The Disrupted and Realigned Self:

Exploring the Narratives of New Zealanders with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis

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ABSTRACT

Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) causes pronounced, debilitating fatigue that is not alleviated by rest, along with muscle and joint weakness, pain, cognitive difficulties and can be worsened through mental and physical exertion. However, it is also without an aetiology, and there is little consensus amongst both medical and patient spheres as to what CFS/ME actually is. In this thesis I draw on interviews with people with CFS/ME and participant observation in a patient-led support group in order to explore the way in which CFS/ME shaped participants' identities and narratives of the self. I argue that participants moved through two stages that I call 'The Disrupted Self' and 'The Realigned Self'. Falling ill with CFS/ME rapidly disrupted participants' understandings of the bodies, their position within their family and the community, interactions with doctors, and all the usual markers on which they had previously formed their self-identities. In this state, I argue that participants and those with whom they engaged viewed both CFS/ME and my participants as liminal, 'betwixt and between' (Turner 1969) social roles and contemporary New Zealand ideals of illness, the individual, and the 'sick person'.

As the initial disruption and confusion of falling ill subsided, however, my participants worked to develop a new secure self-identity, the 'Realigned Self'. They move into a normalised long-term liminal state by prioritising their health, adjusting their expectations of their body, developing their own conception of the aetiology of CFS/ME and forming a positive narrative of their new lives. This identity work utilised wider cultural ideals about the active, responsibilised and authentic self; common to late modern contemporary life (Beck and Beck-Gernsheim 2001, Desjarlais 1994, Giddens 1991, Rose 1996). Yet this realignment was often not reflected in the views of my participants' friends, families and doctors. This illustrates the diverse perspectives and different degrees of liminality that exist within experiences and narratives of CFS/ME and contested illnesses.

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CHAPTER ONE: INTRODUCTIONS

Perceptions

The meeting room for the local Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (henceforth referred to as CFS/ME[1]) support group was exceptionally humble: crammed into the side room of a Community Centre, it was cold and dim, with faded children's drawings about the Bible and Jesus' love tacked to the walls. It first appeared to me as a depressing space, which I naively took as an indication of what was to come at this first meeting. Yet this meeting, the meetings that followed over the next year, and the subsequent formal and informal conversations with members which formed the basis of my research did not brim with the negativity I had mistakenly expected. Rather, I was repeatedly astonished by the perseverance, positivity and humour with which my participants engaged with one another and myself. I often wondered, almost to the point of frustration, whether my participants felt they had been delegitimised at all - a question which had originally been the frame for my research proposal. How could those who suffer from a condition that grants little in the way of medical explanation or social legitimacy feel so secure in their self-identities, their construction of CFS/ME, and their conviction that they were, above all, right?

CFS/ME is a chronic condition marked by unexplained, persistent fatigue that does not alleviate with rest (Fukuda et al. 1994). Other symptoms include, but are not limited to, muscle and joint pain, impaired memory and concentration, post-exertional malaise and tender lymph nodes (Evangård, Schacterle and Komaroff 1999:456). The aetiology of CFS/ME has been the subject of consistent debate since the first definition of CFS/ME was

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[1] I use CFS/ME following the United Kingdom CFS/ME Working Group (2002), who recognised that there were no acceptable "names" for CFS/ME. They argued that until the aetiology of CFS/ME is discovered, the most important goal with regard to names is satisfactory communication between doctors and people with CFS/ME. See Chapter Four for a continued discussion on the importance of naming.

developed (Holmes et al. 1988). Over the last several decades, multiple possible causes, triggers and theories over what exactly CFS/ME is have been proposed, discussed, and disproven, to the point where the "reality" of CFS/ME as a legitimate condition in its own right is still under debate (Leone et al. 2011, Poulton 2012). According to social science research in a range of ethnographic contexts, for people with CFS/ME, this doubt is often experienced as delegitimising, for it makes suspect both their claims about their ill health and their moral worthiness (Cooper 1997, Ware 1992).

I began this research intending to examine the experiences of New Zealanders with CFS/ME, and academic accounts of delegitimisation influenced my initial expectations of the field. However, as illustrated above, my participants' explanations forced me to rethink the focus of my thesis. I seek to answer the question, *how do New Zealanders with CFS/ME understand their condition and manage both their self-identities and their relationships with others in the face of illness?* The experiences of people with CFS/ME are not as simple as I first suspected: instead, my participants engaged with social and cultural understandings of illness and personhood to create complex, nuanced and, most importantly, secured understandings of these three intertwined areas.

I argue throughout this thesis that the experience of CFS/ME is marked by two stages: the 'Disrupted Self' and the 'Realigned Self'. Within the early stages of their illness, my participants experienced what I have called the 'Disrupted Self' (Chapter Two), where the previous personal, familial, work-related, social and cultural roles they used to form their self-identities were no longer available. In this state, my participants were more likely to suffer from the doubt, suspicion and questions that others, such as family, friends and their doctors, placed upon both them and their CFS/ME. It was during the vulnerability of the 'Disrupted Self' that my participants were most likely to feel that they were delegitimised by others and less able to manage this experience.

Yet as Garro (1992) argues, it is too simple to see illness and the disruption of the self in terms of loss. My participants therefore worked to

form what I call the 'Realigned Self' (Chapter Three), within which they sought to rebuild their self-identities. I show that my participants were able to construct a culturally understandable and justifiable sense of self-identity through, firstly, the process of prioritising their needs for health above all else and restructuring their new choices and life-goals as positive. Secondly, my participants also renegotiated their engagement with both familial and work-related roles and the wider social and cultural expectations of individuals in advanced liberal democracies. In this thesis I show the way in which they created specific explanations about their CFS/ME in order to create legitimate explanations of their CFS/ME for both themselves (See Chapter Six) and others (See Chapter Five). These conceptions reinforced the work they had put into their realigned sense of self-identity.

This thesis fits within medical anthropology's focus on subjectivity and lived illness experiences (see Biehl, Good and Kleinman 2007, DelVecchio Good et al. 1992, Dumit 2006, Garro 1992, Good 1994, Kleinman 1988, 1992, 2010). As I detail in the Methodology section, I follow their primarily interpretivist approach in the analysis of my participants' narratives. Furthermore, my work also deals with questions of power, which critical medical anthropologists such as Farmer (1992, 1999), Kleinman, Das and Lock (1997), Petryna (2002) and Rapp (2000) explore. Like these authors, I seek to show how my participants' lived experience both challenge and provide alternatives to biomedical conceptions of illness. My thesis firstly fills a gap within the New Zealand-based literature on CFS/ME experience. While other social scientific studies into CFS/ME have been conducted (see Barker 1991, Gibbons 2010, Horne 1990), these have all primarily focused on the experiences of delegitimisation and stigmatisation. Secondly, my work is the only one in New Zealand to link the identities of people with CFS/ME to their explanations of aetiology, which I argue works to support the personal and public narratives my participants create to legitimise themselves. Within the international explorations of CFS/ME, there have been minimal anthropological *ethnographic* explorations of CFS/ME (for notable exceptions see Cohn 1999, Dumit 2006, Sachs 2001, Ware and Kleinman 1992, Ware 1992, 1988) and even fewer studies that have conducted participant

observational work in a support group (but see Horton-Salway 2000). Finally, medical sociologists and anthropologists such as Balshem (1993) and Williams (1984) have explored the link between narratives of aetiology and identity-formation with respect to other conditions, yet this link has not been made with CFS/ME. While some social scientific research into CFS/ME has discussed patient explanations of the aetiology of CFS/ME, they have primarily linked this to levels of disability and psychological adjustment (Clarke 1999, Moss-Morris, Petrie and Weinman 1996, Richman et al. 2000). My thesis, on the other hand, illustrates the way in which my participants' formed their understanding of aetiology to narratively support both their self-identity work (Chapter Six) and their strategic explanations to others (Chapter Five). This thesis therefore contributes to the continued efforts to understanding CFS/ME and the experiences that go alongside it.

Methods

This research project primarily draws on the narrative productions of nine participants [2], collected through eight interviews. [3] Four of these participants contacted me through an advertisement that I placed in the support group's newsletter, and the other five were met through meetings at the local support group. These interviews ranged from between an hour and a half to three hours, they were all recorded and transcribed by myself, and written consent was obtained. Because CFS/ME sufferers often experience fluctuations in their energy levels (see Fukuda et al 1994), I tried to make the interview process as easy as possible for my participants. All but one of these interviews were conducted in the homes of my participants. I also

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[2] This study originally had ten participants. One participant withdrew for reasons that were not disclosed to me just before I began the writing process of my thesis. While this was frustrating, it was the only interview that I had conducted with an individual who had cared for people with CFS/ME rather than having CFS/ME: seeing as I was most interested in the lived experiences of people with CFS/ME, losing the data from this interview did not have a great effect on my thesis.
[3] This research project received ethical approval for conducting interviews and participant observation from the Central Regional Health and Disability Ethics Committee (CEN/11/09/053) on the 11th of October 2011.

intentionally made my schedule as flexible as possible so my participants would feel comfortable rearranging meetings on short-notice dependent on how well they were feeling. I stressed to my participants that interviews could be conducted in two separate visits, or cut short to be followed by a telephone interview dependant on their energy levels; however, this was not required with any of my participants. The interviews were very loosely structured and all questions were open ended and intended as cues or starting points, as I hoped my participants would focus on what was most important to them in their illness experience. In conducting my interviews, I asked my participants to start "at the beginning", which was often a point before they developed CFS/ME properly (Chapter Six). In this first section of the interview, I questioned my participants about how the initial stage of CFS/ME affected them, how they got a diagnosis, and what their relationships with family, friends and doctors were like at this point (Chapter Two). Secondly, I asked my participants about what their life was like now, how they managed work and, finally, how they felt their identity had been affected as a result of CFS/ME. Although I had questions to ask with regard to the aetiology of CFS/ME, my participants most often voluntarily explained their views of the aetiology of CFS/ME (Chapter Five and Six) as they explained how they developed CFS/ME or why they had remained unwell for such a length of time.

