sister spotted it and laughed at her. “You don’t eat that. You have yoghurt, chocolate biscuits and jam sandwiches!” Despite her sister’s scepticism at how accurate this portrayal was, it does show that Sarah has an aspirational favourite lunchbox in mind, or at least, knows what lunchbox she ‘should’ be aspiring to.

My questions mirror those of James, Kjørholt and Tingstad (2009, 12). I want to examine the “ways in which childhood identities are constructed and mediated through particular foodstuffs and policy initiatives around food consumption”, explore children’s everyday encounters with food, and map the negotiations they have with parents around food and eating. To build on Scully’s (2008a) opening quote, this chapter has three foci:

1) What the young patients think MCADD is as related to food and how this is constructed

2) what are the social interactions inherent in mealtimes telling us about how these children are constructed and how they construct themselves (How mealtime interactions lead to this construction of disease as food)?
3) What identities are being inscribed on these young bodies and how are they being culturally positioned via food and eating? (James, Kjørholt and Tingstad (2009, 12).

I have shown that the first year of life after diagnosis constructs MCADD in a relationship with two main themes: food and drink; and its association with illness. This chapter will expand on how the medicalisation of food discussed in Chapter 4 plays out in daily life. In other words, aspects of life that were once not medical in nature have now taken on medical authority; eating for pleasure has been supplanted by eating for health. First, I examine how MCADD is constructed by children in relation to food.

5.1 What is MCADD? It’s food and drink, right? It’s food and drink!

Children’s constructions of MCADD

If, as James and Hockey (2007, 45) state: “particular kinds of bodies are produced through experience” what bodies are being constructed through the cultural positioning inherent in meals? What performances are taking place through the routines and rituals of everyday nourishment? How is their identity (and that of the recently discussed parent-patient), already fluid in terms of childhood and a wellness–illness continuum, reflexively shifting through this performance?

The centrality of food is apparent in the discussion with George and Jake. The discussion turned to what MCADD stood for and how to spell the acronym. At a later point I asked: “If we were to explain to someone what it’s like having MCADD what are some of the pictures we could use?

George: Like um, food, food.
Pauline: You think food? Ok. What kind of food do you think would be good or bad to show?
Jake: Any food.
Pauline: Any food?
These excerpts highlight that George felt there was a distinct and constant connection between MCADD and food and drink, that he expressed repeatedly during the course of the research period, unlike his older brother Jake. A pertinent example is the conversation at the start of this chapter. George wasn’t the only one. When asked about MCADD during a bodymapping exercise, Tom, age five, scurried to the kitchen pantry to fetch me polycal and Berocca. Andrea, age four referenced polycal as her “special drink”. Seven of the children who included food and drink in their analysis of MCADD were under the age of six. The remainder of those who could verbalise focused on the symptoms and consequences of ill health such as vomiting and IVs, which will be examined in detail in Part III. An exception was Kate (age eight) at the school library, who tried to map the condition her sibling shared, and how food and drink related to it as a means of partially explaining my presence to a close friend: “We’ve got MCADD. When we’re sick we have to eat food but we don’t have to eat that much food. MCADD needs fizzy drinks like lemonade (her voice trailed off)… I don’t know.”

In these examples I highlight the relationship these children explore between MCADD and foodstuffs, including solid or liquid foodstuffs and the contents of an IV infusion. Second, I note the place where most food is prepared and consumed — the kitchen/dining area. The link between food as medicine, medicine as food, and food and health is not novel. Yates-Doerr and Carney (2016) show that dietary prescriptions locate health within the individual body rather than the social unit, disrupting the role of the kitchen as a non-clinical site of care. What was left unspoken in meal observations such as the dinner which followed the storyboarding exercise, were the social norms and values around mealtimes and eating. Snacks, coffee and tea are acceptable bench top fare, as is breakfast. This vignette, coupled with other observations revealed that dinner ‘should’ be eaten at the table, not at the bench or on couches in front of the TV; especially dinners to be filmed for research purposes. Why
film at all if this is going to be an artificial construct? There were of course plenty of dinners I shared with families in front of the television or outside on the lawn. It is precisely these expectations coupled with observation and the discussions after these meals that reveal how mealtimes contribute to the construction of childhood identities, a component of which is the idea of risk.

Mintz reminds us that:

Underlying the rich symbolic universe that food and eating always represent… is the animal reality of our living existence... an integral part [of our humanity]. Only because most of us eat plentifully and frequently and have not known intense hunger may we too easily forget the astonishing, and at times even terrifying, importance of food and eating…. Without at least minimal access to food and water, we die. (Mintz 1996, 4)

A diagnosis of MCADD reminds families of this fact. Starkly put, the child must eat or die (with caveats). If this is true of all children, particularly infants, then why the shock? Is it the temporal dimension, that there is a specific window of time in which a child should eat before potential problems set in? It could be argued that all children share this temporality. Or that there is no quantifiable way of knowing exactly how much time, or if problems will indeed present, that give families such difficulty? As I outlined in the previous chapter, in the first year of life the ambiguity of the diagnosis and its management serves to medicalise infant feeding with an explicit focus upon the prevention of risk, preventing MCADD from presenting. This linkage of food and risk is not restricted to infancy nor is it unique to MCADD. As James, Kjørholt and Tingstad (2009, 1) point out:

The relationship between children and food largely revolves around discourses where ideas of risk predominate as the main ways in which children's relationship with food is constituted and as such this constitutes a largely problematic ‘child’ identity.
The ways in which food is coupled with risk includes obesity, nourishment, food allergies and childhood development. Infancy is seen as a time of risk, for disease, malnourishment and a failure to thrive. The older the child, the more robust and the less susceptible to risk. MCADD is constructed as life-threatening with a higher degree of risk in infants than in older children, but still a greater risk than in (most) children. Food as the preventative, is connected to this idea of risk and there is correspondingly a greater emphasis on the frequency of feeding and volume required. This is not a static relationship; the consumption of food appears on a sliding scale, with heightened focus when children are younger or ill. While clinicians do not advocate over-feeding, parents worry about the volume children consume and err on the side of caution. Parents focus more on observing and measuring this process with their children with MCADD than with siblings. Metrics are reassuring. For parents they are also a good practice in case of hospitalisation, where they will be repeatedly questioned as to how much and what the child has eaten, and when; as well as during clinic visits where the specialist team tries to ascertain what the child usually consumes in a day and with what frequency.

Parents make decisions about what to feed a child based on a number of often contradictory factors. Even though the metabolic team advocate for balanced meals with no dietary restrictions, parents consume public health messages about low-fat, healthy, nutritious food with plenty of fresh fruit and vegetables. However, they are aware that high-calorific food such as pasta, rice, potato and red and white meat will provide their children with long-lasting energy and that sugar is a way to get energy into their child quickly, particularly where the child is vomiting or has expelled a lot of energy with a fever or exercise.

The moral politics around the role of sugar in society (Mintz 1985) came to a head with some families. Betty told me:

George is always worried that he’s going to get into trouble because of the juice in his water bottle. The school has a rule: no juice, no sugar. But that’s ridiculous, right?
How can they tell parents what to give their children? And this just gives him that little bit of extra energy if he’s low.

Similarly, Lily prioritised giving Ribena to her three-year-old son over what she referred to as the “empty calories” of water. This was based on an earlier history of Michael being a poor feeder. Ribena was a way for Lily to ensure he had calories in an easily consumed form, although she thought it caused his constipation problems and that this example influenced Michael’s younger brother (with no MCADD) to refuse to drink water. The Ribena/water choice also raised a concern with teachers at his preschool as he initially refused to drink water. In an extreme example, one family were sending their child to school with daily polycal in his water bottle, which was discouraged by the clinicians when it came up in an annual clinic. These children are not obese, or fed only on a diet of sugar. When parents listen and weigh up the medicalised food messages fed to them by society, and the clinicians’ normalising, moderate message, against the practicalities of getting a child to eat within the competing time frames of siblings’ needs, getting to work and school, and the other demands of daily life, they opt for options that make the most sense at the time.

In addition, they conduct their own online research which can be heavily weighted on US-based medical advice aimed at ensuring patients can obtain the health insurance required in the event of hospitalisation. For example:

Heart healthy diets with appropriate Kcal for age and size are recommended after infancy. Nutritional intervention may be needed to counsel individuals about meal planning so that they get approximately 30% of Kcal from fat, include fruits and vegetables on a daily basis, utilize complex carbohydrates, and avoid overfeeding or exceeding their kcal needs. (http://www.gmdi.org/Resources/Nutrition-Guidelines/MCAD)

This often contradicts the more moderate risk prevention advice given by New Zealand, Australian, and UK metabolic specialists. Consequently parents try to avoid
medium-chain fats such as coconut and palm oil. Their role is to keep their child healthy and well and parents finesse feeding to strike a balance between what they believe to be the best for their child, but also that is practical and manageable on a daily, long term basis.

Despite attempts on the part of families and specialists to normalise MCADD, the children are quite aware of the power their need to eat gives them. As I was leaving a house after a full day of participant observation and role play activities with two sisters, the youngest, Poppy, wanted something trivial from her mother. Grace said “no” and as I left I heard Poppy say in a low, dramatic tone: “I’ll never, ever, eat again”. Mealtimes are one of the settings in which MCADD is constructed as illness and in the following section I draw on existing work by Ochs and Shohet (2006) and James, Kjørholt and Tingstad (2009) on food and identity to show how the primary habitus of food as a preventative, combined with the forthcoming illness narratives (Part III) construct the social and sensory experience of MCADD for these children.

5.2 The carrot and the chocolate stick: social interactions at the dinner table.

It is dinner time at four-year old Eoghan’s house. He and his six-year old sister Emily set the heavy round table with boards, white plates and a knife, fork and spoon each while I chat to their mum, who is creating a culinary masterpiece in the cramped kitchen. I watch closely, hoping I can pick up some tips to take home. The kitchen/dining room/lounge is busy with the signs of domestic life; a clothes dryer in the corner hung with small striped t-shirts, shorts and jumpers for the following day; paper planes in various stages of assemblage and crumpled landings. Prior to setting, the table was covered with paperwork, toys and the ‘stuff’ that seems to accumulate on family tables in households all over the country.

It is my third and final dinner observation with this semi-rural family and I am sad that this will probably be the last time I spend time with them as my fieldwork is drawing to a
close. I recall the first meal; roast lamb, accompanied by well-mannered children with unnaturally perfect table manners. The second meal was ‘easy dinner’ as opposed to ‘good dinner’. I wonder if that's code for ‘dinner we'll eat without a fuss’. Easy dinner was sausages and homemade oven chips and the children, used to me by now, or perhaps having a challenging day, negotiated what seemed like every minute of that meal. I wonder what this chilly evening will bring, especially as they must be tired after a day filled with playdates and a sugar fuelled birthday party.

After a brief sibling squabble, Eoghan gets to sit next to me. He carefully places the small red camera I gave him next to him on the table and glances at mine as he does so. Then he gulps some water from his black Star Wars cup. At around 19.30 dinner is underway. The children dish up their own meals: roast chicken, complete with stuffing, lashings of gravy and roast potato done just right so it is crunchy on the outside and warm and melt in the mouth soft on the inside. Eoghan’s dad watches young Eoghan, steering his table manners with reminders such as “where’s your spoon?” seconds before his chubby little fist aims for a handful of broccoli, and “put some more on,” when he tries to avoid the carrots. “No salt, too much, too much! Mummy salts everything already”. There were peas, not my favourite but I eat them up as I have since I was a child, swallowing them whole and drinking water so as not to offend. After all, they're good for me. Emily, at the opposite side of the table and two years older, escapes notice for the time being.

Eoghan still has not had a bite as the dinner conversation swirls around ‘retro’ video games like Pacman and Emily recites her favourite part from Mr Bean. He has had several drinks of water and gone over his whole plate with the flat of his knife. Eoghan’s dad seemingly has not noticed and reprimands Emily: “Once you’ve drunk all your drink it’s gone. Eat fast.” He points to the hands on the clock. “When you get there [he points to the twelve, making the deadline 20:00] you get no dessert.” Emily asks if it will make a cuckoo
clock noise and he answers: “It’ll go ‘ha ha ha ha’”. Eoghan puts a forkful of potato in his mouth, followed by more water and a vigorous eye rubbing. We are 10 minutes into dinner. He is jiggling in his seat and wants to tell me something but I have two other people talking to me and cannot respond. His dad passes him the fork: “Eat”.

Eoghan tries to talk over Emily who is planning the theme for her next birthday: “When, when I’m an adult…” His dad cuts in. “Show Pauline how well you eat when you have a guest round.”

“I’ll have a rugby and All Blacks party. And you can come if you want to.” Another two minutes pass as he plans his party. The fork waves over his food, prods a potato, tests a piece of chicken but nothing makes it into his mouth.

His mum interjects; “Ok, you need to eat my darling.” He talks over her until she adds: “Eoghan, there’s chocolate pudding.” That gets his attention. The fork is still hovering in the air next to his ear. “Chocolate pudding?”

Dad: “Eoghan doesn’t want chocolate pudding.”

Mum: “Yes, you need to eat up mate.”

Eoghan: “What kind of chocolate pudding?”

Dad: “Chocolate pudding”

Eoghan puts down his fork and drinks more water. It takes 45 minutes until the promised chocolate pudding can finally make its appearance. These 45 minutes are punctuated with long disappearances from the table that include toilet breaks and at one point, an ominous sound of sawing. Approaches include a kitchen timer being used, coaxing, threats such as: “Pauline won’t want to come back and eat dinner again if you’re being silly,” and a countdown, “six minutes”. He sticks his finger in his dad’s drink, dips his elbow in the gravy (deliberately) and uses his small camera to photograph me eating. The parents swap places and his mum helps him eat by feeding him which consists of a forkful of food going into his
mouth in between him weaving, dodging, leaning back, twirling in circles behind the chair and banging his head in the air as if he is listening to rock music. More water is drunk. More threats made including:

Dad: A) She’s taking pictures of this. B) She’s recording this whole thing.

Eoghan looks at me with a little half smile on his face. I am concerned about this approach as I have reassured the children that all my work is confidential yet can sympathise with the parents’ impatience after they have presumably experienced this struggle three times a day, every day for five years.

Dad: Recording this whole thing.

Mom: Please, sit in your chair! (stern tone from the usually soft spoken, gentle mum)

Dad: So. Camera! Taking pictures!

Mum: You won’t be allowed to go to birthday parties if you’re so silly after them.

At one point Eoghan photographs his sister. “I’m taking a picture of you because you're not eating. I’m going to show Pauline this. You’re not eating. Like, your dinner.” He drinks more water. I wonder if it is one of those bottomless cups like they have in children’s story books. I have not seen him refill it. His mum replies: “She’s done a better job of her food than you so far mate,” and Emily adds: “I’m up to my broccoli.” “You need to eat two more potatoes and some peas,” says his Dad. Eoghan snaps a few more pictures. You can feel the tension in the air, an elastic band about to snap in one of those games children play. Emily shovels another two mouthfuls, “Look, I'm all finished.” The plate she displays looks clean enough to pop back in the cupboard. Eoghan’s little chest puffs up, a tired miniature bull preparing for battle. It is like watching actors perform well worn lines.
Analysis

This was by no means an unusual dinner observation, especially with under fives. It was common for children to leave the table, walk around and eat and engage in protracted negotiations around quantity of food, duration of meals and appropriate mealtime behaviour. On one particularly memorable incident a participant’s younger sibling projectile vomited into my plate. Threats and coercion were a staple, with one mother, Grace asking me if others ever used the ‘you’ll have to go to hospital,’ angle to get their children to eat. She said she had with Ivy, although she did not like to. She justified it as fact, especially at the evening meal. It was also common for parents to use my presence as researcher or the camera as a behaviour modifier: look, behave, there is a witness. What kind of behaviour are parents enforcing and what does this tell us about what is socially valued?

Ochs and Shohet maintain that:

Meals are cultural sites where members of different generations and genders come to learn, reinforce, undermine or transform each other’s ways of thinking and feeling in the world… interacting with one another in the course of nourishing one’s body. These practices orient children both to mealtime comportment and to more encompassing dispositions expected of socially differentiated members. (Ochs and Shohet 2006, 47)

If this is the case, the meal described could be taken as a typical example of a cultural site. However, observations and discussions with families reveal that these vehicles of culture often take detours to ensure children have sufficient to eat, particularly with younger children. For example, children’s meals in front of the TV, “because he will eat better that way”, experimenting with earlier dinner times than the rest of the family to make sure they are not too tired to eat (which requires an additional supper or snack before bedtime), feeding children before gatherings with family and friends to reduce the stress of monitoring and
coercing the child to eat or simply not attending/ or changing the timing of cultural events such as birthday parties.

There are also wider social implications when a child leaves the relative safety of home. Jake had his first sleepover party and his mum told me, “I felt like I’d lost an arm or something. I had to have an awkward phone conversation with the mum about what they were having for tea and then ask the mother if they could order pizza with plain cheese as he might not eat pizza with a different topping.” Jake was also very worried it might be a pizza brand that he didn’t like and Betty told him not to worry.

Lily refused any playdates that included dinner times or were at meal times, preferring to schedule these before or after meals. She also told me she has never tried her son on porridge as she is afraid he will not eat it. “See, I’m in a food rut,” she said. Many parents tended to fall back into feeding children what they know they will eat rather than the recommended broad palette. Grace set a daily alarm on her iPhone to remind her to give Ivy morning tea. Meals are prioritised over social imperatives to make the daily lived experience run more smoothly. Birthday parties and activities, vaccinations and other decisions are weighted according to how they may affect meals. Betty said that she would always give the boys toast before bed if they were still hungry as this was the practice when she was growing up, not to go to bed hungry. I observed Michael being fed both at preschool and at home because his “hands are tired”. His mother didn’t know if this was behavioural or a flag that he was “low” and needing more food. However, by the time he reached primary school he was eating much the same as his peers. Parents are constantly tweaking to get the optimal result between meeting the needs of all family members, children having volume meals and ‘good’ social mothering (according to social norms). Mia illustrated this poignantly after her two-year old son had tonsillitis: “This whole week has been very stressful as I’ve had to mediate everything in terms of MCADD”. Similarly Rachael explained: “Chloe has been in to hospital
on a couple of occasions but as yet has not needed a drip. She is a terrible eater so meal times are a struggle and refuses to eat when tired. I sometimes give her bread with sprinkles on and call it fairy bread. Whatever works.”

If “mealtimes [are] cultural sites for the socialization of persons into competent and appropriate members of a society” (Ochs and Shohet 2006, 35), then what narratives are being heard by these children, what values and messages are being passed on to them during these important times? The dominant narrative is that food must be consumed; this is reinforced subliminally by parents asking each other if they think the child has eaten enough, or bargaining for “one more spoon of rice”, or “three more pieces of meat” before the child can leave the table or have dessert. Strategies included withholding food as a bargaining device (dessert or favourite food such as meatballs), and encouragement (engaging play such as using food to create ‘pictures’ or animals on the plate; stories about pirate food and broccoli trees or praise). The only families whose children didn’t dominate mealtime attention were those where siblings had food allergies or sensory aversions to food, in which case the focus shifted to the sibling with what was perceived to be the greater need. It must be noted that those families often had sophisticated techniques and understanding about feeding children, due to their cases being escalated and specialist feeding coaching provided by the health system.

What these observations have shown is that in addition to the modelling of talking about your day and correct etiquette and nutrition there are multiple subliminal texts. Food is quantifiable, with parents often asking each other “do you think she has had enough,” or negotiating further quantities. Adults assume the dominant narrative role at the table, conversing amongst themselves and including children, the objects of scrutiny, only when they are exhibiting ‘good’ behaviour, i.e., eating. Children’s primary role at the table is to eat and if they deviate from this they are reminded, coaxed and threatened to comply.
5.3 “They’ve got rules here and I didn’t make them up.” Illness performance as resistance to inscribed health identities

Ochs and Shohet point out that: “Because food is saturated with emotional meanings, children across many of the world’s communities use it as a medium of resistance, including habitually refusing food as an extreme form of social control” (Ochs and Shohet 2006, 47). There is evidence to suggest that this is consistent whether children have chronic illness or not, with mealtine observations of children of varying ages with cystic fibrosis or type 1 diabetes showing that the time to finish meals increased but that behaviour was roughly on a par with children without chronic conditions (Hammons and Fiese 2010; Janicke, Mitchell and Stark 2005; Patton et al. 2004; Patton, Dolan, and Powers 2006; Stark et al. 1997, 2000, 2005).