Eight of my nine participants were women. While such a small sample cannot be representative, women are suspected to make up to as much as 71 percent of sufferers in a range of settings (Gallagher et al. 2004). My participants were all highly educated: one had received a PhD, another a Masters of Arts degree, and six had some form of higher education: in fact, my only participant who had not received a higher education, Eva, was still in the process of completing her secondary school education. This is at odds with Jason et al.'s (1999) community-based study in Canada, where women and those with a lower level of education and occupational status exhibited "the highest levels of fatigue" in their sample. Three of my participants worked part-time, Eva was still in school, Melissa was currently studying part-time, one had just finished her degree and the other four of my participants were

not able to work. Six of my participants had all worked in either specialised jobs which required a higher level of education or "white collar" jobs prior to developing their CFS/ME; out of the other three, one had been unemployed but had recently received a higher degree, and the other two were Eva and Emily, who developed CFS/ME in their teens. All of my participants identified as New Zealanders of European descent. However, it is worth nothing that a 2009 meta-analysis of research from the USA found that ethnic minorities had a slightly higher chance of developing CFS/ME (Dinos et al. 2009). While there is no sufficient data on the ethnic breakdown of people with CFS/ME in New Zealand, the differences between my participants and community-based samples are likely a result of my recruitment method of the support group meetings. The demographic of most support groups, especially health-based groups, reflects the demographic breakdown of my participants: middle-class, white and educated (Jacobs and Goodman 1989, Clarke 1999). However, my thesis is not aiming to be representative of all CFS/ME sufferers. Rather, I hope to provide a deep exploration of the experiences of my participants and the types of identity-work that they perform, which are linked to their social and cultural positions.

The discrepancies between my participants and community-based samples are outweighed by the benefits the support group provided this research project. Browner (1999) and Lambert and McKevitt (2002) have suggested that basing a research project solely on one-off interviews has the potential to produce standardised responses from one's participants, dependent on the level of rapport between the researcher and participant. In an effort to counter this, I attended seven monthly support group from August 2011 to April 2012, and volunteered to help with the support group collection efforts on 'ME Day'; approximately twenty hours of participant observation in total. I attended two of these meetings while waiting for ethical approval. These do not form part of the data presented in this thesis, but were essential in order to get to know and build rapport with my participants and the initial reframing of my research questions. The data I gathered through participant observation is invaluable to this thesis, as it enabled me to see the way in which my participants both engaged with each other and speakers at special

group meetings, how they worked to form shared presentations of what CFS/ME meant, and allowed me to extend and supplement interview material.

There were several factors behind my rationale to use participant observation at these meetings. Firstly, support groups can be seen as 'natural' research sites that are led by participants without the influence of the researcher; it is not an 'artificial' group formed for the purpose of data collection, such as a focus group (Horton-Salway 2004). Unlike the recent research into CFS/ME experiences in New Zealand conducted by Gibbons (2010), I intentionally avoided leading any meetings so as to try and retain this balance. I often did not speak during the meetings proper, except to make clear my position as researcher to those who were not yet familiar with me, and instead preferred to converse with members during the 'tea break' time of each meeting. [4] The anthropological research into CFS/ME that utilises participant-observation with a support group as a means of data collection is fairly limited. For example, while the recent work by Gibbons (2010) mentioned above involved utilising support groups, all of the meetings she attended were organised around her specific research interests of visual constructions of chronic conditions. Bülow and Hydén (2003) conducted research with a support group in a Swedish hospital, however, this was run by the hospital staff, not by sufferers' themselves. Horton-Salway (2004) worked with a sufferer-run support group in the United Kingdom, however, her published work primarily draws on an engagement between sufferers, herself, and a visiting psychologist, rather than on the usual operations of the support group.

The support group was also useful as I wanted to allow my research to be participant-driven. As many have noted, those with chronic, contested conditions are often wary of medical practitioners because of their experiences of delegitimisation within doctor-patient relationships (See Chapter Two. See also Banks and Prior 2001, Cooper 1997, Dickson, Knussen and Flowers 2007, Dumit 2006, Ware 1992). The relationship between myself and the support

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[4] I am not suggesting that my presence would have had no effect on my field-site. I am aware that in subtle ways my participants might have shifted their behavior with a researcher present in these meetings. However, I made all efforts to have as little effect as possible.

group was constructed on the terms of my participants, yet it enabled me to be associated with them, rather than trying to work from the 'outside'. I found that the support group fully embraced me: I was warmly welcomed, encouraged to place an advertisement in their monthly newsletter and allowed to attend the support group meetings. The only restriction that the support group committee had decided upon before I met with them was that they would not allow access to their membership lists. I had wholeheartedly agreed, as I had wanted to either have participants contact me with their desire to be interviewed or, alternatively, I planned to request interviews with individuals whom I had already met through the support group. My rationale for this was much the same as for why I went through a support group: I had already recognised that the experience of illness could be a highly personal, emotional event in an individual's life (See Chapter Two) and I did not want to cause anyone to feel uncomfortable in turning my request down if they did not wish to be interviewed. Furthermore, as Browner notes, within one-off interviews it can be difficult to establish rapport (1999:138), yet as a result of my repeated attendance at meetings, the majority of my participants were already familiar with me before our interviews, and it made subsequent discussions with my participants possible.

The fact that I was doing my Master of Arts in Anthropology was an unexpected benefit in conducting this research project. When I first met my participants at the support group, I made the point that I was not associated with any health care providers nor did I have a background in medicine. My standpoint as an anthropologist reassured my participants that I would not be analysing their experiences through a psychological paradigm. Furthermore, because these interviews were predominantly led by my participants and focused on experience in general, rather than any specific psychological trauma, I avoided the problems that Gibbons (2010:31) encountered, where participants recognised that her technique of gathering data[5] was very similar to a psychotherapy technique. The importance of representing myself outside of biomedicine became obvious when I started to conduct my interviews; all of

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[5] Her participants created visual representations of their experience in what she called "MeBoxes"

my participants were wary of psychological representations of their CFS/ME and psychologists in general.[6]

Finally, I must make a note on the ethical considerations of this project. My participants were firstly given the option to choose their own pseudonym, which five of my participants did. The other four names were selected by me in order to represent my participants' ethnicities and ages. This thesis is also somewhat decontextualised in terms of both specific details about my participants' and where in New Zealand this project was undertaken. However, this lack of data is necessary in order to protect my participants' anonymity. There were only a small number of people who regularly attended the support group I went through. In aiming to protect my participants' anonymity as a member of this specific group, this data has been removed. Given the small population size of New Zealand overall, there are very few CFS/ME-focussed support groups throughout the country. By not designating the location of my research, I aim to both protect my participants as individuals and the group as a whole.

Methodology

Because I was most interested in focusing on the experiences of people with CFS/ME, I utilise an interpretive epistemological approach to analyse my participants' narratives. Interpretive anthropology, according to Schwandt, focuses on "the goal of understanding the complex world of lived experience from the point of view of those who live it" (1998:221). The interpretivist approach first allowed anthropologists to reconstruct their view of "culture" as less static and more fluid, which enabled them to examine the "meaning" of their participants' claims rather than the structures within which "culture" was presumed to be found (Geertz 1973). While positivistic approaches may attempt to be "an experimental science in search of laws" (Geertz 1973:5), Bryant and Charmaz argue that this approach is often flawed, for their data is

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[6] See Chapter Four and Five for the importance of the physical versus mental condition debate for both patient advocacy groups and my participants in particular.

seen as unproblematic observations of reality (2007:44). When one is drawing on narratives of experience, the ability to note down observations is not always possible, especially as such narratives rely heavily on the interpretations and constructions that a participant has already formed. Dolgin, Kemnitzer and Schneider have suggested that the "concern" of interpretive anthropology should "not [be] with whether or not the views a people hold are accurate in a 'scientific' sense of the term … [rather], that which is thought to be real is treated as real" by the researcher (cited in Lett 1987:11).

While some have critiqued the methodology of interpretive anthropology for the two potential extremes of the approach, such as the claim that nothing at all is 'real' but what is thought to be, to total relativism, where all claims to truth are accorded the same weight (McGee and Warms 2012), my approach is more moderate. While early interpretive anthropologists such as Geertz may have been concerned solely with what a symbol "means", recent interpretive anthropological works have sought to place their participants' experiences within the structures that they inhabit (McGee and Warms 2012:440). Thus, as Good succinctly notes, interpretive practices now explore the way in which "realities are constructed, authorised, and contested in personal lives and social institutions" (1994:5). Likewise, my methodological standpoint has led me to interpret the narratives of my participants within the networks with which they interact or negotiate: the way in which they understand their CFS/ME in relation to cultural concerns of illness, the effect this has on their relationships with family, friends and doctors and the way in which they seek to (re)construct their relationship between themselves and society. I follow Good and DelVeechio Good (1980:176), who argue that a condition or illness, such as CFS/ME:

> condenses a network of meanings for a sufferer: personal trauma, life stresses, fear and expectations about the illness, social reactions of friends and authorities, and therapeutic experiences. The meaning of illness for an individual is grounded in – though not reducible to – the networks of meaning an illness has in a particular culture: the metaphors associated with disease, the ethnomethodological theories, the basic values and conceptual forms, and the core patterns that shape the experience of illness and the social reaction to the sufferer in a given society

One of my core rationales for utilising an interpretive approach stems from Good's (1994) observation that it is not just the anthropologist who acts as an interpreter: rather, my participants also constantly interpreted and managed what CFS/ME meant within the networks of their lives and wider social structures (Martin 1993:270). In a sense, my interviews with participants revealed the way in which, together, we were seeking to make sense of their experience of illness, their self-identities and the construction of their relationships with their families, friends and medical practitioners. In the case of CFS/ME there is reason *par excellence* to adopt an interpretive approach, because it is a site where the "truth" has been contested from all angles; from its name to treatment and its aetiology (see Chapters Five and Six), to 'know' CFS/ME has, so far, remained elusive. Prioritising the knowledge, truth and experience-claims of my participants as 'real' meant that I did not have to take a standpoint on the medical claims that mark the debates of CFS/ME, which allowed my participants to fully explain their view. Furthermore, as I felt early on in the research process, it was not appropriate for me to make a stand on the aetiology of CFS/ME regardless, as I do not have the highly specialised medical training which would be required to make a sufficient judgement.

I have combined a version of interpretivist anthropology with a grounded theory approach, where "theory evolves during actual research, and it does this through continuous inductive interplay between analysis and data collection" (Strauss and Corbin 1994:273). Such a development of grounded theory works well within the context of my use of an interpretivist approach, for it too is focused on the individual's own construction of reality (McGee and Warms 2012:438). A grounded theory approach, combined with the rationale of interpretive anthropology, is therefore participant-driven: illustrating the way in which my participants attempted to negotiate and recreate their self-identities, their relationships with others, and their relationship with doctors and society at large.

Theoretical Backgrounds

Throughout this thesis, I primarily draw on theories of the self and self-identity in late modernity to situate my participants. Secondly, I develop and utilise a theory of liminality that helps to analyse the differing perspectives of my participants within their different stages of illness. Finally, I draw on narrative theories to both understand the way in which academics have explored the lived experiences of illness and as a guiding methodological tool.

Theories of the Self in Late Modernity

Early on in my research project, I noted that despite their CFS/ME, my participants appeared assertive and confident in their self-identity claims. Additionally, I was surprised by how confident my participants were in their conceptions of aetiology. How could a lay person without a medical background be so sure in explaining a medical condition that eluded medical researchers? In order to situate my participants' conceptions of their self-identities, their social and cultural worlds and their understandings of aetiology, I draw on theoretical discussions of the individual in late modernity.

According to Kumar, the overarching aim of the individual within modernity was the "attainment of freedom under the guidance of reason" (2002:81) coupled with the rejection of moral and existential questions (Bauman 1993, Giddens 1991). As authors such as Giddens (1991) have argued, we cannot say that modernity has come to a complete end and that advanced liberal democracies have now moved into a post-modern era: rather, high modernity "is a phase of (over)developed modernity that to a certain extent undermines itself" (Mulinari and Sandell 2009: 495). Within modernity, individuals were ideally able to attain a sense of security in "reason"; however, the authorities of reason within high modernity now make competing claims, they "undermine their own premises", hindering the opportunity for someone to be guided at all (Beck 1992:10). This is reinforced by the proliferation of doubt within the contemporary world. Scientific thought has been driven by the principle of rationality and "truth" since the

Enlightenment (Good 1994), yet lay individuals have become to increasingly sceptical of authorities in high modernity (Giddens 1991, Lupton 1997). This is firstly because, as Kilshaw (2009) and Beck (1992) argue, authorities such as governments, nation-states and institutions such as biomedicine are often regarded as the cause of some of the major risks - such as nuclear war (Giddens 1991) - which threaten both the individual and society. Secondly, the public has become increasingly aware that these authorities cannot keep up with and explain the new multitude of risks which individuals must, in some situations, be forced to deal with on their own (Brown, Kroll-Smith and Gunter 2000).

These fears are a result of increased conceptions of risk, as Bauman (1993) Beck (1992) Beck and Beck-Gernsheim (2001) and Giddens (1991) have shown. While Giddens (1991) acknowledges that there are perhaps less immediate threats to life within advanced liberal democracies, risk-thinking has expanded, especially with regard to the future. The coupling of risk and doubt with knowledge and experts has destabilised the way in which we form our self-identities in the contemporary world, for guidance is now suspect and "most aspects of social activity and material relations [...] are now open to "chronic revision" (Giddens 1991:20). The opening of opportunities and increased global flows result in a multitude of overwhelming possibilities for one's chosen lifestyle; individuals must therefore continually 'work' on their self-identities in order to feel ontologically secure in the face of the choices they make and remake.[7] Alongside these processes that encourage the reflexivity of self-identity, individuals within late modernity are encouraged, as Beck and Beck-Gernsheim (2001) argue, to think of themselves as individualised, operating alone in the navigation of social and cultural institutions as a result of the breakdown of structural groundings for the self.

Some scholars, such as Cohen (1994), have critiqued theories of the late modern self for their sweeping generalisations, lack of ethnographic contextualisation, and for focusing on the forces of individualisation to the

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[7] While early scholars such as Mead (1967) had already argued that the 'self' is never static and always subject to debate, I would suggest (along with Giddens 1991) that the social and cultural circumstances of late modernity means that the markers on which we may have previously been able to form our self-identities have been altered significantly as a result of globalisation and the proliferation of doubt and risk.

point of denying the weight of social and cultural factors. This is a valid criticism. As my thesis shows, my participants' self-formations were deeply shaped by social and familial networks and relationships. In engaging with this literature, then, I see the autonomised, responsibilised individual (Rose 1996) in late modernity, not as a totalising force, but as a powerful cultural *ideal* within Western advanced liberal democracies, such as New Zealand, that is enacted or resisted in a range of ways.

These ideals are paradoxical, for people can be both "free to choose" and forced into making and justifying their choices. These changes are bolstered by what Cohen (1994:171) calls the "rhetoric of individualism", which emphasises personal choice, "individual responsibility, individual initiative, individual freedoms, and even the denial of 'society' in favour of its individual components" (See also Beck 1992, Beck and Beck-Gernsheim 2001, Giddens 1991). I also draw on Rose (1996, 2007) and Rabinow (1992) here to show that these expectations are placed on the sick person as well. Under their conceptions, the unwell are "active", both autonomised and responsibilised in advanced liberal democracies. The sick are expected to drive forward by any means possible, relying primarily on themselves to do so, becoming 'lay-experts' with regard to their condition. As this thesis will show, participants with CFS/ME sought to enact the responsibilised self in a range of ways.

Individuals within late modernity are able to justify their claims about their self-identities through the adoption of certain lifestyles, which provides a framework of "habits and orientations, and hence has a certain unity - important to a continuing sense of ontological security - that connects options in a more or less ordered pattern" (Giddens 1991:82). Developing a sustainable, healthy lifestyle by making a range of choices and decisions for the self was a core goal for my participants, as I explore throughout the thesis.

While Giddens (1991) recognises that the options we have regarding lifestyle and self-identity are limited to some degree by our social and economic positions, the individuals he usually represents as reflexively forming such self-identities are middle-class, relatively secure, and healthy. Such a conception of lifestyle is both too grand and too simple, for cultural

ideals about the contemporary individual play out differently in different places and situations. As my thesis shows, the demands of individualisation and the requirement to hold a reflexive biography can be a much more difficult process when one is unwell. All of my participants were highly educated, middle-class New Zealanders. They had, in many respects, once been the idealised individuals to which both Giddens (1991) and Beck and Beck-Gernsheim (2001) refer. This arguably makes the new illness-based restrictions of developing their self-identities all the more difficult to deal with (see Chapter Two). However, as Snow and Anderson (1987) argue, self-identity formation is vitally important for even the most marginalised groups and members of society. My thesis shows the way in which my participants developed creative, cultural explanations to justify the development of their CFS/ME for both themselves (see Chapter Six) and others (see Chapter Five), the changes in their self-identities and their relationships with family and friends (Chapter Three), as well as their justification of their knowledge-claims to doctors (see Chapter Four).

The Degrees and Perspectives of Liminality

As explained above, it can be easy to misplace and miscategorise people with CFS/ME. As problems of miscategorisation arose again and again within my participants' narratives, I realised that these experiences could be analysed through anthropological ideas of liminality. Liminality was first proposed by Arnold van Gennep (1960), who recognised that rites of passage involved three components: the separation of the individual or group from society, an in-between liminal phase, and the reintegration of the individual back into the classifications of society. Victor Turner (1969) later shifted anthropological attention to the liminal phase of the ritual process. He recognised that liminal beings are:

> Neither one thing nor another, or maybe both; or neither here nor there; or may even be nowhere (in terms of recognised cultural topography), and are at the very least "betwixt and between" all the recognised fixed points in space-time of structural classification (Turner 1987:7).

However, this work by Turner (1969, 1987) primarily focussed on both rituals and tribal societies. Turner later suggested (1992) that liminality and liminal beings had primarily given way to the liminoid, a permanently liminal role or space in the industrialised world, which he primarily conceptualised as voluntary and related to play and theatre (see also St John 2001). Yet as Szakolczai (2009) argues, we cannot say that the liminoid has replaced liminal beings in their entirety. Medical anthropologists have noted the liminal character of both contested illnesses and those who suffer from them (Dumit 2006, Honkasalo 2001, Jackson 1992, 2005, Kleinman et al. 1992). However, these analyses tend to focus on what I show in Chapter Two of this thesis, a stage when *everyone* had trouble classifying the unwell.