While it may be common for children to resist food during mealtimes, I suggest that children with chronic conditions have multiple reasons for their resistance and that social control is just one. I argue that in the case of MCADD, resistant behaviour during mealtimes is a form of illness performance with two ends: one, for the child to test if she is indeed ‘sick’ and if so, to what extent; and two, as a means of making clear their health identity on their own terms, resisting the cultural positioning of their bodies. By ‘rejecting’ food, these children are rejecting their diagnosis, showing that they are in fact healthy and should be treated as empowered narrative protagonists not objects of scrutiny (Ochs & Shohet 2006; Ochs and Taylor 1992).

*Acting the sick role*

In her study on child patients with leukaemia, Bluebond-Langner (1978) states that the acquisition of information is a long and painful process. In the case of MCADD, this is a long and confusing process. Bluebond-Langner (1978, 19) cites Blumer (1969) to note that:
“Interpretations of the self, others, and objects are made in the course of interaction. The meanings of such things (self, others, objects) are derived from and arises out of interaction that one has with one's fellows”. Bluebond-Langner goes on to describe how children behave in a way that would normally be reprimanded. When a child is rewarded instead of reprimanded he interprets his parents’ behaviour to “lead him to a view of himself as very ill, and he forges a line of action in accord with such a view. He acts the sick role and claims his right on the basis of the fact that he is truly ill. ‘Gimme that, I'm the sick one, not you’” (Bluebond-Langner 1978, 20). She further notes that ‘normal’ children do the same, pretending to be sick in a bid for relaxed rules and increased attention (Bluebond-Langner 1978, 29).

Daily meals are an opportunity for children with MCADD to test their ‘sickness’. They are quite aware that there are different rules with siblings’ meals, illustrated by four-year old Evie’s comment about her younger sister who doesn’t have MCADD: “She hasn’t had enough [dinner]. Why must I have more. That’s not fair!” Their mother soothingly commented that Evie was bigger so needed more energy, effectively shutting down an MCADD-related line of enquiry. In turn, siblings complain bitterly about the increased attention children with MCADD receive. Polly angrily asked her mother: “Why do you always have to be with Ivy. Why can’t Dad go?” When children are ill, rules are relaxed: they are allowed to eat in front of the television, are fed jelly and ice blocks, and hand-fed favourite foods in an attempt to entice them to eat. An ill sibling without MCADD may experience similar treatment with one difference, if they can’t keep food down or have a poor appetite they are allowed to rest until the episode has passed. The ill sibling with MCADD must eat or drink frequently, especially if vomiting or experiencing diarrhoea. This is usually a two-hourly polycal drink, day and night, that parents mix with juice or whatever else the child is likely to drink. Parents intersperse this with crackers and anything else the child will
tolerate and keep this up either until the child is eating and drinking normally again or the parents, after communication with the specialists, make the call to hospitalise the child. A two-day bout of illness equates in many cases to a fortnight of upheaval; the time prior to the illness episode where the child doesn’t want to eat and mealtime conflict escalates, the time when the whole family is exhausted from the two-hourly monitoring of feeds and the time after, where the child still has a reduced appetite and no-one has relaxed their monitoring.

**Validating wellness**

As Christensen (1997) discovers in her study of Danish school children, much of this revolves around assessing if what the child says, is ‘true’. Adults translate a child’s subjective experience “I don’t feel well,” or “I’m full” to something they can prove objectively through the body: “is there a disease?” or “have they had enough quantity to feel full, is there another reason they want to leave the table?”. The latter they ascribe to children wanting different food, like dessert, or wanting to play.

As Christensen (1997, 45) notes,

In the every-day illness of children these attributions centre around therapeutic practices… Through these practices children learn not only the instrumental and other contingencies of how to perform sickness in a particular, Danish, context but also how to enter into broad social relations concerned with age hierarchies.

In the context of New Zealand mealtimes, these children learn through the cues described in the previous section that eating is a therapeutic practice. Mealtimes are the stage for a dual performance, one of eating and of either well-being or illness. In Christensen’s study, adults use time and instruments to see if children are speaking the truth about feeling ill. The longer the child claimed to feel ill, the more validity her claim held (Christensen 1997, 45–47). A similar pattern emerged in this study. Additionally, time featured strongly in
discussions about food and eating: what time the children have meals, the time elapsed
between meals and the length of time that it takes to eat a meal. This temporal monitoring
meant that meals often disrupted children’s preferred activities, like playing, drawing or
watching television.

Parents in this study also used instruments to objectively assess a child’s body. If a
thermometer recorded a high temperature this was a marker for illness and what one mother
referred to as “action stations”. Likewise an objective temperature reading released the child
from her ill status to play. ‘Action stations’ comes with a corresponding anxiety, increased
focus on food and a symbolic foodstuff in the form of Poylcal. She told me: “I keep it in the
top of the pantry. Seeing it on top of the bench makes my heart sore. I know he’s really ok
when I can put it away again.” Bringing out the Polycal and the sheet of paper with the
emergency regimen recipe symbolises that the familial daily routine may be disrupted, that
there is the potential for hospitalisation. Blood sugar monitors were discouraged by clinicians
however five families had these and used these when the children were under two and ill, to
assess whether they should take them to hospital. “In this way the performance of the child-
adult relationship mirrors what Kirmayer identified as the important values of biomedical
practices: that is, to keep rational control over and distance from bodily and emotional
experiences” (Kirmayer 1988 in Christensen 1997, 47).

I argue that this control is extended not only with illness episodes but also during
mealtimes, on a habitual basis. However, with MCADD it is difficult even for clinicians to
know how quickly the child will deteriorate after fasting, which is why part of preventative
treatment is to have a low threshold for hospital admissions. As Christensen explains, the
objective tests parents use teach children that their judgement is not necessarily accurate until
an adult has validated this, much the same as the New Zealand child with MCADD. In the
case of mealtimes, a social experience that shifts along a continuum of ‘normal’ family eating
and illness prevention, children engage in performance to show that their subjective judgement is valid and should be taken into account; they are well. They are rejecting the objective controls placed over their food consumption and acting as empowered agents, action that continues outside of the home, at school.

The value of ‘being normal’: Social performance in a school setting

Many New Zealand schools have systems in place to verify that children in the junior levels of primary school have eaten some of their lunch prior to playing. In practice, observations revealed that some schools are more vigilant in monitoring this than others and that children have their own sophisticated techniques of evading notice and prioritising play, such as hiding in the playground when a duty teacher is otherwise occupied, throwing food away or giving it to other children. The last two points are rare. Many schools have a ‘zero waste’ policy and thus children throwing food away are more noticeable and schools are also cautious about food allergies; children are trained from a young age not to share food from lunchboxes.

A consistent trait with all of these observations were that children were erratic consumers of their lunchbox contents. With one exception, they sat alone, rather than with peers and picked at their food. The process was slow. They had periods of staring into the middle distance. Tom, age five, kept moving position amongst the children and when the bell went was first to put his lunchbox away. At a different school, on a different island, Evie, also five took her lunch to the senior playground to eat it, where lunchboxes aren’t checked. The common theme during lunchtime observations was children trying to ‘give teachers the slip’ so they do not get their lunchboxes checked and can go and play. However, over the course of the day, the lunch did get eaten. In a study of this scale it is difficult to determine if this behaviour is more prevalent in those diagnosed with food-related conditions, is a general
behaviour all children engage in or differed from these particular children’s usual lunchtime practice. However, it is not unreasonable to suggest that if these children are adept at constant daily negotiations around food from a young age that this bid for autonomy through resistance would extend outside the home.

A conversation with six-year old Gemma during a school lunch break highlighted her views on the controls placed around food consumption when she had other interests in mind, like playing. She told me: “I only like morning tea because we don’t have to put our hand up. I don't like the lunch because it doesn't feel good. You just have to put your hand up. You can only go if they say ‘yes’ and if they say ‘no’ you have to stay. You have to eat all your lunch. They've got rules here and I didn't make them up, the teacher did.”

When I asked her what her rules might be she said: “My rules? Maybe you can go straight away and do anything we like.” The conversation continued.

Pauline: Did you like your lunchbox? [Gemma had eaten painfully slowly, sitting on her haunches, rocking, with her hand up to summon the duty teacher. The duty teacher had asked her to eat a sandwich before she could go play.]
Gemma: Not really. There were a couple of things I didn't like.
Pauline: What don't you like?
Gemma: I do not like carrots. I do not like eating one short long bit of octopus. [From what I could see neither of these were in her lunchbox]. I like chicken. I don't like carrots. I don't like celery. For morning tea Mum gave me some of my brother’s bread with some raisins in [Designed for children with coeliac disease. She didn't like it. Neither did I] and I had cheese crackers that I like and I had a yoghurt that I like. But I don't like some yoghurt and I had some raisins and maybe some apricots and another raisin box.

Gemma went to some lengths to explain what she didn’t like, not only in her lunch box but also for meals generally. She does not like the “rules here,” in her mind these are not child-friendly rules and disrupt her autonomy and independence. Having to wait for permission to leave her lunchbox is irksome as she shows by her words, and general
demeanour during the break. The ambiguity of MCADD as medical condition and as related to the emotionally-laden, messy social experience of eating intrudes in the school arena. Many of the schools, particularly the primary schools, had action plans that listed the child’s condition and the action: call parents if the child was ill, they should eat regularly. While there is not space to go into an extensive analysis of MCADD as constructed in school, it is useful to note that all children are very aware of action plans and who is on them; these are often up for display in the staff room, office, sick bay or classroom itself. Parents’ strategies for telling schools about their child’s condition varied from mentioning it but minimising the risk factor to, in two cases, applying for teacher’s aides to sit with the children during lunch time. While clinicians as a general rule advised parents not to highlight the more extreme risks they indicated a willingness to meet with the school if necessary.

Teacher interviews revealed that apart from the afore-mentioned examples, MCADD does not feature in the child’s school life on a daily basis, with allergies, diabetes, asthma, leukaemia and visible disabilities taking precedence. The reason given was that there was no visible ‘action’ to take on the action plan, other than contacting a primary caregiver. As the condition is folded into normal school practice, eating, it is not flagged on a daily basis. This frustrated some parents, especially with children in primary school, who would come home with their lunch box barely touched.

The only isolated incident where the condition was clearly misunderstood involved Jake, who at 11 was highly conscious of peer relations. He told me: “MCADD is private, it’s a family thing” and explained how a male teacher told him in front of his peers that his ‘eating disorder’ was none of the teacher’s concern. This embarrassed Jake, who was already self-conscious about his condition and led to anxiety if school activities, such as sports practice at lunchtime, prevented him from eating. He has been responsibilised to know he must eat his lunch and when independent, doesn’t engage in stalling behaviour as described
with younger children. Bluebond-Langner examined sibling relations between children with and without cystic fibrosis and says:

> Being normal, which translates in American society to being like everyone else, is valued. No one knows this better and works harder at it than children. Should a child forget, his peers will remind him. Second, so long as the patient is seen as normal, ‘like everyone else,’ well siblings feel justified in making demands for attention, privileges, and special foods like those the patient gets. (Bluebond-Langer 1991, 139)

This goes some way towards explaining Jake’s self-conscious attitude at school, his teacher’s inappropriate comments and sibling rivalry.

What these examples show is that these children are being culturally positioned as “patients-in-waiting” (Buchbinder and Timmermans 2011). By the time they enter school they are aware that food is connected to MCADD (and in many cases describe MCADD in terms of food and drink), that it is important as part of risk prevention, that illness requires a heightened vigilance around food and, potentially, hospitalisation, and that the consumption of food gives them power. In many cases this is without anyone giving them an explicit explanation about what MCADD is, or the consequences of fasting for an extended period of time. Una, a grandmother in her seventies, highlighted the contradictions inherent in the diagnosis:

> I mean, the problem is that it’s hidden, it’s a hidden disability, and it is a disability. You look at these children and they look normal. And that’s a good thing, it is, but it’s also a huge disadvantage. It has its drawbacks in that it gives children unnatural power over food. Some people do not understand this, because it’s food. I told my brother-in-law and he said, “what’s the big deal — he just has to eat”. Recently he was diagnosed with coeliac disease. I said to him, “what’s the problem mate, you just have to watch what you eat.”

The phrase captures, albeit somewhat acerbically, how the remedy is so tied to existing social behaviour it is seen as no consequence. In society it is a basic ‘rule’ that we
feed our children and we feed them well, with healthy, nutritious, ‘low sugar’ food. This shows how the practice of eating can be so habitual and ingrained that it is overlooked. However, these invisible patterns of behaviour are not static habits, rather behaviour informed by ways of being in the body when eating; to explore this further I draw on Bourdieu’s concept of habitus.

5.4 A diagnostic habitus: the lifesaving, normative shadow

Habitus must not be considered in isolation. Rather, it must be used in relation to the notion of field which contains a principle of dynamics by itself as well as in relation to habitus… first, a space of forces or determinations, every field is inhabited by tensions and contradictions which are at the origin (basis) of conflicts; this means that it is simultaneously a field of struggles or competitions which generate change. In such fields, and in the struggles which take place in them, every agent acts according to his position (that is according to the capital he or she possesses) and his habitus, related to his personal history. His actions, words, feelings, deeds, works, and so on, stem from the confrontation between dispositions and positions, which are more often than not mutually adjusted, but may be at odds, discrepant, divergent, even in some senses contradictory. (Bourdieu 2002, 27–34)

How children diagnosed with MCADD see themselves develops within the constraints of habitus, daily behaviour radiating around food practices and preventative medical intervention shaped by the genetic diagnosis. The diagnosis of MCADD creates a habitus geared to prevent illness in the early, risky years of childhood; a set of cultural dispositions imprinted upon the body that amplify already prevalent food messages. This sense of ‘a feel for the game’ is unconscious and enduring, however it exists in a social space made up of fields, each with their own set of rules, as illustrated by Gemma above. The child’s social practices and actions are guided by her primary habitus but shift depending on if she is at home, a friend’s house, school, an outpatient clinic or the hospital. Included in the tensions
and contradictions that Bourdieu notes above is that the construction of MCADD shifts based on geographic space, from a normalised condition at home when the child is well, to a heightened risky condition when children are outside the home, to a biomedical objective disorder in the clinic and life-threatening when in hospital. If the “body [is] a bearer of value or ‘physical capital’” (Townsend 2011, 91), then the child’s capital shifts in relation to geographic space, different individuals and her health; high at home due to her efforts to exert social control over food consumption yet simultaneously low due to her child status; low during a routine check-up but higher once hospitalised.

In the case of my research, the social and cultural practices and actions include the ways in which mothers feed their children, structure daily activities and social events. This is learned through the shared body of the parent-patient: while parents are learning a new ‘illness habitus’ of parenting, children are learning a normative habitus based on this. When they have to adapt to the ‘new normal’ at age five, when children attend primary school for most of the day, first time parents know no other way of parenting (those with previous children know no other way of parenting this child, and other siblings are attuned to these practices) and children have formed their primary habitus. This experiential, sensory knowledge is learned by the body in the first few years of life. As the child grows up and experiences different enduring social situations, such as schooling, membership of sports teams, and cultural activities, this primary habitus is modified, but it will always remain as a ‘shadow’.

I have highlighted examples where children’s MCADD status has been a focus, but on a daily basis there is not a researcher analysing these children’s meals. For the majority of families, life is ‘normal’, and the underlying maintenance of MCADD is folded into domestic life. There is evidence to suggest this is the case with the daily handling of many chronic childhood conditions, such as asthma (Trnka 2017a), haemophilia (Park 2000), and cystic
fibrosis (Bluebond-Langner 1991, 1996). Parents say: “there is nothing wrong with her”. Clinicians themselves frame this as the dominant narrative in clinics⁴²; “the MCADD shouldn't even be on his radar at the moment except for when he is unwell”, an approach Bluebond-Langer (1991, 140) has described being used by physicians treating children with CF, where children have a shortened life span. “Living a relatively normal life is possible and even expected when the child is doing well. Indeed, physicians encourage families to treat the patient normally and get on with their lives”. The perception, construction and management of MCADD also varied, depending if families had another child with a medical condition or disability or extended family members with chronic illness. For example, siblings had eczema, extreme allergies, psychological tactile issues, ADHD, asthma and family members with cancer.

This diagnosed body is a dis-eased one, with something dis-ordered, not working. Townsend explains this contradiction: “The body works as a symbol of who we are; value is ascribed to how we carry ourselves and perform actions [however] to be able and active is deemed culturally valued behaviour and is a normative way of being” (Townsend 2011, 95). Specialists and parents thus steer this body to normative ways by emphasising ‘normal diet’ and behaviour. However, the ordinary daily struggles described in Part II mean that parents can’t always follow normative social child-rearing practice, and must negotiate ‘good’ parenting through the lens of MCADD. The benefit of this primary health-related diagnostic habitus is apparent, even when modified in later years. It paradoxically enables a ‘normal’ life through life-saving unconscious and habitual behaviours; a habitus that is hard won through disruptive processes in the early life of a child.
Reflections

This chapter set out to examine how children construct MCADD in relation to food, what mealtime observations revealed about the construction of these children and how these constructions led to a particular kind of embodied learning and identity to do with food and eating. As Hockey and James state: “Identities are only meaningful in response to the individual's response to them” (2003, 201). This chapter has shown that children’s identities are enmeshed in ideas about eating and food in multiple ways and that this is a reflexive process depending on place and the health of the child on any given day. Through this process they are at varying times socially identified as children, as children with specific needs around food (much as a child with diabetes) and as children with a health condition that both restricts and allows them preferential access to health care. Identity is a lifelong process and these identities are all temporary. Both childhood and MCADD are social constructions. The young participants in this study occupy the status of childhood. They are always going to have MCADD but they take on that health identity sporadically, negotiating and actively resisting a social positioning that permanently links them to either state.

Conclusions: Part II

Drawing on Bourdieu’s concept of habitus I have shown that a diagnosis of MCADD creates a medicalised body in need of preventative treatment and that an embodied and situated personhood is affected by this treatment (food) in childhood. A shadow habitus remains even after moving through this phase of early prevention.

These children need to eat regularly daily to ensure they remain healthy. As infants, their parents (the aforementioned parent-patient) take on a diagnostic habitus to set up these patterns, which the children then take on as a primary habitus. These include regular meals, consciousness about having a snack before or after physical activity and always going to bed.
on a full stomach. The children’s behaviour around eating (or opposing eating) does not come about arbitrarily. This is because they are embedded in a habitus that “once acquired...
underlies and conditions all subsequent learning and social experience” (Bourdieu 1977, 72–95). The acquisition of this habitus is done through emotional and sensory processes; the taste of food and the experience of hospitalisation⁴³.

Even when that immediate sensory experience of forced taste and pain fades, the shadow of it remains. What is the object that casts this shadow? MCADD itself, the missing or defective enzyme, defined as disease and risk to a child’s life? Or the diagnosis, that casts a shadow across a lifetime? It is none of the above and contrarily all of the above. An answer is that the object casting the shadow is the actions one takes to avoid the effect of MCADD on a child’s life. In the photos that children took to illustrate a typical day, food did not dominate the images — its inclusion was at the guidance of parents. Children’s pictures featured boats, pets, family members, random expanses of grass and skyshows, and sports, etc. Food featured a great deal in parents’ lives because as parents they are responsibilised to ensure their child gets an adequate, nutritious diet that will help them grow. However, if asked to define MCADD or explain what it is to someone else, children equated MCADD to food and drink. This is one answer but it is not the only answer as children actively and reflexively critiqued and negotiated the truth of what MCADD is to them and debated this with others.

What is enduring, is the food patterns and behaviours built up around the prevention of already diagnosed disease affecting the child. I have also shown that the construction of MCADD shifts in relation to the above parameters and to an individual’s perception of chronic conditions. Existing ideas about the risk versus health-related benefits of particular foodstuffs are exacerbated by a diagnosis of MCADD. If the self is a complex concept set up by social interactions, those relevant to a diagnosis of MCADD include food and the clinical/
hospital experience. These experiences in turn set up dispositions inscribed on the body which are powerful and sensory in nature. Diagnosis brings into play a whole structural system designed to treat ill bodies. What the network of care is struggling with, is that diagnosis creates a ‘non-healthy’, non-normative body but that all parties concerned are encouraged to act as if it is a ‘normal’, healthy body. This is because as long as the child eats and is not ill, she will be ‘well’ (or more accurately act according to normative ideas of a healthy body). To benefit from the diagnosis and stay healthy the body has to be treated in the system, as a sick body. Outpatient clinics and hospital admissions help construct the impression of a pathologised body. This is the conundrum of preventative medicine and one that will be explored from the perspective of the child, the tangible body under discussion, in Part III.
PART III: “EXCEPT IT’S NOT REALLY A DISEASE” —
THE CONSTRUCTION OF MCADD IN THE CONTEXT OF ILLNESS
MY NAME IS LOLA. IT'S BREAKFAST TIME HERE AT THE CRAZY HOUSE. IT'S ALWAYS BREAKFAST TIME, OR SNACK TIME, OR LUNCH TIME, OR DINNER TIME.