Instead, I utilise liminality to argue that, in the 'Disrupted Self', my participants and those with whom they engaged, such as family, friends and doctors all saw CFS/ME and my participants as chaotically liminal. No-one knew how to understand or classify the new illness experience. In Chapter Three I argue that my participants stabilised their self-identities and moved into a long-term liminal state. While they had normalised and come to "know" their experience, this is not a form of reintegration into society for, as my participants' recognised, they were still sick with a condition on the cusp of legitimacy. Due to their position on the margins, my participants' doctors, family and friends were still unsure of where they fitted within the usual classifications of friend, family member, or patient. I argue that this illustrates the perspectival nature of liminality, where others can continue to view an individual as disruptively liminal, such an individual feels they have had moved into a stable, normalized stage of long-term liminality. Liminality as a theoretical framework helps to nuance ideas of the late modern self, by showing how individuals and groups who have constrained agency, independence and choice exist within, on the edges of, and outside of wider social structures. It also shows how from these positions, they respond to cultural demands to develop a coherent narrative of the responsible, autonomous, and legitimate self.

Narrative Theories

I also draw on theories of illness narratives and identity-work to describe how my participants made sense of these liminal experiences and shifts as well as the wider cultural ideas that underpin them. During my interviews, I sought to explore with my participants their development of CFS/ME, how they managed this experience, and the effect illness had on their sense of self-identity. Thus, the data these interviews produced must be considered narratives, for they are primarily "reinterpretations of what happened in the past" (Lambert and McKevitt 2002:211) rather than the actual unfolding of events which a researcher has witnessed. I follow Good (1994) in understanding narratives as "a form in which experience is represented and recounted, in which events are presented as having a meaningful and coherent order" (139). Throughout this thesis, I illustrate the way in which my participants' narratives worked to make sense of their reality in two ways: both in order to (re)construct their own biographies and self-identities while also navigating their relationships with family, friends, doctors and socially and culturally salient ideals of the self (Charmaz 1999).

Narrative theories of illness have been predominant within medical sociology and anthropology on the basis that they "reflect [the] human feelings and lived experience" of illness (Manning and Callum-Swan 1994:465. See DelVecchio Good et al. 1992, DelVecchio Good 2010, Garro 1992, Good 1994, Jackson 1992, 2005, Kleinman 1988, 1992 for the use of narratives by medical anthropologists). Medical sociologists such as Bury (1982) Charmaz (1983, 1991) and Williams (1984) found that the development of a chronic illness was often marked by serious "biographical disruption" (Bury 1982) which resulted in a "loss of self" (Charmaz 1983). However, as anthropologists such as Garro argued, "to see chronic illness solely in terms of loss is too simple; almost always there is a reaction to preserve one's identity" (1992:104). My own work reveals a similar pattern: the experience of falling ill completely disrupted my participants' sense of self-identity and they had to work to reformulate and realign their sense of self. However, my work is unique in the illness narrative literature in the application of the anthropological lens of liminality to understand not only why others view

people with CFS/ME as suspect (Dumit 2006, Jackson 2005) but also in the way in which my participants understood themselves.

As Mead argued (1967), the formation of the self is a relational process (See also Snow and Anderson 1987). Consequently, my participants' narratives also encompassed their relationships with others, especially the effect this had on their sense of self-identity. My participants utilised culturally important symbols and justifications in order to explain and legitimise their experience of illness to both myself and to those with whom they interacted. I follow Watson and Watson (2012) and Williams (1984), who both suggest that narratives are used in order to create and recreate the relationship between oneself, one's social networks and society. These narratives draw upon the logic of wider social narratives (Denzin 1997) such as medicine and notions of the responsible, contemporary self to explain and legitimise their new constructions of themselves.

Narratives are not only a site whereby individuals seek to make themselves understood by others; they are also utilised as a means to understand oneself (Charmaz 1999). Narratives are, therefore, a form of *identity work:* "the process whereby people strive to shape a relatively coherent and distinctive notion of personal self-identity" (Watson and Watson 2012:687). Like Smith (1993), I view this narrative work as part and parcel of the reflexive work put into the biographies of the modern self (see also Giddens 1991). I illustrate the way in which narratives are used to make sense of the past and the experience of illness in order to develop a coherent picture of the self which is culturally and socially legitimate within the demands, responsibilities and expectations placed upon individuals in the contemporary world.

Chapter Outlines

My desire to represent my participants' "story as it was told" (Denzen 1997:249) is reflected in the structure of this thesis. My participants' all began

their interviews with the development of CFS and the breakdown of their understanding of the world and their self-identities. In Chapter Two, I also show the way in which family and friends had trouble interpreting the sudden altering of my participants' abilities, and their doctors did not know where to place or how to categorise CFS/ME and its sufferers within their biomedical world view. Everyone affected by CFS/ME at this stage saw my participants as liminal beings. Most often in our interviews, my participants followed these discussions by describing how they sought to realign and rework their understandings of themselves and their relationships with others which demonstrated a strong desire to be responsible and knowledgeable, to enact choice, to be authentic, which privileged their own experiences and beliefs over certain expert opinions.

In Chapter Three, which I call the 'Realigned Self', my participants described crafting and normalising a new positive self-identity. However, I argue that my participants had entered a long-term liminal phase here, for they still recognised they were on the cusp of social and cultural legitimacy, and still sought to get better. Chapter Three and Four illustrate the perspectival nature of liminality, where the networks of people surrounding my participants still characterised them as sharply liminal even when they did not personally identify as such. Relationships with family and friends had to be worked on (Chapter Three) and the patient-doctor relationship (Chapter Four) had to be re-established in order for my participants to secure and assert their sense of self. Chapter Five illustrates the way in which my participants utilised naming and aetiology debates to present new conceptions of themselves to others as assertive and authoritative, and Chapter Six shows how my participants' solidified their self-identities by focusing on their own experiences and by drawing on notions of the immune system, toxicity and diet. Overall, in this thesis I show the transformations that occur when people live with illness over time, and the identity work that they must enact individually and collectively as they respond to wider cultural ideas and their own personal needs to live well and make sense of their experiences.

CHAPTER TWO: THE DISRUPTED SELF

Introduction

Developing CFS/ME profoundly affected and disrupted the previous security of my participants' self-identities. It affected their expectations of their body, their ability to fulfil cultural, social, work-related and familial roles and the other markers which they previously used to construct their sense of self-identity. This experience is, I argue, a form of personal liminality: my participants were "betwixt and between" (Turner 1969:69) personal and social categories of the individual. Furthermore, CFS/ME is liminal in itself: it provides no plans for the future and does not easily fit within the typical classifications of illness within biomedicine. Such an experience leads to what I call the 'Disrupted Self'. This chapter also illustrates the way in which family, friends and doctors alike cast my participants as liminal, because they themselves did not understand or know where to place the sufferer, which reinforced the disruption of my participants' sense of self.

In this chapter, I draw on notions of the contemporary self within late modernity (Beck 1992, Beck and Beck-Gernsheim 2001, Giddens 1991, Rose 1996). I use these theories to show how self-identity is constructed in the contemporary world and the way in which my participants found that they were unable to rely on these usual cultural markers of self-identity. Furthermore, these theories illustrate the way in which my participants' friends, families and doctors reacted to them, and found them difficult to place within cultural conceptions of the sick person. I argue that the situation in which my participants found themselves can be considered a form of liminality in the contemporary world.

CFS/ME and the Disruption of the Self

As discussed in the introduction to this thesis, self-identity formation is subject to a new range of difficulties and consequences as a result of the pressures of high modernity. The multitude of different lifestyle choices available in the contemporary world means that individuals must work to justify which choices they have made for one's life and self-identity (Giddens 1991). Techniques of government, social institutions and contemporary cultural expectations have both "autonomised" and "responsibilised" the individual; one is expected to be simultaneously "free to choose" and prudent, with an eye to risk factors in respect of the future (Rose 1996). Finally, the expression of one's self-identity is expected to be *authentic*, judged as such by both others (Giddens 1991, Rose 1996, 2007, Snow and Anderson 1987) and ourselves (Desjarlais 1994, Rose 1996, 2007, Snow and Anderson 1987). One could argue that the task of reflexively developing a sense of one's self-identity is difficult at the best of times, for healthy and relatively successful middle-class individuals. However, the healthy are often able to offset threats to their self-identity through habit and routine, which form a "practical consciousness" (Giddens 1991:26) that shields against the ever-changing realities of the external world. Their "life-world" can be "a spontaneous experienced reality" (Kaufman 1988:340), where habit and routine work to "bracket out" troubling, existential questions, one of which is illness (Giddens 1991. See also DelVecchio Good et al. 1992).

People with CFS/ME must also manage their self-identities within the contemporary structures that shape identity formation. When my participants developed CFS/ME, however, the ontological security of their self-identities and the extent to which the external world could be trusted was radically upset (Garro 1992:103-4). Illnesses, especially chronic conditions, force individuals to reassess their previous understandings of both body and self-identity; they must engage anew with the now difficult-to-comprehend world (Kaufman 1988. See also Bury 1982). I argue that the effects of CFS/ME itself, the newly-disabled body and the destruction of the sufferer's security in their self-identity were a form of personal liminality for my participants. As Turner

explained, "liminal entities are neither here nor there, they are betwixt and between the positions assigned and arranged by law, custom and ceremon[y]" (1965:95). While Turner's original conception referred to individuals as liminal with respect to social institutions – "law, custom and ceremony" – I argue the destruction of my participants' self-identities meant they felt liminal in and of themselves.[8] This feeling of liminality is a result of the way in which CFS/ME upsets, displaces and separates an individual from personal and social markers of the self, such as one's self-identity, future plans, the 'normal' body, and familial and work-related role-based identities (Turner 1969:95). This separation was made clear in my interview with Noah, as he reflected on what his life was like before falling ill.

> Before I got sick I would think nothing of working all week, partying hard on Friday night, helping a mate out with his gigs on Saturday night, not getting back till 4:30 in the morning, having a nice restful day on the Sunday and showing up to work nice and refreshed on Monday. […] [But] part of the situation with [the] early stages [of CFS/ME] is that you're, you're like a clean slate. Your memory gets wiped. You simply don't remember what you were like before you got sick. You can't imagine ever not being sick. You think that's how you're going to be forever.

Turner has suggested that when one enters a liminal state, the prior work individuals put into ontologically securing their self-identity "gives way to possibility" (1992:50). While this 'possibility' can be a positive experience when one's liminal status is voluntarily accepted (St John 2001), when one is *forced* into liminality, as my participants were, the experience can have serious consequences for the security of one's own self-identity. Noah's experience illustrates this; the initial experience of falling ill seriously disrupted his sense of his biographic narrative, altering the way he was able to view the past, present and future.

The nature of CFS/ME itself directly contributed to both the disruption of my participants' ability to plan for the future and to the experience of personal liminality. Giddens has argued that the reflexive biography in late modernity is marked by "the question, 'How shall I live?'" (1991:14). While

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[8]La Fontaine (1985) points out that there are often ritualised moments such as getting married where individuals are liminal in themselves, however, unlike CFS/ME, these moments are planned for and expected.

this is often a superficial question within the day-to-day lives of the ontologically secure, it takes on a new urgency when the markers of one's self-identity dissolve. In advanced liberal democracies, it is near impossible to live a life that is not planned in some way, and part of this planning means one must consider risks with respect to the future (Giddens 1991:125-129). Yet CFS/ME cannot be predicted, nor is it predictable in itself: it too contributes to the chaos of personal liminality. Firstly, CFS/ME is elusive: it cannot be "found" in the body through common diagnostic tests (Reeves et al. 2003). Instead, it is a "negative" diagnosis, where all other possible conditions with similar symptomologies must first be excluded (Banks and Prior 2001:12). The ambiguity and long testing process involved with diagnoses based on exclusion is often destabilising and confusing for the sufferer (Barker 2002). Secondly, perhaps most importantly, CFS/ME is disruptively liminal because it both puts on hold one's plans for the future and provides no starting point from which new plans can be made. While the average length of CFS/ME is five years (Nisenbaum et al. 2000), many people experience a much longer, chronic form of CFS/ME. Only one of my participants, Alexandra, had been ill for less than two years, all of my other participants had been ill for between four to twenty-five years, with an average of approximately ten years. CFS/ME is therefore between health and degeneration. Unlike acute conditions, CFS/ME does not provide a reasonable expectation that one will get better soon, nor are there any established "cures" to which sufferers can turn. Furthermore, CFS/ME is not a definitively degenerative condition nor is the mortality rate for people with CFS/ME significantly different from standardised mortality rates (Smith, Noonan and Buchwald 2006); therefore, one cannot plan or attempt to prevent worsening health or death. Both poles provide a point of reference for which to plan from: CFS/ME does not.

This ambiguity is especially difficult given the hopes invested in biomedicine in the contemporary Western world (DelVecchio Good 2010). As one of my participants, Alexandra explained,

> I think now more than ever, we're used to everything having [...] a clear aetiology, a clear treatment, a clear this, that and the other. And this thing is so amorphous, this little relic from another century [pauses, then laughs] you're sort of thinking, 'how can

> I have a mystery illness? Nothing is mysterious to science! There *must* be a logical explanation!

In these early stages, my participants came face to face with the reality of "diagnostic uncertainty" that is characteristic of the majority of contested illnesses (Brown, Kroll-Smith and Gunter 2000:10). This realisation dissolved my participants' faith in biomedicine and their doctors' abilities. Without a 'logical explanation' for their experience, my participants often felt frustrated and vulnerable (Barker 2002, Shriver and Waskul 2006). Here, personal liminality rises again: CFS/ME cannot be satisfactorily classified under the rubric of biomedicine; in fact, it cannot be located in a specific site of the body at all (See Chapter Five). Thus, the social institution that my participants first expected to explain and legitimise their suffering could not do so.

Given the importance of 'knowing' oneself in late modernity (Giddens 1991, Rose 1996), the absence of explanations was deeply troubling for my participants. For Nicolette, the first few years of her CFS/ME were especially difficult because she did not know what CFS/ME was and therefore could not adequately express her suffering to others:

> I didn't understand it, I didn't know what was going on, even when they told me what it was, I didn't know what it was. […] You feel silly, saying, "I've got this thing – it does this to me, but I don't know what causes it, and I don't know why I'm like this, I don't know where it came from." You feel really silly. And so you tend to not say anything. And you're also aware that nobody else knows anything about it. And you kind of – so you feel very vulnerable, and you're really tired anyway, so you haven't got the energy to do it, to really talk about it properly. So you just feel really bad, so you just shut up!

Nicolette's comments clearly show the frustration caused by an inability to adequately explain what CFS/ME means – both for one's own understanding and in order to explain the condition to others. Szakolczai has argued that when one is 'betwixt and between' it is difficult to know which way to turn, as liminal experiences are often distressing and "the structures on which 'objective' rationality were based" – in this case, the expectation biomedicine provides solid answers – have disintegrated (2009:154).

My participants' self-identities were also destabilised through the body and the new disabilities their CFS/ME caused. As phenomenologists argue, our experience of the world is mediated first and foremost by our physical body and our understanding of its abilities (Good 1994). However, the psychological disciplines have greatly shaped conceptions of the self in advanced Western cultures; we tend to primarily imagine ourselves as "psychological beings", rather than physical ones (Rose 1996). Yet, as Kirmayer states, "sickness places the body in the foreground" (1992:323). The reality of disability was made starkly apparent to me during my fieldwork when I offered to help with a collection the support group was holding within the region for 'M.E. Day'. I had put almost no thought into this offer, aside from briefly wondering whether it would be boring. However, my offer to volunteer was interpreted much differently by the support group's co-ordinator, who thanked me profusely and said, "It's wonderful to have an able-bodied person on board, thank you!" This comment forced me to realise that what I had considered a minor, possibly boring inconvenience was a *privilege* because, for a few hours, I was simply able to stand. My participants also realised that their bodies had been 'privileged' before they fell ill. This realisation contributed to the 'Disrupted Self': bodies, which had previously operated as they were "supposed to", began to fail. As Alexandra explained,

> You just become so aware of your – I guess some people are aware of their body all of the time. But I never was, you know?
>
> **LB:** *It was just doing what you needed it to do, or?*
>
> Well, I liked it, and I was like, "Woohoo, this is cool!" And you know, I never went on a diet or anything because I figured [...] the whole point of being attractive is to get a boyfriend, or whatever, and I never had any trouble with that, so I just thought who cares if I'm not perfect. But then it becomes like a prison. It's like they've put you in a prison that is the exact same size as your body. And it's just – you're just conscious, and always aware. Your heart would do something bizarre, and you're like, what does this mean? Does this mean I'm going backwards? And why can't I breathe?! Or, what on earth is that pain in my ear? So you get kind of creepily self-obsessed for a while. [...] It's like, the world is this thing, but you're not, so you've got to kind of renegotiate [pauses] what the world is to you, because you can't interact with it the way you could.

Alexandra shows the way in which her experience of her world and self-identity were intertwined with her expectations about how her body should function. It also illustrates how intimately linked our expectations of our bodies, our sense of control and our agency really are. As Charmaz states, "the threat of permanent dependence [due to chronic illness] strips away earlier self-definitions based upon independence" (1991:102). This is especially troubling for sick individuals in Western liberal democracies, where individual agency, autonomy and independence are highly valued (Rose 1996). It upsets our previously taken-for-granted expectation that we can control our future directions, make pre-planned, considered choices, and live an independent, autonomised, self-directed life.

My participants' expectations of themselves faced further disruption as they became aware of the new restrictions and limitations on their abilities, skills and familial and work-related roles. Here, the chaos of personal liminality became apparent, for they no longer fitted within the previous role-based identities that were used to support and reaffirm their self-identities (Snow and Anderson 1987). As I talked with Alexandra, it was obvious how shocked she had been when confronted with the drastic change in her ability to work as a lecturer once she fell ill. She used to "get excited", and "walk around a lot during lectures. And instead, I'd be sitting in a chair, clutching the lectern and drinking all this juice to try and stay alive [laughs]. I could barely make it through, and they were short lectures, too – just an hour long". The trauma caused by the disruption of my participants' expectations escalated as it affected more and more aspects of their lives. For Joan, the loss of her job, the lack of support she received from her husband, and caring for her children's needs whilst trying to understand her new illness seriously damaged her emotional wellbeing and sense of self-identity. When Joan first fell ill:

> I was a lot younger then as well, [and] I felt really embarrassed, because in the end, I was asked to resign from work, because I was having so many days off. I was at home, surrounded by farmers – we lived up in the hills amongst farms – and they all kind of looked sideways, like, "how is she not working, there's nothing wrong with her?" I had been incredibly fit and healthy and doing three-hundred things at once. My husband worked in [the city over] and was never home. [...] At weekends, because he was

> working he had to go and relax, so he would be out doing things. [Before I got sick] I was doing all that, and the job, driving the kids around, doing it all fine, going to aerobic classes, so... the difference was amazing. And I got incredibly depressed, and I thought about suicide every night of my life, I think, because I couldn't sleep for months – six months, probably? [...] I think that the worst thing [was] I totally lost my self-confidence. It was so bad at the start. [...] I remember going to sign a check, and thinking, "What's my signature?" I mean, I thought, "My God! I know my name! But I actually can't remember how to sign".