COME ON LOLA, FINISH YOUR BREAKFAST.

I'VE FINISHED ALL MY FOOD.

BOOY HOY

MATT. LOLA! COME ON. WE'RE GOING TO BE LATE FOR SCHOOL.

MUM GETS REELLY GRUMPY WHEN I TAKE TOO LONG TO EAT. SOMETIMES I JUST DON'T FEEL LIKE IT. EVERYONE IS ALWAYS BOSSING ME.

COME ON LOLA. JUST HAVE A LITTLE BIT MORE. IT'S GOING TO FEEL LIKE AGES BEFORE YOU GET A BRAIN FOOD BREAK.

I HAVE MORE IMPORTANT THINGS TO WORRY ABOUT... WHO WILL I PLAY WITH TODAY?

SCHOOL IS FUN. WE PLAY AND RUN AROUND. MY BEST FRIEND IS SARAH. THE TEACHER CHECKS HER LUNCHBOX TOO, AND THE OTHER YEAR ONES. THEN WE CAN GO PLAY.

OK, SARAH.

ONE MORE SANDWICH LOLA.

YAY! LOLA!
SSH. I'M WATCHING PAULINE. SHE'S AT SCHOOL TODAY. SHE'S A RESEARCHER. I TOLD SARAH SHE WAS HERE FOR ME BUT SHE DIDN'T BELIEVE ME. PAULINE DID DRAWINGS WITH ME. SHE ASKED ME ABOUT MY MCADD.

WHAT IS MCADD? IT'S FOOD AND DRINK, RIGHT?

I DON'T THINK ABOUT IT VERY MUCH. IT'S PRIVATE, A FAMILY THING. EXCEPT SOMETIMES I WORRY...

THE BEST PART OF THE DAY IS COMING HOME AFTER SCHOOL. EXCEPT FOR THE HOMEWORK...
But not today, today I have a boring check up, no pickles, Mum promised.

All they do is talk, about me. It's boring.

What does she normally eat in a day?

Toast or porridge in the morning, fruit at afternoon tea, then when we get home...

I'm hungry, can we go now? Can we go?

Oh Lola, is this because of the visit today? You heard the doctor, there's nothing wrong with you, everything is fine, go to sleep now. Sweet dreams, love you.

Dad, I don't feel well.

That night I had really bad dreams.
I GET SCARED WHEN I'M SICK

MATT, I DON'T FEEL WELL.

I'LL GET MUM FOR YOU.

NO, MUM!

LOLA...

MUM, MUM, YOU NEED TO CHECK MY HOMEWORK.

NOT NOW, MATT.

MATT, HAVE YOU SEEN TEDDY? ARJUNA...

MATT, I DON'T FEEL WELL.
Chapter 6: “Just live a normal life and never think about it” — Narrative constructions of MCADD in the context of illness

‘Health’ and ‘illness’ are, in large part, socially constructed, context-specific categories through which we interpret our bodily experiences and then make judgements about the state and status of our bodies. (James and Hockey 2007, 3)

_The Life of Lola: Totally Normal_ illustrates a day in the life of a child living with a diagnosis of MCADD. It is constructed to portray a typical day that is interrupted by an outpatients clinic visit and is drawn from participant observation of home life, clinics, school meal times, and extended interviews with children. On two visits, three children were hospitalised with gastroenteritis which gave an opportunity for me to observe them on a ward. The comic strip uses Jake’s and other children’s stories to visually encapsulate some of the themes that were revealed over the course of the research.

It is therefore representative of a typical day in the lives of _some_ of my participants at particular times of their lives. However I do not claim that it mirrors the entire life experience of participants. Rather it highlights where daily life intersects with the pathologised body. This comic encapsulates, to paraphrase Scully, the continual tracking between MCADD ontologically, as a way of being, and of MCADD as genetic disorder, “pathologically… medically out of whack” (2008a, 3). It also reveals what was made apparent over the course of the research: that young patients understand and explain complicated medical conditions through tangible and sensory experiences, such as, the treatment (food and drink), symptoms (the sensory experience of feeling unwell, including vomiting), and the hospital experience, (which was characterised by ‘prickles’/pain).

Part III therefore turns to the children to present their points of view. I examine the minutiae of that experience and ask what is the relationship of these children’s bodies to their
diagnosis? How do they make sense of kinship and genetics? What is their understanding of illness and how does this relate to their sense-making of MCADD and their experiences in hospital? And ultimately, what do their narratives reveal about their personhood after growing up under a molecularised lens? Part III therefore explores how childhood illness is experienced through the lens of MCADD, particularly how the cumulative narrative framing of MCADD since diagnosis has shaped children’s experiences.

I use two frameworks to analyse how these children interpret MCADD. The first is that of illness narrative. I examine illness narratives from two perspectives: the stories children tell about MCADD and my observations of their experience of illness, in two spaces: the clinic in Chapter 6 and the hospital in Chapter 7. As Haker (2006, 361) outlines:

The narration of the different biological, psychological and emotional aspects of an illness and its contextualisation in one's life history and in the socio-cultural environment, can affect a change in the understanding of the illness itself, of one's conception of oneself, and of the way in which the illness was coped with.

In the case of these patients, it is illness that underscores the diagnosis of MCADD, which is largely invisible despite its effect on daily behaviour. Illness brings the subconscious experiential knowledge of MCADD to the fore, and changes how MCADD is understood and experienced, but MCADD itself is not illness. A problem that has continually engaged me in my research, as it has engaged other scholars, is how to access experience, an internal state linked to bodily and emotional processes? The lines between the Foucauldian, discursive ‘body as text’ that appears in outpatient clinics and the sensuous, phenomenological hospital experience are not clear cut. I argue that to capture an understanding of lived experience it is necessary to encapsulate both perspectives. This is where a second framework, Bourdieu’s habitus and Scully’s work on the bioethics of disability, is useful as an aid in analysis.
Scully (2008a) draws on Bourdieu as a means to understand the world as mediated by habitus.

Bourdieu is trying to articulate a way in which a physical body interacts with a social world to derive meaning. The individuality of this production derives, in part, from the specifics of the body; what the constraints of biology and physics allow the body to do, and the possibilities that are open to that kind of body in that social organisation… what is the effect on habitus of the experience of being/having a body that is not the standard model? (Scully 2008a, 67)

Scully is referring here to how disability is framed in different social settings and that how a body *is* is a crucial part of how habitus evolves. Her discussion is pertinent as the initial diagnosis of MCADD as disorder sets up a disordered body, one defined as having an ‘inborn error of metabolism,’ articulated by one young participant as “something in me is a little bit broken and can’t be fixed” (Adam, age 4). Using gender as an example, Scully argues that even a subordinate habitus is more comfortable than one that is not normative (such as disability), as there is a place for it that is understood in the world: “The condition of not sharing the effortless habitus of normal embodiment is central to what disability is all about” (Scully 2008a, 69).

I argue that preventative medicine, particularly in the form of screening and diagnosing genetic conditions, sets up a non-normative habitus that shares similarities with Scully’s example above. The ambiguity of MCADD as potential illness (but not illness) means it is difficult to find a place for it that is socially understood in these children’s worlds. Outpatient clinics and hospital admissions are not part of the habitus of normal embodiment however, this is what is necessary to ensure the pathologised body remains within normative (well) parameters.

However, the patient (and her family) is simultaneously encouraged to act according to a habitus of normal embodiment when well, particularly as the child ages. The child will
always have the condition. However, as she grows to adulthood, the risk of decompensation is minimised, so much so that some specialists anecdotally propose that children with MCADD should be dismissed from the health system from the age of five. I argue that as the child grows, the primary pathologised habitus shifts to the dominant social normative habitus, however, the ingrained dispositions set up in those early years, what I have previously called the shadow habitus, remains. This is more than Bourdieu’s (1977) concept of hysteresis — a lag between a change in habitus and field as can be seen in, for example, some people and their slower adaptation to new technologies. Rather, as there is always the risk of MCADD presenting, those life-preserving habits inculcated through early life remain and are for the most part followed.

Scully (2008a, 12) notes that an exclusive focus on body as text risks missing the ontological body as being: “bodies are before they speak or are spoken about”. The sensory, embodied experience of illness and its treatment and how this is related to the body diagnosed with MCADD is key: “Phenomenology recognises that a subject’s sense of self, her perceptions and understandings of the world, are inextricably bound up with her body and its interactions with other bodies and with her environment” (Scully 2008a, 12).

In the following chapter I examine how these narratives about MCADD are conceptualised, described and redefined by the children in this study. I argue that their understanding is modified by the message their parents tell them and embodied in combination with their lived experience of the disorder. Specifically, this section will show that children’s understandings about MCADD were shaped by narratives told directly to them by parents and specialists, by their own embodied experiences, by the narratives they overheard and observed being told to others about them and their condition, and by place.
6.1 Emerging personhood and indistinct MCADD

Mattingly and Garro write about the “need to distinguish disease, as phenomena seen from the practitioner’s perspective (from the outside) from illness, as phenomena seen from the perspective of the sufferer” (2000, 9) and turn to Kleinman’s (1988) illness narratives as a way to achieve this. I similarly turn to stories from two families to explore their understanding of the disease-illness dichotomy, what this tells us about their construction of MCADD, and how it shapes a particular kind of body and interpretation of that body in specific social contexts, such as the home, outpatient clinics and hospital.

Jake, Ebola and the search for social personhood

It’s a cold Saturday in October. There are two boys, John and Steve and they are bullies. Stevie is a Year 7, he’s 12 and John is 13, a Year 8 and they go to school with Sophie. She’s a Year 5, a nice girl. The two boys really like Sophie and they’re really jealous of her because she’s pretty. And then them two boys pick on the girl because she has MCADD. They think it’s like a disease or something. Except it’s not really. They think it’s Ebola because they’re not very smart at school. They need extra help.

(Story by Jake, age 9)

The vignette above was narrated by Jake, age 9, during a storyboarding exercise\(^45\), where he created a fictional story about a character with MCADD. It suggests a crosshatch of interwoven social processes and hierarchical peer relations that are framed by diagnosis and that construct a disease based on appearance, age, ability and gender; emotion snakes through. Jake’s understanding of disease will have been influenced by the biomedical system he has grown up with, one that uses a clinical gaze (Foucault 1994) to define disease as objectively measurable, pathological and affecting the body. Ebola\(^46\) is an easy target. His experiences with childhood illness however, have shown him that MCADD has the potential to turn common childhood illness into a more serious event, although this is not consistent.
‘MCADD’ in the context of Jake’s health, is not one thing, it is dependent on if he is well or unwell, the quantity of food he has eaten within a particular time period, his location and who he is talking to. His vignette highlights this ambiguity: “It’s like a disease or something. Except it’s not really”. As he cannot define exactly what this thing is, never mind pronounce it, it has the potential to impact his peer relations, relations that are structurally embedded in his school hierarchy even though the characters in his story are at home, on a cold Saturday. The potential for these relations to affect him negatively are shown in his portrayal of bullying, however he highlights his own knowledge and social understanding of disease which excludes MCADD. If disease is communicable and stigmatised, MCADD does not fall into this framework. Jake is careful to frame MCADD as not disease, it is not Ebola, and that “bullies” who believe that MCADD is Ebola are “not very smart at school”, and “need extra help”. The end of the story reveals a twist; the boys knew all along that MCADD was not like Ebola but used it to pick on the girl because she was scared of “the terrible” disease. The unknown, particularly when linked to illness, has the power to affect one’s social status which is a partial explanation towards why Jake keeps his diagnosis private as a family matter. I propose that how the management of MCADD is approached in each family is a way of exploring the child’s health identity in relation to personhood.

Garro examines patient personal well being through ‘family health portraits’, proposing that:

From the perspective of individual health promotion, parents are charged not only with optimising their own health but also with optimising the health of their children, and beyond that, for socialising children to appreciate their own independent responsibility with regards to health and well-being”. (Garro 2013, 219)

If social personhood is what the child seeks to attain, understanding health as a matter of ‘family well-being’ gives us a way to explore what is valued as a ‘person’ and
subsequently how the child’s personhood is shaping up through the lens of MCADD (Garro 2013, 217). Jake’s story above indicates that a pathologised body is at risk of jeopardising one’s personhood so in public spaces, like school, he tries to avoid his diagnosis despite the management of his health in the private, home sphere. A family discussion about the genetic origins of MCADD gives further insight.

George: But where does MCADD come from? (he turns to Betty when I don’t answer). It comes from you, right mum? Do you have MCADD?
Betty: I’m a carrier and you’re a carrier and it comes through to you.
George: So does Nana have MCADD?
Betty: Well, she might. It’s genetic so the gene is passed from her to us to you. She’s a carrier and Grandad is a carrier.
George: But if Jake and I have it then why don’t we all have it? We’re family.
Betty: (looking uncomfortable). It’s like you have blue eyes and Jake has blue eyes and so do I and Dad…

At one point in this exchange Jake looks embarrassed and sighs. He says: “It doesn’t come from anywhere. You’re just born with it.” The whole time he is rubbing his face and eyes and generally looks like he wishes it was over. I ask him what he thinks about George’s question. At this point he is standing up, leaning on the chair, hands in pockets. “What question?” he says.

“I asked ‘where does MCADD come from’,” says seven-year old George, clearly not picking up on his brother’s cues.

The boys’ mother intervenes: “Look at him, not bothered, are you Jake?”

Jake walks outside and Betty says, “you see, he doesn’t care, hands in pockets, body language saying - I’m not bothered”. However, Jake appears very sensitive to his diagnosis. He cannot bear to look at a picture of an IV on a computer monitor, and he is anxious not only about telling his parents when he is sick but also about the potential stigma of having MCADD, as revealed by his storyboarding, reluctance for me to attend his school and
anecdotes about what his teacher said about his ‘eating disorder’. He also did not want his friends to be able to ‘google’ his name and find out about the MCADD research.

The children diagnosed with MCADD seem to be testing whether MCADD is disease or illness and, based on their embodied experience, categorise it within the parameters of illness. Siblings without MCADD seem to blur these boundaries, with MCADD dangerous not only to those diagnosed but also to those around them. This was expressed by Imogen, age seven, a sibling who does not have MCADD, in a role play using a series of My Little Pony toys that ended with Imogen growling, meowing and scratching at her younger sister Amber who does have MCADD. Imogen dominated the game and orchestrated the ponies so that Alice, the ‘MCADD pony’ walked along and made the other ponies sick.

*Imogen and Amber: Negotiated personhood in relation to contagion*

Pauline: …And here’s one little pony who does have MCADD. Let’s start the story. Ok is this the doctor pony?

Imogen: No, these two are.

Pauline: Ok so these two? *(indicate the two ponies)*

Imogen: And these two can have MCADD and these two can have MCADD…

Pauline: Well how about we have one with MCADD and one without? They can be brother and sister if you want.

Imogen: Well these two can be sisters. These two can be sisters.

Pauline: Ok. These two…

Imogen: They could both be MCADD! They could both be MCADD ponies that spread MCADD.

Pauline: They spread MCADD? What do you think Amber?

Imogen: *[keeps talking]* They could both be ponies that spread MCADD so like some of them get MCADD by these two ponies.

Pauline: What makes you think that MCADD can spread?

Imogen: Coz other peop… coz MCADD does spread.

Pauline: Oh, ok. What do you mean when you say that MCADD spreads?
Imogen: Like, people get it from other people.

Imogen expressed earlier in the day that she was jealous of all the attention her younger sister gets when she is sick, and Imogen is resentful of the fact that Grace, her mother is always the one to go to hospital with Amber, never her father, so Imogen is always left behind. In the story she was adamant that there are two sisters with MCADD, not just one pony and that MCADD spreads. She qualified “people get it from other people”. Throughout Amber stayed quiet and when asked directly she shook her head silently. Ten minutes later I asked the girls which two ponies get sick. Amber picked two and Imogen argued she could not.

“No! Those two were MCADD and MCADD (as she had named them). Spread the MCADD”.

When Amber again tried to indicate the ‘MCADD ponies’ as being those who get sick Imogen shouted “No, no! They are the ones that spread the sickness”. When I queried this she replied: “Yeah. That’s why I’m saying they don’t get sick”.

For Imogen, the ponies with MCADD carry a disease called MCADD, one that is contagious and can be spread but that does not affect the carrier. From one perspective she could be interpreting carriers of the genetic disorder (as she herself could be but not have symptoms) the same as carrying disease. And normally Imogen cannot ‘see’ Amber’s condition unless Amber is sick with something else, which gains her Grace’s precious attention. In contrast, Amber is indicating that the ponies (who in the game, are MCADD) can get sick but are not contagious, showing an accurate understanding of MCADD through practical logic (Samuelsen and Steffen 2004).
When specifically tasked with creating a script about a character with MCADD not all of the children associated MCADD with illness and even those who did, did not do so all of the time. While Jake’s initial storyboard about a character with MCADD was dramatic and violent, a subsequent story, created four months later was quite benign, written in first person and focused on a pedestrian trip to the dairy to buy donuts. Kate’s story revolved around the lessons her character did at school.48

I use these stories to highlight that children with MCADD generally do not categorise it as ‘disease’ because it does not fall into the parameters of a contagious, ‘spreadable bug’ like Ebola, or something that makes other children (ponies) sick. Children without an embodied experience of MCADD tended to relate it to mysterious conditions afflicting others, like school-learnt Ebola or cancer. Illness is a mostly internal, invisible affliction. In the body mapping activity (described in the methodology section), children were asked to imagine ‘themselves’ as unwell and to add to their drawing to show this sickness/unwellness. Two children refused to draw on their self-image, turned the page over and created a new body map specifically to map ill health. The remainder drew over their self-images.

Their subsequent drawings appeared with representative icons both outside and inside the borders of their body. A dominant theme was vomiting (with a secondary excretion being diarrhoea). As well as naming the action “vomiting”, “throwing up” or “being sick”, children also took relish in detailing and demonstrating proficiency with objects related to vomiting, like a sick bowl or bucket and towel. Thermometers were also commonly mentioned as part of the trappings of illness. Vomiting was often linked to a hospital admission, referenced in drawings with a red cross and verbalised as injections, prickles, drip or a robot. All drew an unhappy face to symbolise being unwell and often tears, only one mentioned spots. Children also drew or fetched a favourite teddy or pillow to show me.
In Part II, children linked MCADD to treatment: food and drink featured in children’s explanations. An escalated form of treatment is in food given via IV in hospital and for children in this study, the IV featured strongly as related to MCADD. However, they did not appear to make the link to the substance in the IV as energy; rather the majority of the children associated being unwell, or ill health, with vomiting; the sensation of nausea with hospitalisation and the sensations felt once in hospital with pain and fear. It is vomiting, as a precursor to hospitalisation that is linked to MCADD. The two are linked in the children's minds and the comic illustrates how the previous sensory experience of being in hospital affects current behaviour — Lola feels unwell after a classmate throws up, and her feverish nightmares include what she imagines may happen; a drive to the hospital in the back of an ambulance, where she will receive a ‘prickle’. This imagined future is conceptually part of the pathologised body set up by diagnosis. Even if the child has never been hospitalised, this is a future they are aware is possible. I have shown where these narratives find their genesis but how does this tie into children’s understanding and construction of MCADD?

Understandings were largely expressed in terms of treatment like ‘food and drink,’ symptoms like nausea and being sick (e.g. throwing up as a trigger to go to hospital) and explorations of disease-illness frameworks linked to examples they were familiar with, like Ebola, cancer and contagious germs. Biomedical health metaphors (e.g. my body is broken/ cupboard stores are not full/ car petrol tank on reserve/ Lego man with bricks missing) were largely driven by explanations from parents or medical professionals. Their focus is not on treatment but on the normalisation of the body that is other. The pathologised body created from the diagnosis has been medicalised to ensure it stays within the boundaries and parameters of ‘normal’.
6.2 Stories clinics tell

“Do you know why you are here?”

“Nah,” said eight-year old Demi.

Her sister Kate added: “We’ll be asked if we know what MCADD is and stuff”.

“You see,” said their mum. “They really don’t know anything about it”.

*Family discussion in a hospital waiting room prior to a clinic*  
*(Field notes September 2014)*

I now turn to the clinic itself to see where these messages originate. First, I analyse the reasoning processes within the outpatient clinic through the lens of illness narrative theory. I argue that between the competing narratives of the medical specialists and the parent-patients lies the acted narrative of the patient itself, the child, who for the most part is a silent object in this process. Bluebond-Langner (1978) and Easson (1970) have discussed the nuances of how a child is socialised to the correct behaviour within a clinical and hospital setting and how the awareness of her condition is evident through her behaviour. With the exception of Dedding *et al.* (2015) there is limited literature focusing on children’s experiences of outpatient clinics, with the majority focusing on the parent (usually the mother’s) attempts to follow health strategies for their child. While I cannot categorically say what children are thinking about these clinics, particularly with younger children, I can present the contextual narratives they are featured in and their reactions to this. I also present extracts from conversations held before and after the clinics, about the clinic experience. This highlights the “invisibility” *(James and Prout 2015)* of childhood and medical conditions and lays the groundwork for further discussion about children’s illness narratives in relation to MCADD. How they view illness is coloured by their knowledge and embodied experience of MCADD, which is formulated during clinics and hospitalisations.

Second, I build on the idea of the clinic as a site of knowledge production to argue that it is the outpatient clinic itself that creates ‘MCADD as disease’, even while the
specialists’ master narrative works to reassure that the child is well. The dominant narrative about MCADD is therefore that it is something not to worry about ‘while they are well’. It is childhood illness that is the trigger for preventative behaviour, for ‘special drinks’ such as Polycal or hospitalisation if they cannot keep the Polycal down. It is illness that therefore transforms the body from normative to that of pathologised other, and it is the pathologised body that is treated in hospital.

I observed 20 patient clinics from December 2014 to the end of 2015. Participants knew me prior to the clinic and in many cases I would arrive with them, or meet them in the waiting room beforehand. Children ranged between five months and nine years of age. In addition I analysed the clinic letters of 12 children that were sent after outpatient clinics and interviewed parents and children about the clinic experience both before and after attendance. Clinics were held in hospitals in a range of locations including Palmerston North, Christchurch, Tauranga, Wellington and Auckland. Of these, only one clinic that I observed was not run by staff from the Auckland-based Starship Paediatric Metabolic Services Team. As a general rule infants are seen every three to six months with this decreasing to an annual basis from two to three years of age, extending to biennially when parents and specialists are comfortable to do so, from approximately five to six years of age.

The clinic is the place where the ‘MCADD as illness’ narrative originates and a master healing narrative is created. The clinic itself has a script, that maps itself to the child’s life course. I have divided the clinics into three categories: the infant clinic that covers the child’s first year where the parent shares the role of patient; the early childhood clinic up to the point the child starts primary school, and the clinic with the young person that engages them more directly in the clinic narratives. While this is a useful rubric, these categories are not discrete and characteristics commonly seen in one could be seen in another, depending on the patient.
Infant clinics have been discussed in detail in Part II, where I argued that these lengthier clinics highlighted risk out of necessity and featured specialist monologues that reinforced key messages about infant feeding, normality, positive long-term prognosis and sought to minimise parents’ fears and answer developmental questions. I also showed that over the short period that this research has been conducted, that these heightened messages of risk have evolved and modified to reflect new findings. While the infant is in most cases present at the initial meeting and then at subsequent clinics, her involvement as a patient is strictly as someone to be observed. At the initial meeting, she is weighed and measured, a further blood sample taken and a urine bag attached to the skin under the nappy. The child is also observed feeding while the clinic is conducted. The narratives that unfold take place between the specialist team and the parent-patient.

The second is young child clinics where developmental checks are made, and queries asked according to an informal script that targets eating habits and frequency, recent illness episodes, developmental milestones, and school readiness. These queries are mostly quantifiable and include age, comparison of height and weight, and timing of meals. They also deal with any unanticipated issues before they become serious, answering questions that arise due to a child’s life course (weaning, solids, preschool, waking/sleeping, primary school, etc), and parent-specialist question-answer sessions. The child is usually directly addressed at the beginning and end of the clinic.

In the third, as the child progresses through schooling from primary school, she is engaged more directly in verbal narrative, and three different narratives emerge, that of the specialist, parent, and child. These older child clinics are annual or biennial, the child is spoken to more directly, explanation sometimes given, and parents use the clinics to reinforce their own messages and parenting methods. Only two of the clinics explained MCADD directly to a child, making use of metaphor.
The following composite vignette is an example of the clinic experience from the child’s point of view from the time they arrive at the hospital to when they leave.

6.3 The clinical encounter: A five-part vignette


Children’s outpatient clinics take up a curious space, a room that shifts and moves between visits, folded within the walls of a hospital. Ivy held her mum’s hand tightly as they navigated the maze from the parking lot, where the parking fairy had delivered a park after only 10 minutes of riding the ramps up and down. “I want to press the button,” she whispered when they reached the lift. They crossed the road and with one eye behind her to check her mother still followed, Ivy skipped ahead to follow the blue dashes that led to another lift, past the emergency department, up some stairs and to reception. There were alternate routes they had taken in the past and all seemed to blur every year, as if the corridors shook themselves out at night and moved to other corners.

From behind her mother, Ivy told a woman her name. The woman was well defended, a long desk in front of her, silhouetted by a tall whiteboard listing specialist names and their rooms for the day. We sat down to wait. There were toys and a TV. Brightly coloured decals stuck on the wall, fish swimming their way towards the ceiling, a destination they would never reach.

Part II: Measurements. George and Jake (age 7 and 9).

A tense game of air hockey was underway in the hospital playroom when the nurse arrived. She took them away from the entertainment to be weighed and their height measured, standard fare for children in New Zealand. The pink-walled weighing room was dotted with cut out yellow stars and featured a row of waist high cupboards under a long bench, like a
kitchen. The doors were sea green, what was inside, a mystery. The bench was not. It was busy with the oddments that speak of healthcare’s battle with germs: a mobile above a changing mat, soap, latex gloves and paper hand towels in a dispenser above the shining porcelain sink. A biohazard bin for waste, a fan, not needed at this time of year. Charts and lotions were reflected in the shining linoleum floor, curved at the bottom so there are no cracks for wilful germs to lurk. I read “Ask the question. Smoking, Inside or outside. Nicotine patches (free). Ask about the elephant in the room (a clipart elephant illustrates the point). Family safety. Any concerns for anyone?”

George slowly took off his shoes and climbed into the bucket seat, laden with stickers. He leant back, cross-legged. “26.45” announced the nurse and walked to her notes to write it down. Then he stood against the grey plank leaning up on the wall, like a folded up flat ironing board. He glanced at the wood shelf above him as if it was going to drop cartoon style on his head. A robot stickered sign next to it read “staff use only”. I wondered if rogue passers-by wander in to weigh and measure themselves, perhaps the invisible elephant.

“Ankles right to the back,” commanded the nurse, pointing at his feet, one hand on his shoulder to make sure his feet were flat. She gently put one hand on each ear and positioned George’s head, so the back of his skull was flush against the board, eyes forward. She tipped it forward, and holding the chin she manoeuvred the wood onto his crown. She mumbled the number and wrote it down. “You’ve grown five point, five centimetres he’s grown,” said Betty.

Jake was next. He hopped through the actions. Afterwards there was heated comparisons about who had put on more weight, who had grown the most in a year. These are higher stakes than air hockey. Later, during Jake’s clinic, the dietician bustled in with an updated emergency regime that matched his current weight. The previous one would not keep him going if he could not eat. I think of all the measurements I have seen marked down in the
field: the boy who was accidentally measured with his shoes on, who for a moment the specialist thought might be at risk of gigantism because, already a tall boy he was off the scale; the pleasure others showed at their gains in weight and height. They are healthy. They are growing. These measurements are the benchmark that discussions rest on.


I missed Gemma’s weighing but I observed, noted and filmed the clinic and its lead-up. It was a frigid, wet morning in the South Island and I arrived at outpatients at 9:50 to hear Susan, her mother, leaving a message on the school phone: “Gemma Jones will be late due to a medical appointment”. Gemma played in front of a gigantic, paned window of coloured glass that revealed the clinic rooms. She was dressed in her school uniform, a tartan skirt and green jumper, the only bright spot her ribboned gumboots, ready to take on the dull weather. Gemma waved and smiled and continued to carefully set a small plastic table for four with a little teapot, milk jug (as the cup) and plates. I sat down on the long, padded bench next to Susan to say “hello”.

A constant hustle of people bustled back and forth, particularly pregnant women and children. The waiting room was fluid with at least four different doctors attending to the patients. Nurses and dieticians called children out of the waiting room for weighing and other appointments. I wondered what the children thought of this? Were they nervous and apprehensive? Bored and want to be called so they can get it over and done with? Or annoyed that their playtime had been interrupted?

I went over to Gemma to say “hi”. I asked her if she knew why she was here. Gemma scowled and shrugged. Her face shut down. I asked her what she was doing (making ‘tea’) and if she enjoyed after school care yesterday (which I had observed, ‘yes’). That got me a cup of make-believe tea. I mimed drinking it. Returning to Susan, I asked her what she was
expecting from this clinic and if she had any questions and Susan said no, nothing had really happened. The family had been here the previous day for Gemma’s brother’s appointment for a different condition and Susan was annoyed the two visits were not co-ordinated better.

Gemma squatted to take a tray out of the cheery white and yellow toy oven. It was laden with hot chips, a burger patty and lettuce (all plastic of course). As I watched, she arranged these artfully in the centre of the table. This waiting room, like the others I observed, had a TV, but instead of Nick Jnr or the Disney channel, an educational DVD, *Dr Bumblebee’s Guide to Type 1 Diabetes* was playing. I watched the little bee talk about sugar and how our blood uses it and transports it around the body. Susan made some comments about parallels between diabetes and MCADD before reassuring me that of course she understood they were different.

The metabolic dietitian walked past and Susan called out to Gemma, “Did you see who that was? Did you give her a big smile?” Gemma looked at Susan blankly. At around 10:00 Peta, the metabolic paediatrician appeared, reading through some paperwork. Susan called Gemma again: “Who’s that?” Gemma squinted and peered but did not seem to recognise her. She ran up to the glass and peeped over the frame so just her eyes showed, yellow from the glass, hiding in plain sight. I did not think Peta had seen her, but she must have as she bent down to Gemma’s height and pulled a funny face. Gemma was delighted.

“Gemma?” I followed the trio to Room 1, where the local dietitian waited. The metabolic nurse was busy with another appointment and joined us later. That made six in the small room, already filled with chattels: a desk, bed, children’s drawing table, cupboards and a sink.
Part IV: The Clinic. Kate and Demi (age 8, 6).

By 9.03 the clinic started and followed the generalised script\textsuperscript{51}. It finished 25 minutes later with the following discussion (Field journal 4: 95).

Peta: Do you guys have any questions for me? Do you understand what we’re talking about when we talk about MCADD? Did we talk about it last time a little bit?
Kate: I don’t know.
Peta: Don’t know. What do you think about it, about your MCADD thing? Does it worry you or do you think “What’s that”?
Demi: You have to eat a lot of food.
Peta: Eat a lot of food.
Kate: And drink.
Peta: Yeah… when you were little you probably had to eat a little bit more than everyone else but nowadays you can just eat a normal diet, totally normal. You are no different from anyone else really. It’s just that what happens is when you are in-between food you get that really hungry feeling and you feel like “oh my gosh I need to eat something” and your brain starts to go “I need to eat something” and sometimes you feel a bit sort of funny in your head. That’s because your brain is telling your body to eat something and it’s switching on all these little hormones and stuff in your body to start using up your stores of energy. So we have the energy that we get from food but we also have little cupboards tucked away in our fat that has energy and other stuff and it’s stored for use in the future, like when you are in-between meals.

And so that feeling of really, really hungry is when your body is starting to want to open up those cupboards and get all the energy and stuff from the cupboards. And your cupboards are a little less full than other people, but only a little bit less full. They are actually pretty good. And it’s only if you haven’t eaten anything for ages that you would find that there wasn’t quite enough energy in those cupboards for you. So day to day you can just live a normal life and never think about those cupboards, those little stores, okay? And the only time that you guys need to think about it and your mum and dad need to think about it is when you get sick and you get that vomiting like you had and you’re not eating for ages and you lose those stores and that’s when
we talk about this thing called Polycal because it just gives you extra energy
during that time to top up. Does that make sense?

Kate: Yes.

Dietician: So you keep your food cupboard full if we have it [Polycal] regularly when
you are sick.

Mum: You might know those [polycal] tins in the cupboard. You probably don’t
actually.

Demi: What tins?

Mum: Down the bottom of the cupboard. (Turns her attention back to Peta). But
Demi will say “I’m hungry” and I know for a fact that she has not long had
lunch, like three hours max in-between a meal, that’s just general kids isn’t
it? I don’t need to worry about it?

Peta: Yeah, it’s nothing to do with… it’s just normal.

Mum: That’s what I thought and I thought “no, I’m not giving her extra just because
she…”

Peta: If you think of how normal they are and how well they are fasting overnight
for 12 hours, basically they could go all day without eating and you would be
fine.

Mum: Did you hear that?

Peta: But if she’s hungry then that’s a different thing.

Mum: I think she can smell something or see it and go “mm” you know, as people
can do. (Addresses her daughter). Nothing wrong Kate.

Kate: I know.

Peta: Doesn’t mean you get it just because… you can’t pull the MCADD card on
mum. “I’ve got MCADD, I want that something or another”, whatever it is.

Mum: But day to day they don’t even realise.

Peta: Excellent. That’s how it should be. I think the more important thing is to make
it all pretty as mellow as possible and things like that just medicalise it a lot
more than necessary I think.
Part V: Post-clinic. Andrew (age 6).

Pauline: What did you think of that visit Andrew?
Andrew: Good.

Roger: (The dad, Roger, intervenes) It was good wasn’t it. They’re a flying act.
(Chuckles)

Andrew: Why are you recording? (Roger answers for me)

Pauline: What did you think of the visit?

Roger: (Answers for Andrew) It’s my first time with Peta. So pretty good.
Andrew: I put papers in her office.
Pauline: Did you?
Andrew: Hmm, hmm

Roger: Let’s put it this way, we learn something from them every time. It’s on the cutting edge. So the blood sugars are up, they’re an indicator but actually the sleepiness is more important.

Andrew: (Shouting over us) I need to… I need to ring my cousin when that girl’s [Pauline] gone.

Pauline: Andrew, you were saying you were a little bit bored at one point. How come?
Andrew: Coz, coz and guess what I put paper in one of, one of the other doctor’s offices.
Pauline: Hmm.
Andrew: Is that good Roger?
Roger: (In a measured tone) I think you know the answer to that. (Laughs)
Pauline: And is it weird? What do you think about having people talk about you?
Andrew: (long silence)

Roger: (interjects after 10 seconds) It’s all right Andrew, isn’t it?

Andrew: Yup

Roger: You don’t mind getting your height measured and your weight.

Andrew: (small voice) No. (Silence)

Pauline: Ok. (Silence. Roger laughs)

Roger: I mean it’s fairly non-intrusive really.
Andrew: Walks over to the vending machine. Dad, I want some chips.

Roger: I don’t think you need that now.
Andrew: I’m hungry. I want chips.
Roger: No Andrew.

Andrew: *Kicks vending machine. When Roger intervenes he throws an epic, on the floor style tantrum. We leave as quickly and as calmly as possible with a yelling, thrashing child.*

### 6.3 Pantry stores and car fuel: Heteroglossia, competing narrative and story-making in the clinic

This extended, composite vignette reveals two ways in which the clinic constructs a particular type of MCADD and corresponding body: through multiple narratives and the experience of place. It also reveals how these narratives are resisted and negotiated by the children themselves.

Drawing on Mol’s discussion of ‘different’ atherosclerosis and applying this to a metabolic condition: ‘MCADD’ as disease “is never alone. It does not stand by itself. It depends on everything and everyone that is active while it is being practiced. This disease is being done” (Mol 2002, 31). In these examples the children who were weighed and measured fell within the normative range for their age; if they had lost a significant amount of weight, or were generally underweight, *that* MCADD would be different and the clinic handled in a less routine manner than the ones described. I observed one clinic where a mother had described how she had rushed to hospital after her five-year old son was admitted following a seizure. The parents were separated, and the boy had slept away from home. She was sure the treatment protocol of a full stomach before bed and fasting for no more than 12 hours had not been followed, which had resulted in him deteriorating. The clinic however, focused on general management of the child's health, and glossed over the seizure as potentially to do with MCADD but could be something else. The specialists did however take great care to ensure that all protocols were up to date and that copies were distributed to all family members and an extra note placed in the hospital file. On another occasion a family said they
were quite surprised to be presented with a precautionary bag of dextrose and corresponding documentation to take on a Rarotongan holiday, despite being told in an initial consultation that any problems could be dealt with quite easily by local staff. These examples show that narrative and place work together in ways that can be slippery and difficult to detangle. What can the deconstruction of these clinic encounters reveal?

The clinic is the meeting point of competing narratives, what Kirmayer (2000, 169) refers to as “the heteroglossia characteristic of all clinical encounters,” where parent-patient voices speak on behalf of themselves, their children and other family members; young patients’ bodies speak (although they themselves may not do so verbally) and specialists speak with the sometimes paradoxical voices of medical authority, institutional requirements and their own concerns that these children are not unnecessarily ‘overmedicalised’.

I analyse the stories the specialist uses in the clinics to argue that these reinforce a master reassuring healing narrative, an attempt not to pathologise the body with an overarching message that the child is normal and that nothing is wrong with them. A concealable chronic illness does not prevent a healthy body. However, the child receives multilayered, complex messages and even in clinic IV (Kate and Demi), one of the few clinics I observed where MCADD was mentioned by name and explained directly to the patients, MCADD as a condition, is negated. Peta emphasises normal three times: “you’re no different from anyone else really”, “cupboards are only a little bit less full… actually pretty good”, “just live a normal life and never think about those cupboards”. MCADD is identified as belonging to the patient, “yours,” with Demi and Kate given the responsibility to “keep your food cupboard full”, top up with Polycal and not “pull the MCADD card” to get what they want. Paradoxically they are encouraged “not to think about it” unless they are sick and vomiting, with an emphasis on not overmedicalising the condition.
Mattingly (2012, 3) uses the concept of therapeutic emplotment to argue that clinicians and patients “not only tell stories but sometimes create storylike structures through their interactions”. While Mattingly uses the example of physical therapists wanting to create something memorable, in contrast the specialist dealing with MCADD wants to make the outpatient clinic a non-event, something that normalises and minimises the potential trauma and disruption to life of a positive screening for MCADD.

Story-making tended to happen when specialists needed some sort of metaphor to relate the abstract nature of the condition to a child. In one instance the specialist described behaviour in relation to a car fuel tank, “you must never let the arrow go onto ‘empty’ and always top up if the arrow is in ‘reserve’”. Peta spontaneously used a combination of sensory examples (hungry feeling, a bit sort of funny in your head), medical explanation of enzyme function (brain switching on hormones to access stores) and the metaphor of little cupboards that store energy to explain “your MCADD thing” to the children. In the case of MCADD, their cupboards are “pretty good” but still “a little less full than other people”.

However, this does not mean children are oblivious to the implications. While the verbal narratives given to parents and, less often, directly to children, are reassuring, the ‘theatre’ of the clinic tells them otherwise, enacting MCADD in this context, with this particular group of people, as disease, and the body as something afflicted with MCADD, to be corralled and managed to stave off illness. Through an interpretive lens (Csordas 1993; Kleinman 1988; Mattingly 2012), the ambiguity inherent in the lived experience of MCADD creates drama in the peaks and troughs created by childhood illness. Unlike much of the medical anthropological and sociological literature that examines illness narratives, cure is not on the horizon as the condition is manageable and if managed correctly will never become symptomatic. When the mum says, “they don’t even realise” the specialist says “Excellent. That’s how it should be. I think the more important thing is to make it all pretty as
mellow as possible and things like that just medicalise it a lot more than necessary I think.” But for the child who hears: “[except] when you get sick and you get that vomiting… and you’re not eating for ages and you lose those stores,” childhood illness is a trigger.