Joan's frustration at this point during our interview was candid. Her failure to meet her previous expectations of herself compounded to the point that her self-identity was totally disrupted. This is tellingly illustrated in her inability to assert herself through one of the basic symbols of modern individual identity: one's name and signature. Joan went on to state that the experience of a disrupted self-identity,

> lasted a long time, actually, I always felt completely different because I couldn't do a lot of things. Even going to watch my kids play soccer, I knew I couldn't just sit at the grass at the side, or stand for hours, as well as drive them miles to get there, so I just felt [pauses] a bit of an outcast, really, amongst society almost.

As Giddens (1991) points out, "fateful moments" are the biggest threats to the security of one's self-identity under late modernity. In these moments, "the individual is likely to recognise that she is faced with an altered set of risks and possibilities. In such circumstances, she is called on to question routinised habits of relevant kinds, even sometimes those mostly closely integrated with self-identity" (1991:131). However, with CFS/ME the future is unknowable, which meant my participants could not readily reassess these "altered set of risks and possibilities". As Joan's experience poignantly illustrates, my participants found it difficult to meet the expected roles and position within the family or work, as well as the demand under late modernity to hold onto a stabilised sense of self-identity. Participants such as Joan felt they were 'outcast from society', in much the same way as the liminal beings Turner discusses (1969:128). As Szakolczai recognised, "situations that are liminal in more ways than one" can drastically affect one's understanding of the self (2009:159). For my participants, the amorphous nature of CFS/ME itself and the initial disruption caused by falling ill – to one's expectations

about one's body, to one's work and family roles, and finally, to one's self-identity – can be seen as a form of personal liminality occurring under the conditions of late modernity.

Family, Friends and the Disrupted Self

During the initial stages of illness, the responses, actions and opinions of family and friends were the most disruptive for these relationships and my participants' self-identities. As Dickson, Knussen and Flowers (2007) found, rejection within close relationships were the most painful for people with CFS/ME, as such bonds tend to be the most important and highly regarded in people's lives (Shriver and Waskul 2006). I argue that this disrupted view is a result of the way in which others, such as family and friends, also saw my participants as 'betwixt and between'. My participants' family and friends found it difficult to place CFS/ME, the rapid change in my participants' health and their sudden inability to fulfil both familial expectations, and social and cultural ideals of the individual. While this mirrors what my participants were struggling with internally, my participants were still hurt by the change in their family and friends' interpretations of them. As Nicolette acknowledged, this is often exacerbated by the sufferer's own attempts to understand CFS/ME and the difficulty of doing one's own research while in the Disrupted Self state. She explained that:

> [In] my family, you don't say anything unless you know what you're talking about. [...] You've got to have everything nutted out – to the last nth degree, like you're in court. You don't bring anything up, unless you know what you're talking about, so it was really hard, I was really exhausted, I was... I was brainfogged, I was, you know, I was stressed out of my tree from my marriage and breaking up, and [caring for my daughter] Eva, and... I was not in a position to do that?! So that didn't help either. And then of course, there were one hundred and one questions if you did actually say anything. And there was also, at that stage perhaps, not very much research done, and very inconclusive research, so... You couldn't really say anything, you know, that was going to really impress [people, so they would] take you seriously.

Nicolette later explained that she believed she should not have had to continually defend and justify being unwell to her family. This reveals the tensions between our claims about our own abilities and roles versus the way in which close family members may interpret them (Snow and Anderson 1987). It also illustrates the way in which family members had trouble verifying the claims made about CFS/ME. In these situations, the "truth" of my participants' claims was questioned and doubted, which further disrupted my participants' understandings of themselves. For Dickson, Knussen and Flowers' (2007) participants, continually explaining what CFS/ME was to partners and family was interpreted as "a lack of trust" which resulted in "a loss of confidence in defending their illness to others" (2007:859). For my participants, the requirement to defend oneself was understood as both a continual defence over what their illness was and a defence of the self as a whole. Zola (1972) states that this is because "illness by itself does not provide absolution from individual responsibility, accountability and moral judgement" (cited in Barker 1991:21). Such questioning threatens the security of one's self-identity, especially individual responsibility and accountability are hallmarks of an (outwardly, at least) well-functioning individual within Western individualisation (Beck and Beck-Gernsheim 2001). When one of Anna's partner's friends doubted how sick she was;

> I felt angry. And I felt like, I'd like to f-ing well tell him what it's like, and I felt a bit violated I suppose, a little bit um, like… [*sarcastically*] "Hell, don't I even know what's going on with me? It's nice to know I've got experts about me! I just really need that, like, you know, God, I haven't got a brain anymore…" I felt gutted. I did.

Anna explained that she really cared about her partner's friends, and this lack of trust in her illness-claims caused her to doubt her own ability to assert herself. Giddens argues that the "plurality of choice" in late modernity also extends to the formation of relationships, which are now primarily dependent on commitment, intimacy and trust (1991:87). As Anna and Nicolette illustrate, when one of these core elements – trust – is under threat, it jeopardises both the relationship itself and the "linked processes" that create "shared histories" which help to form and authorise one's self-identity (97). In these instances, the true fragility of trust was revealed to my participants. However, I would also suggest that such issues with family and friends may

not have arisen if CFS/ME itself was knowable. The actions of family and friends were often not intended to be malicious: my participants acknowledged this. Rather, they were the result of misclassifications, which illustrates both the liminal nature of CFS/ME and the way in which others can disrupt an individual's sense of self through casting someone as liminal.

The unpredictable variability of symptom severity contributed to the difficulty surrounding the claims to 'truth' that my participants made to family and friends. CFS/ME is an 'invisible' condition: the body itself bares no testimony to the physical disabilities CFS/ME causes (Cooper 1997). As Kleinman et al. argue, one social side effect of invisible conditions is that the experience of the sufferer is difficult to share, and while being unwell "is absolute private certainty to the sufferer, [chronic] pain" – or CFS/ME – "may become absolute public doubt to the observer". This can also lead to "a pervasive distrust that undermines family as well as clinical relationships" (1992:5). This is also true for other contested illnesses, such as fibromyalgia (Barker 2002) and Gulf War Syndrome (Kilshaw 2009, Shriver and Wuskul 2004). Furthermore, the severity of an individual's CFS/ME symptoms can fluctuate on a regular basis. Understandably, such variability in abilities combined with the invisibility of CFS/ME is often frustrating and confusing for sufferers and their family and friends alike. In the worst situations, people with CFS/ME face outright rejection or questioning as a result of these frustrations. For example, Rosalind told me that one of her friends with CFS/ME sometimes needed a mobility scooter.

> I think people have real trouble understanding that side of it, for people who walking is too hard, because if your leg isn't broken, if you're not paralysed… why aren't you walking? And it's really hard for people to grasp these fluctuations. They'll go, "I saw you walking! Why aren't you walking now?" You know, that kind of thing. Or, "you must be faking it! You just want that car park", or something. So, you're in that car park, but maybe you don't need your scooter that day, but you need to be close [pauses] and so you look like there's nothing wrong with you, you know?

The uncertain nature of disability within the CFS/ME experience allows others to question or delegitimise the sufferer. The lack of visibility in conditions such as CFS/ME also contributes to the difficulty for both sufferers and their family and friends to accept, understand and renegotiate the

sufferer's ability to fulfil their social and familial roles. As Emily explained, her old flatmates and a previous boyfriend's family simply could not understand that CFS/ME could be long lasting, for they assumed she was now 'well' due to the absence of physical cues. Nicolette told me that Eva faced a similar situation with her school friends. Such rejections were highly disruptive both emotionally and for her social world.

> It was so isolating for her, because friends were horrible, and good friends! That's what I couldn't understand! Good friends! [They] got all shitty because she wasn't at school, and I felt like obviously it was hard on them, but they got like, "Oh, you're wagging" and [trails off]. [...] Just really, really nasty. Good for a while, I have to say, but they got fed up, with you being away so much. *[Eva murmurs agreement].* But then instead of just accepting [that] and making new friends, they got nasty to you, you know, and even - oh, it's just bizarre. Just, just awful.

Both Emily and Eva's experience shows how others can view an individual as liminal. When an individual falls outside or between accepted cultural categories or social behaviour, such as beliefs around school attendance, they can face distrust or rejection. This rejection is often a result of our attempt to protect the "logical and reassuring" construction of social and cultural expectations (Leach 1964:35). If we reject or distrust such individuals, we can "affirm and strengthen" our beliefs about the way in which individuals 'should' behave (Douglas 2002:49). While Mary Douglas states that we can "try to create a pattern of reality in which [the anomaly] has a place" (2002:48)[9], people with CFS/ME are liminal in a multitude of perspectives: for example, within the view of doctors and biomedicine (to be discussed shortly). Reconstructing reality is not easy when such a reconstruction is not supported by other cultural institutions.