**Silent narratives and resistant agency**

Disease offers an important basis from which to respond and act because people, especially those with chronic illness, have a long and intensive experience of their disease, their body and the health-care system… they are intimately acquainted with the imperfections and limitations of medical thinking and acting. The lives and empirically tested knowledge of the children undermine the idea of a medically defined truth, or at least puts it into a broader perspective. (Dedding et al. 2015, 2126)

The children in the vignette are for the most part silent. Similar to Dedding *et al.* (2015, 2125), I see this silence as deliberate and indicative of a form of practical logic. It is clear from both the opening comment and clinic observations that children draw on their own experience of living with MCADD to negotiate how they relate to it. Demi may say she has no idea why they are at the clinic but her sister’s response: “they’ll ask us about MCADD and stuff” shows the girls do have some idea about the clinic proceedings, even as their mother takes this as an indication they are oblivious to MCADD in their lives. Dedding *et al.* (2015) too found that in their observations of diabetic children in the Netherlands that:

The analysis of how children enact agency and the resources they have at their disposal clearly indicates that social processes, within and outside the medical arena, are not only determined by impregnable institutional structures or medical regimes of professionals but that children influence the interactions in the consultation room. Dedding *et al.* (2015, 2127)

What can we learn about children’s construction of their own health identity from analysing their silent clinic narratives and bodily movements? Most of the children sat, quietly for the most part, listening as their eating habits were critiqued in terms of ‘good’ or
‘bad’, their developmental and schooling trajectory probed and other behaviour queried. Even the least sensitive parent walked a fine line between protecting their child from hard truths like: “her behaviour is terrible at mealtimes” (likely to reinforce the behaviour) and expressing the reality of their current lived experience in order to get advice. Despite their apparent silence, some children reinforced their own stories though action. When Peta asks: “Are you a good eater or do you give your mother a hard time?”, Gemma sticks out her bottom lip and fixes her with a hostile stare. In another clinic, every question about the school readiness of hyperactive Kade is punctuated by him picking up a ‘forbidden’ object like a stamp, paperwork or stethoscope. Loud groans and “When are we going home? I’m bored,” coincided neatly with the details of the build-up to Ivy’s last hospital admission. In Andrew’s case above he loudly demanded junk food from a vending machine, perhaps to prove he was a good eater and when this was denied proceeded to exercise his frustration with a highly visible, public display of anger. Grunting and single syllable answers from ordinarily chatty children, hiding behind a parent or under a chair, kicking their feet, tapping and changing the subject were all included in a patient’s repertoire. These observations mirror those of Dedding et al. (2015, 2125) who noted: “Sometimes agency is simply an expression of resistance against the continuous discipline that the treatment regime imposes,” with the body itself acting as a source of agency\textsuperscript{52}. Children skilfully use interrupting devices to control clinic proceedings and express their thoughts within the parameters of acceptable childish behaviour. Mattingly and Garro draw on Wilkan (1995) to argue that “silence too, when artfully deployed, may speak more loudly than any words” (Mattingly and Garro 2000, 188). What power does silence hold? Are children in clinics being silenced or merely silent, gathering information?

While children will not openly contradict or act against medical professionals, especially with their parents in the room, they do use their bodies and non-verbal responses to
communicate their interpretation of events. I propose that these actions fall within Mattingly’s (2000, 189) concept of emergent narratives as “improvisational and embodied stories”, that represent a way for some children to resist the implied label of ‘disordered’ and that these disrupt the script of master healing narrative in two ways. First, they are a way for the patient to disassociate themselves entirely from the diagnosis of MCADD, thereby negating the need for a script that reinforces the message “you are normal”. Second, they are a way for the patient to demonstrate their reading of the confusing and conflicting dual message gleaned from the master narrative: a direct message that all is well; a secondary message that underlying this is something, an MCADD that warrants all these questions, what Jake eloquently expressed in the story board extract at the beginning of the chapter as “It’s like a disease or something. Except it’s not really”.

White (1981, 22–23) states that narrating and moralising are inseparable, while Townsend explores how patients and their parents demonstrate a “recognition of appropriate behaviours, inculcated through the habitus”, seeking a favourable position “given dominant discourses of illness self-management and responsibility” (Townsend 2011, 96). In the clinics observed in this study parents would downplay their concerns in the clinic, or ignore seeming contradictions with previous advice, then discuss this privately post-clinic. These post-clinic parental narratives revealed a tension between appreciation of the specialist support they get for a condition “not as bad as what it could be”, frustration that the potential severity of MCADD has been downplayed, and maintaining a balance between being both a ‘good’ caregiver who follows medical advice and a ‘good’ parent who is autonomous in the care of their child and does not follow advice blindly. As has been shown, children are treated as children and subsequently act according to their roles as children (Dedding 2015; James, Jenks and Prout 1998) rather than as patients with knowledge of their own condition.
The narrative scripts that play out in these clinics are known to all parties: parents, children and specialists, and apart from the emergent narratives (Mattingly 2000), they are aware of the role they are performing. Similar to Townsend’s observations, their words are ritualised in order to convince the listener of [their] moral identity, “words are consistent with the habitus, formed from exposure to normative illness behaviours and illustrate how structures of the social world are revealed in personal narratives” (Townsend 2011, 98).

These structures are consistent with that identified by scholars such as Rose (2001, 2009) and Scully (2008b, 2017) in their discussions on bioethics and the implications of preventative medicine. Peta’s narrative in the observed clinics reveal that children are held responsible for eating (“are you giving your mum a hard time about eating?”), not burdening the health system if they do not (“at age five you really shouldn’t be coming in”), and not trying to use their condition for gain (“you can’t use your MCADD thing to get what you want”). Although White (2002) found that “children are rarely held responsible from a medical point of view” (cited in Dedding et al. 2015, 2126) for their behaviour in clinics, in this case, they are held morally responsible for maintaining treatment, in this case eating appropriately and confirming to compliant behaviour to reduce a burden on the health care system. It was apparent that specialists and children both have a focus on “being normal” despite the diagnosis, with in-clinic messages including: “The MCADD shouldn't even be on his radar at the moment except for when he is unwell,” “you want to be normal,” and “we don't get many five-year olds plus coming into hospital”.

The last statement neatly encapsulates how place, illness and temporality fit together. Age five, the entry point for primary school, is a convenient milestone, a point at which some fussy behaviours developed at home may be modified by exposure to one’s peers and that children have survived most exposure to early childhood diseases. It is at this point that parents report, “it gets easier”. However, during this research children over five were
admitted to hospital for gastroenteritis and surgical procedures such as tonsillectomy. For those who were not, for a child sitting in a hospital outpatient clinic, listening to the message that after five they should not be in hospital, the literal translation cannot be overlooked as they are indeed, in a hospital building, a place symbolic of ill health, and with a pathologised body with all its associated emotion and affect. These children’s habitus includes visits to hospital for vomiting, in addition to clinic appointments. This is not the habitus of a child who does not have a chronic illness. This is not part of a ‘normative’ childhood habitus.

Conclusions

Degnen identifies: “a theoretical perspective on place that grants an active, agentive role to place (“acts of place”) but also acknowledges place as an agentive force that is inextricably linked to the “magnetizing” realm of affect” (2018, 17). Children know and identify a hospital through sensorial recognition: the sounds of machines and the nurses’ call bell, the smells of disinfectant, the emotions linked to being on a ward, experience “constitutive of our sense of place, always emergent, potential, and not fixed” (Degnen 2018, 17). All the child participants in this study share these steps in the clinical encounter; they navigate their way from home to hospital, they wait for their turn, usually engaging in play and are weighed and measured prior to the start of the clinic. This is standard for the majority of medical visits for any child in New Zealand. At some point, they experience their first hospital visit, for some, the first of many.

The clinic experience frames and foregrounds every experience the patient has about and around MCADD. It is the place where the diagnosis is initially given and explained (although the child at this point is too young to understand), the place treatment is reinforced and ‘normality’ checked. The clinic narratives link a normative body to the absence of illness, however only a pathologised body, defined as such from a diagnosis, has entry to the health
care system and its associated care. However, the trigger that transforms this body from being to pathologised is predominantly childhood illness.

Dell Clark (2003, 19), writing about diabetic children, states: “Having a child in hospital signalled ‘crisis’ to the family’s entire social network… business as usual was interrupted, as the culturally meaningful setting of the hospital dictated.” Hospital visits are for sick people: the images on the wall, the long corridors, cramped rooms, clinic instruments — all of these speak of ill health, not good health. In the next chapter I examine how the sensory illness and hospital experience shapes and constructs a place where MCADD is embodied and is linked to the symptoms of childhood illness and pain of preventative treatment.
Chapter 7: “Vomiting and prickles” — The sensory hospital experience and making MCADD real

Gemma: Yeah, I’ve been at the hospital. She sounds much younger than 6 here, more like 3. ‘Babyish’.

Pauline: What was it like?

Gemma: Hesitant, or thinking out loud. Quite... It was, a bit, it wasn’t kind of fun.

If, as Csordas (1993) maintains, illness is found both in the embodied level of experience as well as the everyday lived experience, then hospitalisation is a profoundly physical experience and the body is the primary way in which these children experience MCADD. However, as Hinton, Howes, and Kirmayer (2008, 147) caution “cultural and personal history will greatly affect the somatic mode of attention in a specific situation, and the subsequent meaning of detected sensations and other discovered body states”.

This chapter explores two aspects of hospitalisation: the sensory, embodied experience of being on a ward; and the emotional, somatic memory created about the hospital experience. I argue that cumulatively, the recollection of this multi-layered, hospital drama allows MCADD to become embodied and ratified as ‘real’. This reinforces the habitus set up in early years, that to have a body diagnosed with MCADD, not the “standard model” (Scully 2008, 67) means interaction with and habituation to the hospital environment.

However, before the children are hospitalised, they need to be unwell. Parents are educated during outpatient clinics to bring the child in to hospital after two vomits. There are other reasons children are hospitalised, such as not eating as an infant or for procedures like tonsillectomy, but the majority of children with MCADD present to hospital after some form of illness with vomiting or diarrhoea and fever. In this instance, the body that in clinics has
been presented as ‘normal,’ becomes *potentially* non-normative and pathologised. A hospital admission is needed to ensure it remains within normative parameters.

### 7.1 “No, vomiting you have to go to hospital”: Children’s narratives about MCADD and illness

The legacy of this construction of child health is that children who are sick… are doubly marginalised. Not only do they, as children, share in childhood’s conceptual isolation from the adult world but, through… disease, find their social personhood subject to further qualification. (James 1993, 82)

Many children are hospitalised at some point in their childhood, even those without genetic conditions and presumably share many of the physical and sensory experiences as the children in this study. At what point does MCADD become disease for the children in this study? What does it mean for their construction and understanding of what MCADD is, that these children recall their hospital admissions with fear? As Leader (cited in James and Hockey 2007, 58) states: The functioning of the body “is not usually a matter for the conscious mind”. I argue that this strong sensory and emotional hospital experience, apparent even in the retelling, helps to construct and embody an MCADD that until this point has been shadowy and nebulous in the child’s mind, loosely linked to food with unspoken consequences that do not eventuate. After a hospital admission, ‘ordinary’ childhood illness is linked to pain and by association to MCADD.

As the following vignette illustrates, the children in this study associated ‘sick’ with vomit, and being unwell creates anxiety for them. There is also an ambiguity about whether you go to hospital for vomiting (as the younger brother George maintains) or for not eating (which the elder argues).

Pauline: Jake, what are you going to add or change in the picture to show you’re sick.

George: You can get a bowl. You can get a towel.
Jake: Unhappy face, upset.
Pauline: What’s the first thing you think about when you start feeling sick?
Jake: Being sick.
George: We hate going to hospital and getting prickles. *(He stops colouring, looks at me intently as he says this, using his right hand and the crayon to run an imaginary line from his elbow to the end of his forefinger, then holds on the forefinger tip and shakes it)*
Jake: It’s not called prickles. It’s called a drip.
Pauline: So George, you say you get worried going to hospital?
Jake: I do too. Well, to be completely honest, sometimes, sometimes I get a wee bit nervous telling the parents.
Pauline: Ok. Why’s that?
Jake: I don’t know. It’s just normal for me.
Pauline: Once you’ve told them you’re feeling a bit sick, what happens then?
Jake: I go and get the bowl.
Pauline: Ok and then what?
Jake: Then I might be sick or I might not be sick. *(Threws up his hands and drops them to his side. Still standing on the centre of his picture, where the stomach is)*
Pauline: When do you go to hospital?
Jake: Ah, we only go to hospital because I, if I don’t eat.
Pauline: Oh, ok.
Jake: Vomiting would just be fine.
George: No, vomiting you’d have to go to hospital.
Jake: No, it’s not George.
Pauline: What happens when you have to go to hospital George?
George: I get worried.
Pauline: You get worried? How come?
George: Because. I don’t feel like going. *(He turns his back to me and carries on colouring in the outline of his body)*

(Field notes, June 2015)
The same boys were asked to photograph five things associated with MCADD. George refused (sending a fairly strong message) and Jake googled IVs on the computer and picked five images, one of which was a luer. Betty told me that Jake said of the luer\textsuperscript{53}: “I just can’t look at it, take it away” and she said she did not realise how strongly he felt about it. When she directly asked him how he felt, he picked a ‘not bothered’ face to illustrate his feeling, a straight-line mouth. Gemma, age seven, did the same exercise and also photographed an image of a hand with a luer and IV to photograph. She recalled seeing it in a children’s hospital brochure, identified it with her treatment and raced upstairs to retrieve and capture the image. Gemma associated MCADD with hospital, luers and an IV but not with food. Her description of vomiting was entirely sensory, linked to her throat and mouth and unrelated to MCADD: “Your throat feels bad. When you vomit, you get like a sore throat. Like a lump in your throat, in your mouth even before I’ve vomited.”

Other children also associated being unwell with vomiting. Demi wrote a story about her teddy bear Gizmo who had MCADD. Her narrative had Gizmo staying in hospital but when she went to check on him he was “perfectly fine”. When she created the comic strip for the story Demi was quite particular about finding a picture to illustrate Ohakune,\textsuperscript{54} the specific hospital she had visited and at the last minute jumped up to fetch her teddy and a bowl so she could stage manage a picture for the story (see Figure 7.1).

For Demi, the connection to MCADD included an association with vomiting and hospital but also indicated a feeling of abandonment. The sick bowl featured prominently. Because Gizmo had a bowl next to him Demi could go skiing and leave him there. The implication was that the character was “perfectly fine” when they had a bowl and were in hospital, echoing in part the narratives expressed by specialists and parents that once they are on a luer they are fine until they recover — that whatever ails them is trivial and they would not be in hospital if it was not for MCADD.
Figure 7.1 Demi’s storyboard
These children interpret vomiting or fevers as a body that is ill and might need an IV. “Once we pay attention to children’s embodied experience of illness we gain insights into the ways in which they participate in the negotiations that take place around the instability of the body during illness” (Christensen in James and Hockey (2007, 155). These negotiations are not always verbal.

As these children explained, being ill or unwell, particularly vomiting, carries the risk of hospitalisation. MCADD was defined not in terms of a biomedically defined, abstract, disease but according to treatment and perceived suffering.

These findings mirror those of Dell Clark’s young asthma and diabetes participants (1996) and Bluebond-Langner’s (1978) leukaemia patients.

Children related the suffering of illness to the hardships of treatment, not to the illness per se. The dilemma of coping with being ill seems to be translated, in the child’s perception, into a problem of coping with the treatment regimen. (Dell Clark 1996, 4)

None of the children in the study liked being in hospital, as Gemma explained: “It wasn’t kind of fun”. This was one of the mildest expressions of the hospital experience, with all of the children associating hospital with strong negative emotions even though some of the children had only experienced one or two admissions or the majority of their admissions when they were infants.

Two of the children in the study had never been hospitalised but had siblings with MCADD who had been admitted to hospital and reported the same strong aversions and fears as their siblings. In addition to the emotions verbalised by the children, their body language and voices changed when talking about the experience; they spoke softly, in a whisper, or not at all, simply shaking their head. In contrast to their hushed recollections, observations of hospital admissions show loud crying, noise, thrashing, moaning, pulling out of IVs and nasal gastro tubes; a highly physical and vocal rejection of these objects.
The data presented in the following section is drawn from six children’s recollections about their previous hospital experiences, a sibling who has not been admitted, and observations of three children in hospital. The observations include two-year old Poppy undergoing a nasal gastro tube insertion; nine-month old Connor and four-year old Michael with IVs.

7.2 Non-cooperation and crying: physical responses to sensory experiences

The following case study describes part of Poppy’s hospital admission over a weekend. On Friday 10th, Poppy is dressed in warm, pale yellow PJ pants dotted with birds and flowers and a pale blue t-shirt. She has little makeshift mittens, made from bandage sleeves and tied at the end, to stop her pulling the tube out. The polyurethane tube is green and snakes its way into her left nostril and down her oesophagus into her stomach. It is taped to her left cheek and attaches on the other end to an upended plastic bottle with a purple lid that looks like the tomato sauce dispenser at her home. Tomato sauce is an invaluable tool at home. She’ll eat most things if dipped in red sauce. Except this sauce is clear liquid dextrose that drips into her at a rate of 57ml per hour. The nose snake looks uncomfortable. Poppy wrinkles her nose and pushes her lips into a perpetual kiss. A thin line of drool drops at the end of her chin. The neck and upper chest of her shirt is dark and damp with it. The amber teething beads round her neck mirror her hair, pale fire. She spends time in a bed with white metal side bars that can be raised to stop her climbing out or lowered so she will not roll out in her sleep. A pale pink, fluffy teddy lies facedown, pushed against the bars. The TV remote is suspended under the battery of power points, dials and stethoscopes. It looks like a cockpit.

Food is strategically scattered in spots all over the room. A purple water bottle to the left of the cot, pizza crackers and croissants on the purple chair, a red bucket of biscuits on
the table, a green Tigger baby bottle with milk in, teat uncovered as if it has been discarded mid feed.

Later she plays on the floor, trying to feel playdough through her mittens. The tube snakes behind her on the floor like a tether. At around 15:00 a blue gloved nurse puts a pulse oximeter on her right big toe and she cries, perhaps not sure which of these machines might hurt. She sits on her mum’s cross-legged lap for this, Jill firmly holds her ankle so Poppy’s foot stays still. Jill’s nails are uneven and some have dirt underneath. It’s been days since she slept properly. The oximeter has four little die cut out dolls — two blue boys and two green girls. Next Jill’s hand engulfs Poppy’s small forehead and the nurse uses an ear thermometer to take her temperature. Poppy’s eyes close, drool streaming from her mouth and nose, making her lips glisten pink as if wearing lip gloss. Her mum smooths her hair as the nurse pops a lance out of its protective metallic packaging, pricks her left big toe, squeezes a drop of blood out which the test strip thirstily absorbs. After, she writes down everything Poppy has eaten or drunk since the last shift. Jill has a list ready.

Sunday 12th. We are still here. The view of the park is bounded by a metal fence, containers used as makeshift construction site offices as damage from the earthquake and aftershocks is repaired. When Poppy first threw up three days ago Jill thought it was because of the earthquake, that she was scared. She’s still not eating much. No one really knows — yet another unexplained childhood virus? I watch a male nurse insert a nasogastric tube into Poppy’s left nostril. She cries the whole way through. Jill holds her hands and using her right forefinger, the tube. This is clearly not the first time she has done this. Even now the static image on my computer upsets me. Time stamp: 11:23. Her legs are drawn up, knees like little hills pointing at the sunless ceiling. She cries. Jill soothes.

Today Poppy is all in pink, like the DreamWorks Animation troll. Again, snacks are scattered around the room: on the melamine trestle table; a lonely arrowroot biscuit, bare
and discarded, an empty double coffee cup carrier, purple water bottle, plastic, resealable snack bags with two pieces of apple and raisins, a turquoise container of tinned fruit salad in juice, the lid of a cookie bucket, two pieces of paper towel. And Poppy, glaring at the world, eyes hot and damp. Not happy.

Analysis

As Trnka, Dureau, and Park (2013, 2) state:

As embodied beings we do not merely taste our food, see bodies around us, hear sounds or observe the dimensions of our environment. Rather, these things readily submit to perception as, for example, distinctive food-ways, somatic norms, appropriate soundscapes, spatial hygiene and so on. They can become, in other words, perceptual epistemologies and normative cultural phenomena.

While Poppy may have actively resisted her treatment this experience has become part of her normative childhood habitus. It was not her first admission. Periodically Poppy would either stop eating or start vomiting and be admitted to hospital. She recognised the food, the toys and the procedures used, like the nasal gastric tube, and was as familiar with these as her mother, who played her part in immobilising and comforting Poppy.

The hospital experience described affects at least eight of Hinton, Howes and Kirmayer’s (2008, 144) 11 varieties of sensory experience: visual (they were not at home), auditory (technology beeping, constant human traffic), olfactory (disinfectant and medicine), gustatory (they had to eat before they could go home and the food was different, described as bland and tasteless), proprioceptive–kinesthetic (their motion was restrained to the room, by an IV or NGT, and the cot), vestibular (in the case of NGT patients, their head motion felt curtailed), temperature (they often had a fever on admission and if not, the temperature of the ward was controlled and different to home or the outdoor ambient temperature, metal objects were cold on the skin), and skin pressure (objects were pressed on chests, and toes, there were
plasters and bandages and needles). Poppy’s reactions to these experiences were physical. She wrinkled her nose, frowned, pursed her lips, closed her eyes, and tried to turn away or withdraw her foot or hand. These were all external, expressive signs of her interior emotions, using her body. Poppy clearly did not like this experience. Although she did not use language to express this, she did vocalise with moaning, yelling and crying, indicators of distress. And she could clearly hear the conversations about how much she had or had not eaten, when MCADD was mentioned (no matter how veiled or coded), and whether or not she had vomited.

Aside from the discussions around MCADD, the other topics of conversation, like checking how much a child had drunk or eaten, if they had a wet nappy or vomited could be standard measures of health in a hospital. However, as has been described in previous chapters, up until this point, most of these measures have been specifically associated with MCADD and have differed from how siblings and friends are treated. It is logical that Poppy would discern that these questions are specifically related to her and MCADD. Even though MCADD presenting is not the direct cause of Poppy’s admission, she has heard the specialist say: “she wouldn’t be here if it wasn’t for the MCADD”. The experience of her illness confirms MCADD as disease for her through the changing materiality of her body.

In hospital, even though Poppy and others are clinically not presenting with MCADD, the reason they are in hospital is to prevent the life-threatening complication known as decompensation\(^6\). The child experiences this in a sensory manner as they embody MCADD, it entitles them to a bed in a ward. It means they must have the smells and sights and sounds of the hospital. The hospital colours their experience of childhood illness and creates a narrative of MCADD as serious enough to warrant hospitalisation without acknowledging the part played by MCADD as disease. Even here though there is disagreement between children about why they get hospitalised as can be seen in the extract from George and Jake, above.
If we return to the idea of place as an agentive force in a relationship with affect (Degnen 2018, 17), then the space the children in this study occupy when in hospital is of relevance. The hospital experience takes the ‘shadow’ and casts it into visceral, stark relief. Illness already restricts mobility as they do not feel well or active. The hospital removes them from home and confines them to a room, particularly if infectious. They are isolated from social relations and confined mostly to a bed, sleeping in stiff, unnatural positions, arm stretched out straight as they unconsciously try to avoid the luer or as parents consciously try to position them to prevent the IV coming out. There are bandages to stop them pulling the IV or NGT out of their feet, arms, hands or nose. This is a visceral and sensory experience. They cry, they are held down, things are done to them. There are a lot of restrictions. These are obviously for the safety of the child and I do not want to give the impression that these are unnecessary. However from a child’s perspective this represents sensory restriction and limited space. Children cannot go to the playroom and sometimes toys cannot come to them either, for example, during Michael’s hospitalisation a norovirus outbreak meant toys were quarantined.

In the room the child is tethered to an IV or NG feeding pump. To stop them accidentally pulling this out or hurting themselves they are confined to a bed with high walls. This tells a child “you are sick”. This shrinking of space is part of the illness experience and adds to an understanding of MCADD. However, as parents and children get accustomed and familiar with their new environment they explore the boundaries. Children walk to the toilet and back, accompanied by their parent and the IV. They sit on the floor and play, when they are on the mend they wander to the playroom and back (if not infectious), wheeling their IV stand with them (parents supervising of course).
Nichter (2008, 94) states that:

Social relations are articulated at the site of the body through somatic modes of attention that index bodily ways of knowing learned through socialization, bodily memories, and the ability to relate to how another is likely to be feeling in a particular context. If this is the case, these examples show an embodied learning that begins with social interactions during mealtimes and culminates in an overwhelmingly sensory hospitalisation. This is a particularly powerful and largely unconscious form of learning and one likely to supplant any clinic master narratives about a normative body that has nothing wrong with it.

7.3 Hate and fear: The emotional hospital recollection

In the following pages I examine how physical, sensory experiences were linked to strong emotions and explore the links between the body, self and personhood, as the “onset of bodily illness may begin to unravel this meshing of body, agency and self” (James and Hockey 2007, 58). I argue that the two overwhelmingly dominant emotions of hate and fear affect how the relationship between MCADD and illness are perceived.

Children’s responses to questions about hospital admissions were guarded. When I, the pesky researcher, probed Gemma about “not much fun” hospital (we were paging through a hospital booklet) she deflected. She described her bear in detail. She nodded instead of answering. She said “nnnnnn”, but not actually “no” then quickly added, “don’t know” (what her care bear thought about the hospital). These silences and changes in voice modulation and tone are important. Her and other children’s answers are communicating reticence, although at time the flashes of recall they show are vibrant and coloured with emotion. “Emotions affect the way in which the body, illness, and pain are experienced and are projected in images of the well or poor functioning social body and body politic” (Schepers-Hughes and Lock 1987, 28) and children responded to conversations about the hospital with strong
emotions. The word ‘hate’ featured prominently when talking about hospitals, and is often linked with the IV in phrases like “We hate going to the hospital and getting prickles” (George). Words included scary or scared, horrible, hate it, frightening, nervous, worried, and it really hurts. When they talked about the hospital children’s voices changed. The volume dropped, they spoke softly, sometimes almost in a whisper. And they reverted to an almost babyish cadence and manner, with a seven-year-old talking like a much ‘younger’ child, even though this was not the voice they normally used in interactions with me. In some instances they did not want to look at the IV or even images of it. Instead of verbalising they nodded, as if to speak the word would give it power. The dominant theme was a dislike of the IV, also referred to as ‘prickles’, injections, a ‘robot arm’, or drip; secondary themes included fear of the objects used on them, a lack of choice, food, care from family and staff, the bed, and displacement from home.

These strong emotions were not felt only by the patient. Siblings watching hospital admissions expressed the same emotions using the same language as the children who recalled their personal hospital admissions, as can be seen in the following conversation with Mark, age five.

Pauline: How do you feel when Mary or Toby are sick?
Mark: I don’t feel very happy.
Pauline: What are you worried about?
Mark: I just don’t like it when they are in hospital, I just get nervous.
Pauline: You get nervous?
Mark: Just don’t know if they’re feeling good or not. It makes me scared.
(He pauses here). It makes me scared of the injections.
Pauline: What do you think the injections are for?
Mark: To help you get better.
Pauline: Do you have any ideas how it works?
Mark: No. (Later he tells me in a halting quiet voice...)

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Mark: I get scared because I don’t like it when they are away from home. No, I don't like the feeling of it.

When Mark talked about his two younger siblings, his feelings and emotions were dominant. He was “not happy”, “nervous”, worried about their feelings, and “scared”. His fear is linked to their physical displacement from the home and to the IV (“injections”). When he was asked about his siblings being sick he automatically associated illness with hospitalisation. A similar conversation took place with George and Jake.

Pauline: And what do you prefer when you’re sick. To be at home or in hospital?
George: *(instantly)* Home.
Jake: Home.
Pauline: Why is that?
George: Because I like home.
Jake: Because home is home.
George: You get cool stuff and you get better like you can have cornflakes, you can have toast.
Pauline: You can have anything you want at home?
George: Yeah.
Pauline: Do you feel you can’t really have anything you want at hospital?
George: *(Sadly)* No.
Pauline: Alright.
George: *(Shouts)* Coz they don’t have ice.

In both recollections, home was synonymous with safety and with personal freedom and control. Jake very simply answered: “Because home is home,” while George explained he “gets better” at home. Despite hospitals offering children cornflakes and toast, George used this as an example of a curtailed freedom which may point to a temporal factor; he had to wait for someone else to give him food at a time of their choosing, not when he was hungry. Removal from home signalled a crisis for all social networks and the children were cognisant of this.
Despite this, hospital experience recollections were not completely negative. Gemma’s “not that much fun” hospital critique was followed up shortly afterwards with a modifier, “well I did have an ice block and stuff” as if she was trying to be fair. Things children seemed to like at the hospital included TV on tap; access to games, activities and programmes on phones; toys from the playroom; ice blocks and gifts from family members.

However, the expression of positive experiences within the hospital did not match the heightened language used to describe negative experiences. Doctors and nurses were “nice”, they referenced toys and ice blocks but did not “love” them. Ahmed (2004, 30) argues that a physical sensation like pain could become transferred so that the person seen as responsible for causing pain could be hated for hurting, however in these case studies the children said: “I hate going to the hospital and getting prickles” because it “really hurts”. The hatred was directed at the hospital and the IV but not at the staff administering the IVs. Staff were described in terms of care: “they look after me”.

Reflections

The power of the first hospitalisation for a child with MCADD must not be underestimated. This is a pivotal moment for parents and children, the moment where MCADD no longer is a condition that can be normalised and treated at home, but one that requires invasive treatment in a biomedical facility. Hospitalisation creates a narrative of MCADD as serious enough to warrant hospitalisation and sets childhood illness as a catalyst, despite disagreement between children about whether they are there because of a failure to follow treatment adequately (treatment) or symptoms (vomiting). Parents report being in denial and that this ‘made it real’ for all involved. There is a great deal of emotion. These are predominantly fear and guilt, pivoting around the potential death of their child for a condition they have incorporated into daily life and feel they have been led to or have voluntarily
underestimated. It is the hospitalisation that makes real what until that point has been an abstract potentiality, and helps to construct and embody an MCADD linked to pain and the spectre of death from childhood illness.

Lancy, Bock and Gaskins (2010, 6) argue that “Learning as a process is influenced by the fact that children are simultaneously being and becoming. Children can be seen as acting in the moment, behaving appropriately for their age, but also moving on a developmental trajectory towards adulthood”. It is this duality that needs to be considered when viewing the treatment of MCADD in the initial few years of life. The management of MCADD is in order to protect the future adult, to ensure that the child will indeed continue on that path towards adulthood. In the moment, illness could disrupt that future self, creating a breach in the personhood to be attained. As Bluebond-Langner (1978, 24) explains, physical setting plays a part in the interpretation of self: “Regardless of whether the child was sicker when he came to clinic than he had ever been when hospitalized, he saw himself and was seen by others as being in better health than when he had been hospitalized”.

Conclusions: Part III

The graphic medicine comic that introduces Part III illustrates a particular cultural and personal history through Lola, a composite character created from experiences observed and shared by the young participants in this study. It highlights how some of these children feel at specific points; frustrated by the power differentials at mealtimes yet using knowledge of their condition to test social parameters, concerned about their peer relations at school, ambiguous and agentive about and during their outpatient clinic appointments, and frightened when they do develop or contract a childhood illness as they believe this leads to hospitalisation.
The metaphor for MCADD used with children follows a mechanical approach as the body is broken down into parts reminiscent of Descartes and early biomedical models (Foucault 1994). The children’s bodies are pantries with empty cupboards, cars running out of fuel, bodies with a piece missing or something not working properly. While it is not always openly expressed to the children, they have picked up on the message that to get sick is to potentially die, that not to eat is potentially serious leading them to nervousness around nausea, and implied comparisons to Ebola, cancer and other diseases that spread.

MCADD is both external and internal to them: they cannot see it, they cannot feel it, other than when they are feeling sick from something else, there are no visible cues like inhalers or insulin to mark it, and they are continually told to ignore it and not to think about it. Yet it is inside them, intimately connected to them through family genetics — it affects family social networks and relations, and it is related to the food and drink they consume and burn up. MCADD is paradoxically both life-threatening and a non-concern, depending on where they are, their current state of wellbeing and whom they are talking to. If we return to Scully (2008a), what becomes evident during a hospitalisation is a body that errs into the realms of being pathologically “out of whack” where children have learnt an uncomfortable habitus that is neither the dominant normative habitus nor one that has established patterns of social behaviour to follow. The clinic is the place where these insights are initially formed, although paradoxically it is also the place where a narrative of normality is linked to the absence of illness. As a patient-in-waiting it is only once a child has been hospitalized that she sees herself as ‘sick’ and her social networks internalise the potential severity of MCADD.

In the conclusion, which follows, I draw the threads of these three parts together; the biomedical story, the stories created and enacted in the domestic spaces of home and community; and the child’s embodied experiences of clinic and hospitalisation. I reflect on
the research and the approach I have taken, and advance some recommendations that may soften the social impact of screening for these and other normalised conditions.
Chapter 8: Conclusion

In the few months before I submitted this thesis a three-day old baby died in Australia while her Guthrie test was in transit to the lab\textsuperscript{57}. An autopsy revealed she had MCADD. The mother was understandably devastated and joined the Facebook support group where she received an outpouring of supportive messages:

- Heaven has gained an angel.
- I can't even imagine how you must feel.
- Please know we are like a family here. We are all here to support you.

This tragic and unavoidable event brings into focus that children do die from MCADD, that they are at their most vulnerable in early childhood and that the treatment after diagnosis does prevent death. After dwelling on ethics of the potential for harm from the medicalisation of food, I felt this as a short, sharp shock. From the response of the families in the support group, this was a poignant reminder of what could have been their own fate and prompted a spontaneous outpouring of shared emotion about near misses and sickly newborns in hospital before diagnosis. This event encapsulated the complex, intertwining issues at the heart of diagnosis.

Before expanded newborn screening was introduced in New Zealand in 2006, infants with MCADD were diagnosed only after an autopsy, or when a younger sibling was diagnosed after newborn screening, as in the case of Jake. Doctors therefore saw only the acute cases. Since screening in New Zealand, no children diagnosed with MCADD have died. They are diagnosed before an acute episode and subsequently may never have one, although the threat of the consequences of MCADD are a constant concern for some families. As a result, family mealtimes and feeding practices are affected and children’s developing habitus, personhood, and ways of thinking about MCADD shifts to incorporate the diagnosis. Once
diagnosed, narratives identify the child’s body as medicalised and if ill, pathologised. Screening has also changed how MCADD is understood and constructed by medical professionals, with a wider spectrum identified now than before the global expansion of newborn screening programmes.

8.1. “Questions and answers”

In my opening chapter I quote Jutel (2011, 65) who asserts that illness is a story derived from a doctor’s interpretation of an individual’s illness narrative. She also states that diagnosis is both the story of medicine, and the fulcrum of the medical narrative. The medical narrative in this case aims at preventing children with MCADD from dying after fasting. The narrative is successful because it promotes preventative alertness and actions carried out on behalf of and by the young patients. The narrative succeeds, as explained in Chapter 4 and 5, in mobilising parents to set aside other expectations and to feed their baby round the clock, being ‘good’ mothers and parents. And children, as is seen in Part III, long after the early years of suffering experienced by their parents to keep them well, bear the marks of a shadow habitus in their understandings and actions around MCADD as disease or illness.

*Personhood through the frameworks of habitus and children’s narratives*

I started this research hoping to first discover whether individual personhood can be affected by the lived experience of a potential, future illness; particularly one diagnosed at the start of life. By the end of this journey I can confirm that the data supports this hypothesis: a body diagnosed with the potential for illness has as much capacity to transform a young life as illness itself. Drawing on Bourdieu’s concept of habitus I have shown that the diagnosis creates a medicalised body in need of preventative treatment, while outpatient clinics and hospital admissions help construct the impression of a pathologised body. This thesis finds
that personhood, as embodied and situated, is affected by the experiential, sensory knowledge of MCADD treatment (feeding and hospitalisation) in the first few years of life and that the enduring marks of this habitus, what I have referred to as the ‘shadow habitus’ remains even after moving through this phase of early prevention.

As a means to explore personhood, I wanted to find out about children’s stories; how children conceptualised, described and redefined MCADD and how this affected them. I found that children drew on existing illness or disease explanatory models, teasing them out as Ebola, the flu, and MCADD in relation or in opposition to contagious diseases. They framed their narratives in the context of social relations, peer networks and the quest for normality. Tracing the multilayered and nuanced narratives of children and their caregivers highlighted that families often do not entirely understand what MCADD is. This is in part due to the complexity of genomics but also, as I have shown, that the definition, construction and understanding of MCADD has changed since it was globally incorporated into newborn screening programmes. It is seen to occur with greater frequency and more variation than was previously understood. Therefore one of the key themes that has been untangled in this thesis, is that families and specialists are working with continually evolving knowledge.

The evolving habitus

As a result, rather than diagnosis providing closure and a structured narrative, it creates uncertainty around the social practice of feeding, the management of childhood illness and some social activity. An argument could be made against the current policy of treating all variations, from mild to ‘classic’, the same, as in some situations this undermines families’ trust in the specialists’ knowledge. The majority of the parents who participated in my research have tertiary qualifications, all have access to the internet, spend considerable time self-educating and make their own informed decisions, often based on accessing information
from European and US websites and querying why this differs from the New Zealand protocol. They then do not know whom to trust or believe, often erring wildly on the side of caution. Many of the parents have had experience of other hospital systems, either living abroad or on holiday, and are very appreciative of, and grateful for the Metabolic Services Team. However, what they perceive as the trivialising of MCADD concerns them and they struggle with relaxing feeding times as their child grows. When incidents do occur they are then surprised as they have internalised the message to relax. However, the conundrum that was introduced in the beginning of this conclusion still stands, that even specialists cannot be absolutely certain that it is safe for a child diagnosed with MCADD to fast for an extended period of time (Smith et al. 2010).

Despite the disruption to ‘normal’ social eating, children do not identify themselves as ‘MCADDers’, rather, the prevailing shadow habitus works in some ways to set up a habit of eating, even when children have a poor appetite, are unwell, are busy and especially when exercising. However, as Trnka (2017a) and others report, with chronic illness there is often a process of normalisation, so that as children grow older, this is not all encompassing, it is just the way things are done. The threat recedes but is still there, casting a shadow. There is still the potential that if they are ill, or if they are physically overtaxed, or get drunk to the point of vomiting, MCADD could present. But that temporal factor is gone. There is not the same sensitivity to timing between meals and risk of acute illness as in early childhood. As they move further away from a childhood identity, it is likely that their health identity transforms, a potential area of future study which is discussed further in the reflections on this thesis.

Habitus as a concept proved to be a particularly effective way to track invisible patterns of behaviour that originated through ways of being in the body when eating and when undergoing preventative treatment in hospital. The relationship between the habitus and its inherent tensions and contradictions in different fields lends itself to a medical
anthropological lens on an ambiguous disorder. It is also useful in that the concept of habitus concerns itself with how actors act according to their capital (Bourdieu 2002) and children and the unwell possess especially fluid capital.

**Narratives and embodiment**

A second question asked is what medical narratives biomedical practitioners relay to families and how these were interpreted. I discovered multiple narratives were relayed to families, and that these in turn were interpreted in varying contextually-driven ways. I have shown that outpatient clinics construct a master healing narrative to normalise the pathologised body but that the location of these clinics in a hospital setting leads children to construct MCADD as life threatening and the body as pathologised. I also queried how children interacted with and embodied the technologies they encountered during hospital admissions and discovered that this overwhelmingly sensory experience embodied an MCADD linked to pain and fear.

I was interested in finding out how parents coped with the transformed identity of their expected newborn. Landsman (2009, 61) talks about gradations of personhood, how disability, or the diagnosis of a condition, diminishes or removes formerly attributed personhood. This was the case for some families, with aspirations for ‘normal’ adventure-seeking milestones that were imagined for their children prior to birth, no longer seen as options. However, this does not mean that a life with MCADD is devalued. I discovered that even after one child was diagnosed with MCADD, the ‘one in four’ risk was not seen as a deterrent to having more children, or as a reason to seek further testing for MCADD during a pregnancy. A child with MCADD had personhood that was valued, but one that was framed in certain aspects by the diagnosis.
Representations of ethnography

This thesis aimed to explore ethnography as both method and practice and used different forms to show different actors’ voices: a diagnostic letter, a personal diary and a graphic narrative. The last, the comic, collated ethnographic observations, interviews and drawings into a multi-layered visual impact that is intended to represent the voice of the child participant more clearly that of a purely textual ethnography. Presenting multiple ethnographic modes is a way to represent voices that may otherwise not be visualised, or not heard (McMullin 2016). Working with children and parents has required a variety of methods of data production, resulting in multimodal information. This has proved to be an effective way of capturing differing viewpoints, opening up space for the interpretation of what were often mixed and contradictory messages.

Time and space

This research has also identified a spatial and temporal configuration to MCADD, with narratives shifting and intersecting in different spaces to construct different forms of MCADD and different bodies inhabited by MCADD. These include home, the hospital (for episodes of illness and outpatient clinics), school, preschool, church and sports clubs. These narratives intersect with the child and with time. Treatment advice changes as the child grows heavier: watching, waiting and home management instead of emergency hospitalisations, the parent-patient differentiates into a patient and a parent, and the doctor’s views change as well over time.

The children grow towards this state that is promised from one year of age, that everything is fine and will be fine. Slowly, haltingly, stepping back after every hospitalisation they progress towards the next rite of passage, that of entering primary school. The achievement of this state is linked to their passage away from infancy in time, and away from
the physical location of the home in distance. The further they are from home, the less controllable their food, the more time they spend away from parents, the less the parents can influence their food consumption.

8.2 Diagnosis at a vital level

This research has shown that a body diagnosed with MCADD is described ontologically, as just another way of being, while simultaneously it is treated as a pathologised body. People have social and cultural frameworks to make sense of both modalities, and it is the tacking between the two that brings into sharp focus social and cultural issues, such as what makes a ‘good’ mother, how to be ‘normal’ amongst one’s peers, how illness and disease are constructed, and how to feed and raise one’s child according to an increasingly medicalised parenting model.