My participants' experiences of social, role-based demands were far more intense when coming from family members. Melissa told me that there had been "constant, constant fighting" in her family ever since her mother passed away. She felt that she was being expected to "fill in a bit of what my Mum would have provided" to her brother and sister-in-law, such as helping to care for or look after their children on occasion. However, for Melissa, it

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[9] Shamans are an example of liminal beings that are culturally sanctioned (Ohnuki-Tierney 1980).

was often far too exhausting to meet these expectations. This illustrates the way in which women in contemporary New Zealand life, as in many other Western settings, face a range of competing pressures and tensions – to work, to care for the self, to be independent, but also to contribute to the family and bear the majority of work in raising children (Beck and Beck-Gernsheim 2001). Melissa's physical inability to take part was devastating both because her family still expected these roles of her and because, as she explained to me later, she wanted to but could not fulfil these roles. In the most extreme cases, this inability could lead to outright rejection of the sufferer. As Noah explained,

> People just won't tolerate being let down all the time. Because there are days where you just can't do anything, and if you've got something organised, you can't do it, you can't get there. And people don't want to put you in that position, so they don't make these sorts of appointments or anything like that. And people, like I find out after the event that my brothers and sisters have had, you know, a party somewhere. I was never invited. That happens a lot.

Noah explained that part of the reason for these sorts of situations is that often people compared the previous abilities of sufferers to their current abilities, without taking into account the chronicity and severity of the illness:

> Often people don't treat you like a serious contributing member of society. Like you're bludging off the benefit. And you could do better. Especially people that had known you before, when you were healthy. They know that what you're doing now is so far below your capabilities that there's got to be something wrong. And it's not the M.E. they think. A lot of people see M.E. as a character flaw, rather than a medical issue.

Noah illustrates the difficulties of a life influenced by the cultural ideal of individualism, where one is meant to take responsibility for one's condition, to 'pull oneself up from the bootstraps', and not rely or depend on others excessively for support (Beck and Beck-Gernsheim 2001, Charmaz 1991, Cohen 1994, Rose 1996, 2007). Such expectations are not merely abstract values; Hyde (2005) has shown that this has had a direct consequence on health practices in New Zealand, where one's body has "become a project to be controlled, managed, and modified", for which one is expected to take responsibility (235). Thus, the above shows the clash between the social expectation that one should freely take responsibility for one's health (Rose

1996, 2007) and my participants' actual ability to be able to do so. Finally, it illustrates that the initial experience of CFS/ME is not just liminal for the sufferer – others also do not know where to 'place' those with CFS/ME, as CFS/ME cannot be seen by others, nor could my participants fulfil social and familial expectations. In the worst of cases, then, if one cannot adequately control the body, one's character as Noah astutely observed, becomes suspect (Kirmayer 1992).

The Medical Encounter and the Disrupted Self

Interactions with medical practitioners also threatened my participants' conception of their self-identity whilst they were in the vulnerable state of viewing themselves as liminal. Like with family and friends, when my participants felt they had been devalued by doctors, it was seen as both an attack on one's understanding of one's illness and an attack on the self. As Bury (1982:172) argues, a biomedical diagnosis is the most legitimate way for the sufferer to assert that their illness is separate from their "true" self-identities and not mentally produced or simply 'deviant' behaviour. For this express reason, the support group I attended had a list of 'sympathetic' doctors in the region which members could see if they had trouble with their previous doctors. All the participants in this study were keenly aware of the requirement for diagnosis and the subsequent potential consequences if they had not received one: everyone said that when they eventually were diagnosed by their doctor or a specialist, it gave them legitimacy, recognition, and "kudos" with both the medical establishment and friends and family.

However, when medical practitioners doubt sufferers' claims, their claims to sickness can become tenuous. As Dumit argues, there is an "intense interplay between diagnosis and legitimacy: without a diagnosis and other forms of acceptance into the medical system, sufferers are at risk of being denied social recognition of their very suffering" (2006:578). My participants thus felt delegitimised, that they had lost agency and authority in their sense

of self-identity when they experienced doubt from doctors (Ware 1992). This doubt, I argue, reveals the way in which my participants were viewed as liminal by their doctors for, as stated earlier, CFS/ME does not easily fit within biomedical conceptions of the body and illness. The experience of being viewed as liminal and suspect forced my participants to realise that, despite the rhetoric of choice within late modernity, which even Giddens presupposes when he suggests one can just decide between either biomedical or alternative medicine (1991:84), some authorities, such as health professionals, are invested with very real power to define and decide who is and is not allowed to claim certain roles, such as the sick role (Parsons 1991). For example, Alexandra explained that before she fell ill, she had always believed that if she experienced a work-related loss, she could choose to temporarily work in a job that was not equal to her skills or education levels. However,

> Now these aren't options. When you're sort of lying there, unable to move, you're thinking, "Wow, I couldn't, there's not a lot I could do for myself." It does change your sense of agency. And having doctors talk about you in the third person as if you're this passive –

> *LB: While you're there, they're doing that?*

> Yeah, yeah. And they write to each other and CC you into it where they're talking about you [trails off, pauses]. It does give you this sense of yourself as kind of an object. An object of – kind of vague investigation, usually! But you know: a problem. You become a [cuts off, pauses] and because your body has become a problem to yourself, as well. [...] You sort of have this really weird, it changes the way you think of yourself, well, for me it changed the way I thought about myself as a member of a community, of a society. [trails off, pauses again]. I became this problematic... blob... that lay around at home and let people feed it.

Here, Alexandra clearly shows the effect of being depersonalised through experiences within the medical establishment. She stresses how she felt like 'an object' for examination in which, furthermore, her doctors barely appeared to be emotionally invested. Depersonalisation within encounters with medical professionals directly impact on one's sense of self-identity and our imagined relations with society and the world at large. It forces us to realise the limited level of choice we really have in deciding which roles we will take up. It also

illustrates my point that *everyone* at this stage of my participants' CFS/ME saw my participants as liminal beings. Doctors, like family and friends, had trouble "placing" CFS/ME and my participants, especially as the diagnostic process is difficult for both practitioners and sufferers. However, seeing one's own self-identity as disrupted is one thing; it has very real consequences for both our view of ourselves and the level of social recognition that we are granted when an authority such as a biomedical practitioner views an individual as liminal.

As pointed out above, my participants often felt they were not knowledgeable about the condition during the initial stages of illness. This lack of knowledge was disempowering in the context of the doctor-patient relationship, especially given the expectation within contemporary individualism that patients should be "active" with regard to their conditions (Hyde 2005, Rabinow 1992, Rose 2007). For instance, Anna had been asked by her GP whether she was experiencing symptoms of depression. Even though her doctor eventually concluded that she was not depressed, the possibility of disbelief had caused Anna great anxiety. However, if her doctor *had* stated she was 'depressed':

> I would have rationalised myself out of it, and thought, 'Oh, she's entitled to that,' and I'm quite good at that, looking after myself that way... Um, but I still would have [doubted myself]... Because I'm exhausted and more vulnerable possibly to that, I don't know. [...] You become public property! And hey, by the way, guys, I'm not public property! But here I am, too tired to say no, to stop you on your – *this* is what it's like, *this* is how I feel! You know, there they are and I'm too tired to say, "Stop it! No go!" and I answer what they're saying, I end up justifying [myself] [...] and sometimes I can [say] "hey, it's not worth going into" but other times I'm so exhausted, physically and mentally I'm not good, I'm fuzzy brained, and I end up justifying myself. I come away feeling like garbage.

Anna's experience illustrates the different cultural weight of 'objective' diagnoses versus 'subjective' bodily experience. 'Objective' knowledge-claims can be used to refute the claims we make about the truth of one's lived experience. This can be especially troubling as it not only calls into question the legitimacy of the condition itself, but may also lead individuals to doubt or question their own ability to "know" themselves authentically (Desjarlais 1994

and Smith 1993). This was the case for Joan, who had a joint diagnosis of CFS/ME and fibromyalgia. One of her core symptoms when she first became unwell was muscular weakness and pain. While her doctor had initially suspected that she had CFS/ME and was happy to diagnose her as such, Joan was so concerned about her these symptoms that:

> [My doctor] said, "I can send you for muscle testing at the hospital," and I said, "that sounds really good!" I went and did that, and I had an old fashioned, aged, male doctor. [...] The old guy tested me, and said, "you're absolutely strong, I don't know what you're complaining about, maybe you're just weak." [He] really kind of told me off, and made me feel stupid, and I wanted to cry but he had almost insinuated that I was a nervous wreck, so I thought, 'I can't get angry, I can't show any emotions!' just go, "Oh, thank you very much, sir!"

Here, not only did Joan feel devalued but, once again, the power imbalance within the patient-doctor relationship became visible. She still faced the imperative to thank a man who, in this context, had effectively insulted her understanding of her body and her emotional stability. Most tellingly, it indicates the inability of medicine to 'know' certain contested illnesses like CFS/ME and fibromyalgia. Yet as Kirmayer (1992) has noted, individuals are often forced to hold the burden of blame when their experience does not fall within the explanations of biomedicine; blame returns legitimacy to the doctor who, as my participants later found, cannot give adequate answers to the problem of CFS/ME.

Conclusion

Within this exploration of Disruption, I have shown the way in which the security of my participants' self-identities were disrupted through the personally liminal experience of CFS/ME. Their roles within families and work, their bodies, and their own identities were in flux. Furthermore, CFS/ME itself contributes to this liminal experience: it falls outside of the usual ways in which illnesses are classified under the rubric of biomedical

discourse and it provides no sense for the future, which upset my participants' plans for both the present and their future goals.