There is a dissonance between how to socially treat a normalised, ‘well’ body versus that of a pathologised, ill body, and the patient-in-waiting inhabits a space that encompasses both. I have shown that this is necessary to allow for a child to live a relatively ‘normal’ life treated with food away from hospital, but it also enables access to ongoing medical advice during the critical period of early childhood and a low threshold to hospital admittance. This duality shares disruptive elements much like any other illness, however in this case, even after returning home from hospital and being back in ‘normal’ life, MCADD is always present as a risk factor. I have shown that habitus is a way of understanding the daily lived experience of MCADD. The practice of preventing the risk of MCADD presenting is ingrained in daily life and shapes what children do. If actions shape identity, then these children can be seen as inhabited by MCADD, shaping the behaviours they will need for survival in later life.
If the aim of diagnosis is to bring about a good health outcome (Joralemon 2017, 24), then the diagnosis of MCADD has succeeded on a vital level: there are fewer infant deaths from MCADD in New Zealand since expanded newborn screening was implemented than before (Wilson et al., 2016). This welcome outcome comes with some other more quotidian effects.

1. Children identify the disease according to symptoms and treatment, not an abstract disease model. When they do try to explain it, they use examples of other diseases they are familiar with such as cancer or Ebola.

2. Parents find they need extra support in daily lived experience for the first two years.

3. The focus on eating and the sensory experience of hospitalisations in the early years sets up a shadow habitus.

4. The shadow habitus sets up long-term habits and behaviours around the avoidance of fasting, however ‘picky’ eating was observed in younger children.

5. Children may not understand the condition but do understand the treatment.

6. Newborn screening and the potential for illness has changed the daily lives of these families and has an effect on social personhood much as illness would. However, when compared to the potential ramifications, treatment is effective.

Specialists are struggling with the same bioethical dilemmas — will diagnosing a child with MCADD, who once diagnosed may never present, do more or less harm than the risk of death? Parents of infants who have died from MCADD before a diagnosis was made are often confused as to why the Guthrie test cannot be taken immediately after birth and feel this could have made the difference for their child’s life. And it is these stories, these reality checks of the social ramifications and shockwaves that spread through a community at the death of a child that make it clear how disruptive a non-diagnosis can be, even if diagnosis has an impact on families.
8.3 Reflections

Limitations

I identified two limitations within this study: the first regards diversity and the second, cohort ages. Although this was a nationwide study which invited all diagnosed families, those who agreed to participate were mainly middle-class, homeowning New Zealanders of European descent. Although such people represent about three-quarters of the population of New Zealand and the majority of the MCADD patient population, future work with patients from other ethnicities with particular food preferences and foodways, and a variety of meanings surrounding food would be of benefit. In particular a more nuanced discussion would be developed with the inclusion of Māori, Pasifika, Chinese and Korean people resident in New Zealand — a rich area for future research.

Further, as the cohort grows older, it would be valuable to study the way they make sense of MCADD and themselves through adolescence and as young adults. Further studies with young adults, as this first generation grows, would be useful to assess the ongoing consequences of the shadow habitus, especially in light of studies that have noted that young adults with PKU lapse with dietary adherence, despite its effects on their health (Frank, Fitzgerald and Legge 2007).

The future of screening

It is rare for adults to die from MCADD presenting and the daily difficulties encountered by parents and children in the first few years of life are minimal compared to preventing death. Yet diagnosis is disruptive. It enmeshes an identity with food practice, health and morality but this only disrupts on a domestic basis, within the field of the home. Its influence wanes the further from home a child goes, but the shadow habitus they hold stays
with them. This is not necessarily a negative effect but rather a silent safety net of habits and ways of thinking about oneself and one’s food practices that protect over a lifetime. Like a shadow, it is two-dimensional, can only be seen when cast in bright light and follows you everywhere. Where the problem lies is in long term confusion: around the diagnosis, around eating and food practices and around the difficulty of explaining it to children. Compared to other genetic conditions, like haemophilia, it is difficult to explain as it is invisible and by large, unfelt.

What can this study tell us about personhood in a future in which genetic testing and screening could identify some disorder or risk thereof in everyone? I have highlighted the relationship between treatment and how a diagnosis is constructed. I have shown that diagnosis creates a medicalised body, one that needs to be treated to keep it normative. During periods of heightened risk, this body is pathologised. Future screening for other conditions and testing would need to weigh up the risks of not treating the condition versus treating a potential risk and transforming one’s social personhood.

What is at stake for these families’ daily lives includes a daily existence that is ‘normal’, fluid, and follows the patterns of other families; one where food does not feature so prominently and children’s lives are not changed according to MCADD. As a modest contribution towards this end, in the next section I explore the contributions that this research can make to minimise the social impact of screening in the case of MCADD and the management of other disorders that have become normalised in childhood.

### 8.4 Recommendations

In an afterword Bluebond-Langner (1996, 265) considers: “some of the ways that clinicians might help well siblings…,” outlining both general guidelines “useful in dealing
with a wide range of responses and issues,” and an “approach to intervention, one that [is referred] to as ‘shuttle diplomacy’”.

The specialists involved in the care of children with MCADD are clearly committed and caring, as evidenced by their availability at all hours on mobile phones and their ongoing care of their metabolic patients after childhood. This study therefore makes four recommendations while recognising that structural and budgetary constraints may make these unattainable in the short term.

The first is provision for parents and children to ask questions independent of each other, without each other in the clinic. This could decrease power imbalances and enable parents in particular to make queries about MCADD-related treatment without children feeling they are ‘naughty’ for not eating or becoming scared due to the veiled conversations they are privy to.

The second recommendation would be a truly centralised or standardised nationwide approach to care, as in practice it appears that specialist recommendations are not always followed. This study has revealed that some families, particularly those outside of the Auckland area, still experience problems with hospital admission, even if regional hospitals have been told about the child’s condition. It has indicated that if families move from one district health board to another, they sometimes encountered confusion about treatment and conflicting advice from some local paediatricians, particularly with younger children.

Third, routine specific feeding advice, courses and/or counselling in the first few months after diagnosis could alleviate some of the pressures parents, particularly mothers, feel about feeding their infant as they are reluctant to contact busy dieticians (despite encouragement to do so) or to appear socially incompetent in what is perceived as a basic foundation of ‘good’ mothering.
Finally, families and specialists seem to be undecided as to how to explain the complexities of an easily managed, yet life threatening, condition to children. Unlike other conditions that have become normalised, like diabetes, asthma and even childhood cancers, adults seem to have difficulty in explaining MCADD to their children from a young age. Families in particular are unsure what an appropriate explanation is or what level to pitch it, perhaps as it is so ambiguous for all concerned. This study has shown that this ambiguity transfers to the child, who well into primary school, is unsure precisely what MCADD is and how it affects them. I therefore suggest that a multi-stage explanatory model is developed that families can choose to use or not, with different levels of explanation based on each individual child’s potential level of comprehension.

8.5 Afterword: Toward an applied anthropology

Early in this study I discovered that families did not have somewhere they could get support for the everyday. They were well supported in terms of health literacy from the metabolic services team and supported in the case of illness but it was the everyday minutiae of parenting a child with a metabolic disorder that they struggled with. Once identified, I set up the closed Facebook support group discussed in the methodology chapter.

I am also in Stage I of developing the information and resource website www.mcaddhelp.info. The site is deliberately designed not to look like a biomedical resource, and instead is intended to be an easily accessible, parent-friendly resource. This includes ‘lifehacks’ to help parents during the early phases described in Part II and, based on analysis from Herbst (2016), is a resource that parents can dip in and out of when they need to. Stage II of the project will incorporate feedback after consultation with participants and the metabolic services team. Later phases will incorporate recipe ideas for fussy eaters and children with allergies\textsuperscript{61}, printable resources in line with the explanatory models outlined in
the recommendations, and a section for the young children who took part in this study. In a few short years these children will be entering young adulthood, the phase that specialists flag as enhanced risk. This will include a confidential forum where they can talk to each other about their concerns and thoughts about life stages, social lifestyles and how to manage MCADD in these contexts.

In the interim, I am pleased and heartened that a small but dedicated group of 88 members is forming a community that helps one another with the day-to-day trials of the early years via the Facebook support group. It is even more heartening that parents with children who are reaching the threshold of young adulthood are still helping parents of newly diagnosed infants: with tips, with reminders to keep an eye on the future, and reassurance that this does get easier, that this “story of medicine” (Jutel 2011) can have a happy ending.

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1 Speech will be indicated by double quotation marks, and word emphasis with single quotation marks; an example follows: *The word 'hate' featured prominently when talking about hospitals, and is often linked with the IV in phrases like ‘We hate going to the hospital and getting prickles’.*
2 Further details about research design and participants are provided in Chapter 3.
3 Despite the risk being managed, parents have an abiding fear that their child may die. Further detail on parents’ management of risk versus fears as expressed on a Facebook support group is discussed in Herbst (2016).
4 The parent shares the role of patient.
5 Personhood is discussed more fully in Chapter 2.3.
6 Eating is the major daily focus of this experience with hospitalisations occurring only during acute episodes of illness.
7 See Appendix D.
8 New Zealand specialists do not advocate any specific diet, low-fat or otherwise as they do not want to over-pathologise the condition.
9 Initially parents were introducing solids at six months, now an earlier introduction is encouraged.
10 A detailed explanation of the construct ‘child’ was given in section 1.2.
11 This research is affiliated to the Marsden research project ‘Troubling Choice’, which was granted ethical approval under the auspices of the University of Otago ethics committee. Primary ethical approval was obtained from the Health and Disability Ethics Committees (HDEC), approval number 14/NTB/47. Additional approval was sought from and obtained from the Auckland District Health Board to attend clinics and hospitalisations. All participants have been given pseudonyms and exact locations are not used.
12 Loft (2011) shows how strained interpersonal relationships between parents with a newborn are further exacerbated by child disability or the diagnosis of chronic illness.
13 Actual locations of the families remain anonymous as some cities may only have one family with a child with MCADD and others may have multiple.
14 Education in New Zealand is free for domestic students up to 19 years of age. Costs do however include school uniforms, stationery, exam fees and annual donations.
15 See Chapter 3.3, *Facebook*.
16 A support organisation for “families and whanau of people with disabilities and health

17 A detailed explanation of the definition of ‘child’ as pertaining to this research project has been given in Chapter 1, section 1.2. ‘The Framing of the Child’.

18 Although parenting itself is socially and culturally constructed and is therefore not a homogenous practice, this did give us common ground to build on.

19 General support groups include Parent to Parent and the New Zealand Organisation for Rare Disorders (NZORD).

20 For more information see Herbst (2016).

21 See Appendix A.

22 From preliminary research observations.

23 Sub-sections of this chapter have been previously presented in draft form. See Herbst 2014, 2015 and 2016a. I am grateful to panel attendees for their insightful comments.

24 This has been discussed in Chapter 1 and will be further assessed in the concluding Chapter 8.

25 At the time of writing I only knew of one mother who had been advised by a local doctor (not the Starship Metabolic Services Team) to have amniocentesis to discover if the baby had MCADD.

26 Newborns were treated as if they had MCADD until the Guthrie test results were received.

27 Neonatal Intensive Care Unit (NICU).

28 This idea could stem from the initial diagnostic letter parents receive as seen in the example at the beginning of this thesis.

29 Approximately 0.1% (1 in 1000) of women will miscarry as a result of amniocentesis. CVS has a 0.2% (1:500) risk of miscarriage above the background risk for natural miscarriage (Auckland District Health Board 2016).

30 Neonatal Intensive Care Unit (NICU).

31 The Guthrie or heelprick test.

32 Discussed further in Part III, Chapter 6.

33 This was not always the case. The health care system bears an ‘alphabet soup’ legacy of structural change.

34 A cultural rite of passage for many young New Zealanders finishing school or university.

35 Emergency department.

36 The name of the hospital has been fictionalised.

37 Here inconsistency refers both to the shifting nature of diagnosis already discussed and the different management of children in different areas. While the centralised management of MCADD through Starship is consistent, as has been shown, other regional areas do not always follow the emergency protocol and additionally sometimes advise treatments such as cornstarch before bedtime.

38 The complex carbohydrate prescribed for emergency scenarios.

39 The exception is siblings with other food or health related concerns.

40 I conducted extensive interviews with the heads of schools and class teachers. This data will form the basis of a separate paper.

41 I explore the reasons for this in Part III, where I discuss children’s understandings and constructions of MCADD in the context of illness.

42 An indepth discussion of this follows in Chapter 6.

43 To be discussed in Part III.

44 Using the multiple, child-centred methods outlined in Chapter 3.

45 For the full story, see Appendix C. Details about the exercise can be found in the methodology chapter.

46 Many school children learnt about Ebola at school during the recent epidemic that was highly publicised from 2014-2016 and coincided with the fieldwork period. Jake’s mother Betty revealed that the children worked on a school project on Ebola that “put the fear of God into them so that every snuffle was Ebola” which in all likelihood influenced Jake’s framing of the story.

47 See Appendix B.

48 See Appendix C.

49 An overview has been provided in Chapter 2.

50 At the time I was reviewing final drafts of this manuscript, some children’s reception areas had been refurbished to feature an open-plan layout.

51Outlined in Chapter 6.
Here agency is determined as “complex and multidimensional, inclusive of emotions and practical logic” (Dedding et al. 2015, 2123).

A luer is the word used most often by staff and families when referring to an intravenous catheter, which is inserted into a vein to administer fluids or medication.

It is quite common for New Zealand children to ski at Mt Ruapehu in winter. Ohakune is one popular accommodation village.

The movie Trolls came out during this project and was very popular with some of the children. The lead character, Princess Poppy is bright pink from head to toe and perpetually happy.

Blood tests can only be taken after a 48-hour period and unless a test is expedited due to suspicion of MCADD from a sibling or deterioration, can take several days to reach the lab.

A Guthrie test can only be taken from 48 hours after a child is born or there may be a false positive. Some parents don’t understand why the blood test can’t be taken sooner. There are also often unforeseen delays on the way to the lab.

MCADD predominantly affects people of European descent and at the time of the study, there were fewer than five families who were not of European descent. It is only recently, as part of the evolving nature of diagnosis and broad population screening, that MCADD has been diagnosed in people from ethnic backgrounds previously thought not to have MCADD (Liang et al. 2015).

Anecdotally, adults with MCADD have reported headaches, nausea and aching muscles when fasting or overexerting. Similar complaints voiced by children in this study were attributed to ‘growing pains’ and ‘normal’ concerns and dismissed as unrelated to MCADD by medical professionals. Parents were undecided on a case by case basis.

This is a popular topic on the Facebook group.
APPENDICES
CALL FOR PARTICIPANTS

For parents, legal guardians & families of children with MCADD and young people & children diagnosed with MCADD

Research Topic: An ethnography of children diagnosed with medium-chain acyl-CoA dehydrogenase deficiency (MCADD).

Primary Researcher: Pauline Herbst, PhD Candidate

Children and young people diagnosed with the genetic disorder Medium-Chain Acyl CoA Dehydrogenase Deficiency (MCADD) and their parents and families, are invited to take part in a University of Auckland anthropology study. The reason for the research is to assist in understanding if the diagnosis of a chronic genetic disorder impacts on a child’s identity; and document how children develop an understanding of their disorder and learn to manage it.

Participants can choose which level of involvement they would like to engage with the study. Initially they will be asked for up to three interviews, which will be audio-recorded. Interviews will last approximately 60 minutes. They can also join a closed Facebook MCADD support group, set up for New Zealand and Australian families.

Additionally, if the parent gives permission, children will be asked to draw, talk, take photographs, play games, and tell or write stories about their disorder. Children will be given a small digital camera so that they can participate in the research project. At the end of the study this will be theirs to keep. All families will receive a summary of the research findings.

All responses and recordings will remain completely confidential at all times. If you are interested in participating or would like to know more please contact Pauline Herbst at p.herbst@auckland.ac.nz for more information.

This study has received ethical approval from the Human and Disability Ethics Committee: REF 14/NTB/47.
PARTICIPANT INFORMATION SHEET/ASSENT FORM

For children

TO READ TO CHILDREN WHILE SHOWING THEM THE PICTURES

Hello, my name is Pauline. I am a researcher. That is someone who likes to learn about things.

I would like to learn how children like you feel about being well and being unwell.

I want to do this so I can help other families and doctors when children are sick.

If it's ok with you I’d like to:

- Spend time with you at home
- Visit you at school
- Be with you when you have clinic visits
- Visit you in the hospital
I will also take photos and videos of our time together. If you want to, you can take photos too.

If it’s ok with you I’d also like to:
- Talk to you and
- Talk to people like your teachers, parents and doctors.

Nothing in this study will hurt you or cost any money.

I would like us to do some activities together like:
- Drawing
- Telling stories
- Playing games

Please write your name here or colour in the face if you feel this is OK:
**Research Topic:** An ethnography of children diagnosed with medium-chain acyl-CoA dehydrogenase deficiency (MCADD).

**Primary Researcher:** Pauline Herbst, PhD Candidate.  
Email: p.herbst@auckland.ac.nz. Tel: 021 66 82 60.

**Declaration by member of research team:**

I have received a consent form from the child’s parent or legal guardian giving permission for the child to take part if they wish. I have given a verbal explanation of the research project to the child, and have answered any questions about it.

I believe that the participant understands the study and has given informed assent to participate.

Signature: ____________________________ Date: __________________________

This study has received ethical approval from the Human and Disability Ethics Committee: REF 14/NTB/47.
PARTICIPANT INFORMATION SHEET
For parents, legal guardians and families of children with MCADD

Research Topic: An ethnography of children diagnosed with medium-chain acyl-CoA dehydrogenase deficiency (MCADD).
Primary Researcher: Pauline Herbst, PhD Candidate

Introduction
You are invited to take part in a study that looks at how children diagnosed with genetic disorders understand their disorder as they grow from an infant to a young adult; how they explain it to others; and how they develop their identity and sense of self over time. The research will be conducted by Pauline Herbst, a PhD candidate in the Department of Anthropology at the University of Auckland, who will specifically focus on families with children diagnosed with medium-chain acyl CoA dehydrogenase deficiency (MCADD).

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep. This document is 5 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

About the Study
The reason for the research is to assist in understanding if the diagnosis of a chronic genetic disorder impacts on a child’s identity; and document how children develop an understanding of their disorder and learn to manage it. This study will take place throughout New Zealand and potentially Australia, from 2014-2017 and involve in total, approximately 110 people.

I am interviewing the parents or legal guardians of approximately 35-40 children diagnosed with MCADD, as well as the children themselves, extended family, and health professionals and educational staff who have dealt with a child with MCADD. Legal guardians will be asked for up to three interviews, which will be audio-recorded. Interviews will last approximately 60 minutes. I would also like to observe the activities of families of children with MCADD in different places: for example your home, clinic visits and hospital admissions.

You are also invited to join a closed Facebook MCADD support group, set up for New Zealand and Australian families. If you join the group, any messages you post to the group page cannot be seen on your timeline by anyone who is not a member of the group. Members of the group will be able to see your profile name although they will not be able to see your individual page details.

Your participation in these interviews is entirely voluntarily. You can choose to take part in the study with or without your children participating. If you choose not to take part this will not affect the medical treatment your child is receiving. If you do agree to participate you are free to withdraw at any time. You can also stop an interview at any time and do not have to answer all questions.
**Child/ Young Person Participation: Further Details**

Children will be asked for their assent prior to participation. Depending on their age, children will be asked to draw, talk, take photographs, play games, and tell or write stories. I would like to observe their activities, particularly during mealtimes, hospital or clinic visits and potentially at school. I would also like to photograph and video children and families while they are involved in these activities for later analysis. The amount of footage taken will depend on what you and your children are comfortable with at each visit. Identities will be kept anonymous, for example, a film may include the child’s voice but focus on a child’s drawing instead of the child themselves. If I would like to use any of this visual material (e.g. photographs or video where people can be identified) in resources to help further the understanding of MCADD, I will seek your permission before use.

Children will be given a small digital camera so that they can participate in the research project. At the end of the study this will be theirs to keep.

**Benefits, Risks and Safety**

The study aims to benefit children diagnosed with MCADD and their families. I intend to use the results of this research to create resources such as a booklet or film for families to use, and to help others understand the disorder and how to manage it. The study poses no risk or cost to participants and the only inconvenience is the time taken for participation.

**Confidentiality & Results**

The results of this research will be published. If the information you provided is included in any reports, your identity and the identity of your children and family members will be kept anonymous. No identifying characteristics will be used and all references to you or your children will use pseudonyms. A summary of the results of the study will be made available to you if you wish.

**Further Information**

If you have any questions, please contact any of the following:

*Principal Researcher* – Pauline Herbst. Phone: 021 66 82 60. Email: p.herbst@auckland.ac.nz

*Supervisor* – Prof. Julie Park. Phone: 09 373 7599 ext. 88589. Email: j.park@auckland.ac.nz

*Supervisor* – Assoc. Prof. Judith Littleton. Phone: 09 373 7599 ext. 88574. Email: j.littleton@auckland.ac.nz

If you want to talk to someone who isn’t involved with the study, you can contact an independent health and disability advocate. This is a free service. Phone: 0800 555 050. Email: advocacy@hdc.org.nz.

You can also contact the health and disability ethics committee (HDEC) that approved this study. Phone: 0800 4 ETHICS. Email: hdecs@moh.govt.nz.

If you require Māori cultural support talk to your whānau in the first instance. Alternatively you may contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext 2324.
If you have any questions or complaints about the study you may contact the Auckland and Waitematā District Health Boards Māori Research Committee or Maori Research Advisor by telephoning 09 4868920 ext 3204.

**Counselling Services**
In the unlikely event that a topic discussed in the interview causes you some distress or concern, recommended independent counselling services you can contact include:
Auckland: Carol Shinkfield. Phone: 027 413 5202. Email: carol@shinkfield.co.nz
Auckland: Jill Buchanan. Phone: 021 0657535. Email: jill.buchanan@ihug.co.nz
Christchurch: Kiri Kamo. Phone: 027 629 3502. Email: tkrkamo@hotmail.com
Christchurch: Jo Doyle. Phone: 027 490 8840. Email: jodoyle@childpsychotherapy.co.nz
Wellington: Gabriela Whitman. Phone: 021 986 151/ 04 806 0002. Email: Gabriela.w@xtra.co.nz
Wellington: Jill Clarkson. Phone: 022 011 9769. Email: jillec@orcon.net.nz

**Approval**
This study has received ethical approval from the Human and Disability Ethics Committee: REF 14/NTB/47.
CONSENT FORM

For parents, legal guardians and families of children with MCADD

Research Topic: An ethnography of children diagnosed with medium-chain acyl-CoA dehydrogenase deficiency (MCADD).

Primary Researcher: Pauline Herbst, PhD Candidate. P.herbst@auckland.co.nz

Please tick to indicate you consent to the following:

<table>
<thead>
<tr>
<th>Consent Item</th>
<th>Yes</th>
<th>No</th>
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<tr>
<td>I have read, or have had read to me in my first language, and I understand the Participant Information Sheet.</td>
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<tr>
<td>I have been given sufficient time to consider whether or not to participate in this study.</td>
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<td>I have had the opportunity to use a legal representative, whanau/ family support or a friend to help me ask questions and understand the study.</td>
<td>☐</td>
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<tr>
<td>I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.</td>
<td>☐</td>
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<tr>
<td>I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.</td>
<td>☐</td>
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<tr>
<td>I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.</td>
<td>☐</td>
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<tr>
<td>If I do not want the information collected about me up to the point of withdrawal to be used I understand that reports may have already been published using information gathered during the research period and that any future reports written will exclude my data as requested.</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
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<td>☐</td>
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<td>I consent to my clinic visits being observed.</td>
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<td>I consent that my child/ren, age _________ on the signed date below, can take part in this study.</td>
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<td>I consent to my child’s hospital admissions being observed.</td>
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<td>I consent to my child’s school activity being observed.</td>
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I consent to my interviews being digitally recorded and understand that,
even if I agree, I may choose to have the recorder turned off at any time. Yes ☐ No ☐

I consent that interviews and interaction with my child can be digitally recorded and understand that, even if I agree, I may choose to have the recorder turned off at any time. Yes ☐ No ☐

I would like to join the closed Facebook MCADD Support Group. Yes ☐ No ☐

I know who to contact if I have any questions about the study in general. Yes ☐ No ☐

I understand my responsibilities as a study participant. Yes ☐ No ☐

I wish to receive a summary of the results from the study. Yes ☐ No ☐

Declaration by participant:
I hereby consent to take part in this study.

Participant’s name: ____________________________

Signature: ____________________________ Date: ________________

Declaration by member of research team:
I have given a verbal explanation of the research project to the participant, and have answered the participant’s questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher’s name: ____________________________

Signature: ____________________________ Date: ________________

This study has received ethical approval from the Human and Disability Ethics Committee:
REF 14/NTB/47.
PARTICIPANT INFORMATION SHEET

For medical professionals

Research Topic: An ethnography of children diagnosed with medium-chain acyl-CoA dehydrogenase deficiency (MCADD).

Primary Researcher: Pauline Herbst, PhD Candidate

Introduction
You are invited to take part in a study that looks at how children diagnosed with genetic disorders understand their disorder as they grow from an infant to a young adult; how they explain it to others; and how they develop their identity and sense of self over time. The research will be conducted by Pauline Herbst, a PhD candidate in the Department of Anthropology at the University of Auckland, who will specifically focus on families with children diagnosed with medium-chain acyl CoA dehydrogenase deficiency (MCADD).

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep. This document is 4 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

About the Study
The reason for the research is to assist in understanding if the diagnosis of a chronic genetic disorder impacts on a child’s identity; and document how children develop an understanding of their disorder and learn to manage it. This study will take place throughout New Zealand and potentially Australia, from 2014-2017 and involve in total, approximately 110 people.

As part of this research, I am interviewing approximately 10-15 medical professionals about their experiences in dealing with families and children diagnosed with MCADD, and how the disorder is explained to the children and families and managed over their lifetime.

You will be asked for one interview, which will be digitally recorded. Interviews will last between 30-60 minutes. I would also like to observe the activities of families of children with MCADD (who have given prior informed consent and in the case of children, assent) during clinic visits and hospital admissions. I would also like to photograph and video you, children and families while they are involved in these activities for later analysis. Identities will be kept anonymous, for example, a film may include your voice but focus on a lure in a child’s arm. If I would like to use any of this visual material (e.g. photographs or video where you can be identified) in resources to help further the understanding of MCADD, I will seek your permission before use.

Your participation in these interviews is entirely voluntarily. If you do agree to participate you are free to withdraw at any time. You can also stop an interview at any time and do not have to answer

1 The Medical Professional Participant Information Sheet and Consent Form (PISCF) was used as a template for the Educational Professional PISCF.
Benefits, Risks and Safety

The study aims to benefit children diagnosed with MCADD and their families. I intend to use the results of this research to create resources such as a booklet or film for families to use, and to help others understand the disorder and how to manage it. The study poses no risk or cost to participants and the only inconvenience is the time taken for participation.

Confidentiality & Results

I aim to publish the findings of this research. If the information you provide is reported or published, the organisation of which you are a part may be identified. You may choose whether you wish to be identified as the source of this information, or if you wish to remain anonymous. A summary of the results of the study will be made available to you if you wish.

Further Information

If you have any questions, please contact any of the following:

Principal Researcher – Pauline Herbst. Phone: 021 66 82 60. Email: p.herbst@auckland.ac.nz
Supervisor – Prof. Julie Park. Phone: 09 373 7599 ext. 88589. Email: j.park@auckland.ac.nz
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Auckland: Jill Buchanan. Phone: 021 0657535. Email: jill.buchanan@ihug.co.nz
Christchurch: Kiri Kamo. Phone: 027 629 3502. Email: tkrkamo@hotmail.com
Christchurch: Jo Doyle. Phone: 027 490 8840. Email: jodoyle@childpsychotherapy.co.nz
Wellington: Gabriela Whitman. Phone: 021 986 151/ 04 806 0002. Email: Gabriela.w@xtra.co.nz
Wellington: Jill Clarkson. Phone: 022 011 9769. Email: jillec@orcon.net.nz

Approval

This study has received ethical approval from the Human and Disability Ethics Committee: REF 14/NTB/47.
CONSENT FORM
*For medical professionals*

**Research Topic:** An ethnography of children diagnosed with medium-chain acyl-CoA dehydrogenase deficiency (MCADD).

**Primary Researcher:** Pauline Herbst, PhD Candidate. P.herbst@auckland.co.nz

**Please tick to indicate you consent to the following:**

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<tr>
<td>I would like my identity to remain anonymous.</td>
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<tr>
<td>Even if steps are taken to keep my identity anonymous, I understand that there is some risk of my identity being known due to my association with the organisation that I work for.</td>
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B: Children’s storyboards

**Bay's Adventure**

Once upon a time, there was a little dog called Bay.

**Let's Go Play Soccer**

Wait, I forgot to eat my breakfast.

Ok, eat it fast then, why do you have to eat anyway?

Because I have MCADD.

So I won't starve.

In the River!

Kapow!

Woof woof

What's MCADD?

Ah, ah, I don't know.

I loved playing with you today.

Thank you for coming over.

They went home tired at the end of the day.
TOM AND ZAC WHO HAVE MCADD

THEY HAD MCADD

HL. I'M TOM.

I'M ZAC.

YAY!

ONCE THERE WERE TWO BROTHERS

IT WAS THEIR BIRTHDAY

GO ENGLAND!

GO ARGENTINA!

THE END!

THEY WENT TO A FOOTBALL GAME

TIME FOR A SLEEPOVER

GOOD NIGHT TOM

GOOD NIGHT ZAC
Once upon a time there were three animals. Rose says, "Oh, what are we going to play?" Swimmy responds, "I just need a snack first." Penny snatches it from her, saying, "Give that back to me. It isn't your bowl. It isn't your breakfast." Swimmy replies, "I'll have that!"

Poor Rose had to go without breakfast. Rose found some strawberries. She jumped into the river and ate the fish quickly.
C: Children’s stories

i) Jake’s Story (with help from George)

It’s a cold Saturday in October. There are two boys, John and Steve and they are bullies. Stevie is a Year 7, he’s 12 and John is 13, a Year 8 and they go to school with Sophie. She’s a Year 5, a nice girl. The two boys really like Sophie and they’re really jealous of her because she’s pretty. And then them two boys pick on the girl because she has MCADD. They think it’s like a disease or something. Except it’s not really. They think it’s Ebola because they’re not very smart at school. They need extra help.

And they live in the same neighbourhood and the parents like each other so they want each other to have a sleepover. But the parents decide to have a BBQ instead. Steve goes to the kitchen because he’s very quiet and gets a knife out of the drawer, a steak knife, and they take her to the corner in the garden. And then they say, ha, ha, you have Ebola and they threaten her with the knife. Sophie punches both of them and runs away and tells mum.

And mum goes “don’t be silly”. So Sophie goes upstairs and locks the door in her bedroom and the two bullies go upstairs and they keep knocking on the door and they yell ‘let me in’ in deep voices and they punch the wall. And then the mum comes upstairs and she says “oh, what are you doing?”. Then they say “oh we’re just trying to ask her a question but she won’t open the door”. And then Sophie gets told off and loses her electronics for a month. But Sophie is too nervous to tell her mum because she didn’t believe her the first time.

Then the bullies eventually stop and she climbs out the window. And it’s an upstairs house. She climbs down. She sneaks in the kitchen and grabs the telephone and calls the police. And then the police come to the door and surround the house and she’s just like and the mums just going, “What’s happened. Why are the police at my house?”
Sophie doesn’t come down to dinner. Then mum gets angry and says “hurry up Sophie otherwise you’re going to lose your electronics for a month and a week now”. Then the two bullies feel guilty so they tell her mum and she tells them off and she gives the electronics back. The bullies knew she had MCADD and were pretending she had Ebola. Just to be mean. They knew she had MCADD. They were just trying to pick on her. They thought Ebola was a terrible disease. And she hated Ebola. She was nervous she was going to get it. And they got scared. And then that’s the end.

ii) Kate’s story

Leo is at school. He does art, maths, reading, spelling. At art he does Maori. At maths he does fractions on a paper. At reading he does a play with the class.
DRAFT COMIC SCRIPT

TITLE Life of Lola: Totally Normal

Note: Descriptions of scenes in caps. Captions are in italics. Notes to artist in square brackets.

STRIP 1: [Split panel of three (clock porridge is the middle one). Breakfast time.]

Panel 1a
TYPICAL MORNING DOMESTIC SCENE. BREAKFAST TABLE WITH DRINKS, FOOD, HOMEWORK BOOKS. SCHOOL HAT HANGING OVER THE BACK OF THE CHAIR OR SCHOOL BAG OR SOMETHING. IRIS IS SITTING AT THE DINING TABLE, HAND ON CHEEK, SLOUCHED FORWARD OVER A BOWL OF PORRIDGE. HER TEDDY (OR SOMETHING ELSE IF YOU HAVE AN IMAGE IN MIND) MUST BE IN THE FRAME SOMEWHERE. HER BROTHER, SLIGHTLY OLDER, HAS HIS BOWL UP TO HIS FACE AND IS SLURPING IT.

Caption: My name is Iris. It's breakfast time here at the crazy house. It's always breakfast time, or snack time, or lunch time, or dinner time.

Mum [speech bubble coming from outside the panel, don't see Mum]: Come on Iris, finish your breakfast.
Matt: I've finished all my food.
Mum: Good boy Matt. Iris! Come on, we're going to be late for school.

Panel 1b: [To show passing of time and that this is a constant.]
CLOSE UP OF A BOWL OF PORRIDGE BEING STIRRED FEROCIOUSLY, MAYBE YOUR PIC OF THE MANY ARMED FOOD MONSTER IN IT AND THE ARMS ARE THAT OF A CLOCK TICKING DOWN.

Panel 1c: [How it affects everyday life.]
THE BACK OF A CAR WITH IRIS AND MATT IN. IRIS IN A BOOSTER SEAT TO SHOW HER AGE (AROUND 5YO).

Caption: Mum gets really grumpy when I take too long to eat. Sometimes I just don't feel like it. Everyone is always bossing me.

Matt: Come on Iris. Just have a little bit more. It's going to feel like ages before you get a brain food break.
Mum (disembodied voice again): IRIS!

STRIP 2: [School as one of the geographical spaces]

Panel 2: Lunchtime observation from the child's POV.
A SMALL JUNGLE GYM AS THE BACKGROUND WITH SLIDE. TWO GIRLS IN UNIFORM (SKORTS, A SHORT SLEEVE T-SHIRT AND WIDE BRIMMED HAT) WITH LUNCH BOXES. ONE SITTING ON THE FLOOR CROSS LEGGED, HAND UP. IRIS IS LEANING ON AN ARM, ALMOST LYING DOWN, WAVING HAND IN THE AIR. A TEACHER WITH THEM.
Caption: School is fun. We play and run around. My best friend is Sarah. The teacher checks her lunchbox too. And the other Year Ones. Then we can go play.

Teacher: Ok, Sarah.
Sarah: Yay.
Teacher: One more sandwich Iris.

Panel 3:
IRIS LYING ON HER TUMMY IN A BUSH, CHIN ON HANDS, WATCHING SOMETHING. SURROUNDED BY BRANCHES/ FOLIAGE. HIDING FROM THE RESEARCHER. IMAGE OF A BURGER AND CARROTS HANGING FROM THE BRANCHES ON THE LEFT LIKE SOME SURREAL CHRISTMAS TREE. ADD SOME JUICE BOXES. THE FOOD AND DRINK ARE HER THOUGHTS ABOUT MCADD.

Caption: Ssh. I'm watching Pauline. She's at school today. She's a researcher. I told Sarah she was here for me but she didn't believe me. Pauline did drawings with me. She asked me about my MCADD.

Iris: What is MCADD? It's food and drink, right?

Panel 4a:
A BOY IN THE CLASSROOM THROWING UP ON THE DESK. KIDS LEAPING AWAY FROM HIM, CHAIRS FLYING. IRIS IS ONE OF THE KIDS - THERE WILL BE A CLOSE UP OF HER IN THE NEXT PANEL.

Caption: I don't think about it very much. It's private, A family thing. Except sometimes I worry...

Soundbytes: Argh. Yuk. etc. [Put in POW BAM vintage comic font?]

Panel 4b: Inciting incident
CLOSE UP OF IRIS OR JUST PART OF HER FACE AND SHOULDER WITH A BIT OF VOMIT ON IT. BEHIND HER AN IMAGE OF AN 'ACTION PLAN' ABOUT IRIS' CONDITION (SENT AS A SEPARATE FILE) AND WHAT NEEDS TO BE DONE.

STRIP 3: [Home environment - happy. A series of interconnected panels].
Caption: The best part of the day is coming home after school. Except for the homework.

Panel 5a:
IRIS AT THE TABLE WITH A PLATE OF SNACKS, FRUIT (SOMETHING EASILY IDENTIFIABLE LIKE BANANA, APPLE, MANDARIN SEGMENTS), A BISCUIT, SOME PRETZELS OR TINY TRIANGLE SANDWICH OR TWO.

Panel 5b:
IRIS DRAWING [this could just be a hand with a pencil and a stick man].

Panel 5c:
KICKING A SOCCER BALL ON GRASS WITH MATT [likewise maybe just focus in on the feet] ADD A SCRUFFY LITTLE DOG CHASING THE BALL WITH THEM.
Panel 5d: 
CHECKING OUT A HEDGEHOG/ LADYBUG IN THE GRASS OR MAYBE PLAYING WITH A PET MOUSE/ RAT [could also be a close up of the mouse on the shoulder]

STRIP 4: [The clinic]

Caption: But not today. Today I have a boring check up. No prickles. Mum promised.

Panel 6: 
IN THE CAR WITH MATT, MUM AND RESEARCHER. SNACKBOX ON LAP. HOSPITAL THROUGH THE WINDOW (SAME VIEW AS WITH THE TEDDY IN NEXT SCENES?)

Panel 7: 
AERIAL VIEW OF A CRAMPED ROOM WITH A DOCTOR AT THE TABLE, 4 NURSES, A BED, 2 CHAIRS WITH PARENTS. [I’ll send you a sketch of room object placement from my field notes]. IRIS LYING ON THE FLOOR UNDER HER MOM’S CHAIR SO ALL YOU CAN SEE IS HER HEAD AND FEET STICKING OUT. HOLDING HER TEDDY.

Caption: All they do is talk. About me. It’s boring.

Doctor: What does she normally eat in a day?
Mum: [text getting smaller and smaller till it fades away) Toast or porridge in the morning, fruit at morning tea, then when we get home…
Iris: I’m hungry. Can we go now? Can we go? [does she have an imaginary bubble where she is somewhere else - can leave it out?)

Panel 8a: 
IRIS IN A NIGHTIE IN BED WITH HER TEDDY, BUNNY NIGHT LIGHT (OR UNICORN OR SOMETHING), HOT CHOCOLATE KID MUG (NB), HAVING BEDTIME STORIES.

Iris: Dad, I don’t feel well.
Dad: Oh Iris. Is this because of the visit today? You heard the doctor. There’s nothing wrong with you. Everything is fine. Go to sleep now and have sweet dreams. Love you.

Panel 8b: 
Moon through window, sleeping (or this could be incorporated into 8A above).

STRIP 5: Feeling sick/ worrying about feeling sick

Panel 9: 
MOON HAS CHANGED POSITION. IRIS HAS A TEMPERATURE [DO YOU DEPICT THIS WITH A VOLCANO ABOVE HER HEAD/ OR WAVY LINES OFF HER HEAD/ OR A BUILT-IN HEAD THERMOMETER - IDEAS WELCOME]? CURLED UP HOLDING HER TUMMY. FEELS NAUSEOUS. GLASSES NEXT TO BED ON BEDSIDE TABLE. WHAT IS THE TEDDY DOING? LYING ON THE FLOOR? HALF OFF THE BED?
Panel 10a: [Nightmare sequence to show hospital impression]
INTERLINKED PANELS: IN WAVY LINES TO SHOW IT'S A DREAM. TEDDY BEAR IS VOMITING INTO A BUCKET. POLYCAL TIN AND GLASS OF JUICE NEXT TO THE BED OR ON A TINY TABLE WITH A PLATE OF CRACKERS. THE TEDDY CAN BE A CLOSE UP.

Caption: That night I had really bad dreams.

Panel 10b
THE BACK OF AN AMBULANCE, TEDDY PRESSED AGAINST THE WINDOW, BOTH HANDS AGAINST IT. THE AMBULANCE IS HEADED TO A HOSPITAL, EVIDENT BY THE CROSS.

Panel 10c
TEDDY IN A BED. A DOLL IN A NURSE OUTFIT COMING TOWARD HIM WITH A GIANT SYRINGE.

Panel 11:
THE KIDS IN THEIR BEDS. SUN IS UP THROUGH THE WINDOW.
Caption: I get scared when I'm sick.

Iris: Matt I don't feel well.
Matt: I'll get Mum for you.
Iris: No, don't tell Mum.
Matt: Iris...

Panel 11b:
IRIS THROWING UP INTO A BUCKET. MUM RUBBING HER BACK.

Matt: Mum, Mum, could you…
Mum: Not now Matt.

Panel 11c:
MATT IS VERY JEALOUS. HOW WOULD YOU PORTRAY THIS? A CLOSE UP? HIM THROWING TEDDY OUT THE WINDOW OR OUTSIDE SOMEHOW.

Panel 11d:
TEDDY LYING SIDEWAYS UNDER A BUSH, MAYBE NEXT TO A SOCCER BALL.

Iris: [disembodied voice]: Matt, have you seen Teddy? Muumm…
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