Secondly, I have illustrated the way in which the doubts of family, friends and doctors, further weakened my participants' sense of their agency, the place within their social networks, the security of their understanding of their life-world and their self-identity. I argue that this shows the way in which liminality is not just an experience that an individual or a group of individuals can go through. Rather, others can see and cast an individual as liminal. As discussed in the following chapters, however, this is predominantly a temporary position, affected by conceptions of knowledge and the gradual rebuilding of identity.

CHAPTER THREE: THE REALIGNED SELF

Introduction

While Chapter Two illustrates that falling ill was profoundly disruptive for my participants' sense of self-identity, in this chapter, I show how they sought to construct a new identity. This reconstruction involved firstly, the prioritisation of one's own needs for health and secondly, the renegotiation of their abilities and the roles that they were willing to either accept or reject. Thirdly, they reworked their relationships with work and employment, society, and modern life itself. I have called this narrative work the 'Realigned Self', for, as this chapter shows, my participants normalised their experience of illness and their self-identities. However, my participants sometimes revealed the fragility of this narrative work, which I argue shows my participants' struggle with their long-term liminal status and the difficulty of stabilising themselves while suffering from a condition on the cusp of legitimacy.

My participants' new claims about their self-identities were not always accepted by family and friends. I argue that this reveals the degrees and perspectives within liminality: even if one does not see oneself as chaotically liminal, one can still be cast as such by others. I show that my participants were required to rework these views or reject these relationships in order to legitimise themselves as realigned.

In this chapter, I draw on notions of the responsibilised patient (Rabinow 1992 and Rose 1996, 2007) and theories of authenticity (Desjarlais 1994, Elliott 2003, Giddens 1991) to show the way in which my participants justified their new self-identities. I also utilise theories of the modern self (Beck 1992, Beck and Beck-Gernsheim 2001, Giddens 1991) to show how my participants legitimated and situated their claims about their self-identity.

Realigning the Self

The first step toward the Realigned Self began as my participants increasingly prioritised their own needs for health over both their own and others' previous expectations. This change in priorities is *an intensification* of the demand we all face in advanced liberal democracies to assess and develop our self-identities. There has been an increased emphasis on "the responsibility of individuals to manage their own affairs, to secure their own security with a prudential eye on the future" (Rose 2007:4), an attitude which is also crucial in relation to one's health (Beck and Beck-Gernsheim 2001). However, destabilising sickness that "unmakes the world" (Good 1994:118) is hard to imagine for the ontologically secure: as DelVecchio Good et al. argue, "in a society of instant crises and quick remedies, of risk management for the unexpected, the very idea of *chronicity* … is unacceptable" (1992:205). 'The health project' is only one part of the myriad ways healthy individuals 'work' on themselves. My participants, on the other hand, placed their health projects at the forefront of their priorities. As Nicolette stirringly told me toward the end of our interview, "I'm an educationalist, and I really value education, but I've learned through this that health is the most important thing. Other than love, health is the most important thing in your life". My participants can therefore be seen to be complying with the ideological demand to quest for health, yet with an intensity not required of the healthy (Rabinow 1992, Rose 1996, 2007).

Nicolette's experience illustrates this: she had been unwell with CFS/ME for five years before she could properly search for a diagnosis. She had not been able to prioritise her health because she was trying to raise her daughter Eva (who, at this point, was around ten years old and had not yet developed CFS/ME), work part-time and finally, look after her increasingly unwell (now ex-) husband, who had post-polio syndrome. Nicolette was visibly exasperated as she reflected on the stresses involved in caring for two people while unwell herself; Eva and her husband, who was "making my

health worse [with the] demands and stresses that he was putting on me". These combined events lead to the breakdown of her marriage.

> One of the reasons I left… the biggest reason was my health. […] [It] was getting too much, and I was concerned that I [would] actually [pauses] lose my health completely, and not be able to look after Eva. So I could just see this downward spiral happening. […] And then when I was out of that situation, I could turn around and take stock and say, "Okay, now my health is important".

Here, the end of Nicolette's marriage was justified through the two frames: firstly, through her gendered desire to continue caring for Eva and the socially legitimate ideal of the responsibilised subject (Rose 1996, 2007). In this way, she rejected one situation where she believed she was getting sicker and embraced the new opportunity to prioritise the 'quest for health'.

The way in which my participants' intensified their health projects led to a greater prioritisation of the self as a whole. They increasingly examined and reassessed their previous needs, values, abilities and self-identity. These reassessments were primarily constructed as positive; in this way, my participants normalised their experience following the chaotic liminality of the 'Disrupted Self' (See Chapter Two). However, my participants were often still just as sick at this stage of their lives. We can see these changes as a shift from 'chaotic' liminality to a long-term liminal state. This work is not just the mere normalisation of suffering; rather, my participants reconstructed their new self-identities in order to claim their "life to be a good life, a meaningful life" (Elliott 1998:182). As Williams argued, positive narrative (re)construction in the face of chronic illness is required to "reaffirm the impression that life has a course and the self has a purpose" (1984:178). This reconstruction was visible in my interview with Melissa. Before CFS/ME, Melissa had worked in a high-powered and pressured environment. She was stressed a lot of the time in this risk-assessment role, which she said required her to be critical and "negative".

> I got to the point where, I felt that [quality management] was kind of [pauses] changing my personality for the worse. Because you have to be, you were always looking for problems. […] So even though you don't like to get sick… It's kind of helped me to find my passion.

Throughout our interview, Melissa emphasised her new love of organic horticulture, which she originally became aware about in the 'quest for health'.

> It's something that I enjoy, I'm passionate about it, I was good at [quality management], but I wasn't really passionate about it. Whereas with organics, I'm passionate about it in so many respects: not just for my personal life, but for business, for the environment, and just for people in general. So I think that will help, trying to focus on things like that, that I'm passionate about, I think that will help me.

Falling ill enabled Melissa to 'step back', reassess her life direction, move away from 'negative' areas of her life and increase her attention to new, positive activities and life goals. She justified her decision to accept voluntary redundancy after her workplace was restructured by framing these decisions within values that are culturally and socially salient in contemporary New Zealand. Leaving a job that is "negative" is legitimate because it falls in line with the expectation that one's job should be emotionally and psychologically satisfactory (Rose 1996). Secondly, Melissa saw her altered life-plans as improving her life, which Kleinman (1992) argues is a culturally valued goal within the habitus of contemporary middle-class worlds. Finally, framing one's choices as positive helps to authorise the realignment of the self, for positivity is increasingly intertwined with the authentic, "true" self in late modernity (Elliott 2003:29).

Other participants had to consciously develop their Realigned Self-identities as positive. Joan had to radically rework her understanding of herself in order to move out of the personal liminality of the Disrupted Self:

> I think I was someone who felt I was inferior, and always apologising for basically being alive, almost. I think that was my nature way back. Partly being English, partly my parents, the type of schooling back then, all those type of things made you feel pretty insignificant. And I... when I got this, as well... I felt, you know, like a speck of dust, basically. So I had to really think about this... [and] come to realise what I had been like, and think, "If you don't think anything of yourself now, nobody else will" [pauses] And I, you know, I used to be quite pretty, and I didn't say much and I observed and I was just, like, people thought, "God, she's lovely", you know: little quiet thing that never spoke, a mouse, basically. And then I had to sort of think, "I can't rely on appearance anymore, I have to actually use my brain to talk to people, and interact or I am insignificant!" And that was a huge thing, I'd been more physical. You know, [...] more than thinking I was mentally very capable. So I had to

talk myself into thinking that I did have a reasonably good brain. [...] I did a lot of talking to myself like that, so I had to... basically change my personality.

While this identity work could be seen as characteristic of the reflexivity Giddens argued is part and parcel of life in late modernity (1991), I argue that these reconstructions were not simply matters of 'choice' amongst a diversity of lifestyle options. My participants had to frame these decisions as culturally and socially legitimate, for both their CFS/ME and their new self-identities still existed on the border of acceptability. Representing the changes in their self-identity and roles as positive was one way of doing this, for as Charmaz notes, this sort of narrative work fits within cultural ideals of the individual-as-actor: "the person not only preserves moral status but may claim moral superiority for remaining in control and not caving into suffering" (1999:37). Such representations are vitally important when the security of one's self-identity was, or still is, under serious threat; as Snow and Anderson found in their exploration of 'identity work' amongst American homeless people, "carv[ing] out and maintain[ing] a sense of meaning and self-worth seems especially critical for survival, perhaps because it is the thread that enables those situated at the margins ... to retain a sense of self and thus their humanity" (1987:1365). While this form of "humanity" is very much a cultural construct which emphasises the primacy of one's own inner experience (Desjarlais 1994), it is a prominent conception for Western, individualised actors such as my participants.

Through the development of the Realigned Self, my participants defended the new way in which they reassessed, engaged with, and sometimes rejected social, cultural, economic and familial roles. The choice to opt out of such roles, especially those roles that return economic security or gain, is particularly unusual within advanced neoliberal democracies. As Kleinman (1992:180) points out, the "cycle of self-improvement and self-promotion" for individuals in advanced liberal democracies is intimately linked to economic prosperity and success. Consequently, "not to rise is a threat to social persona and social [e]steem; it is often experienced ... as a shameful moral weakness". My participants instead realised they could justify their decision to opt out of economic values and roles through critiquing capitalist individualism.

Alexandra found that her new limitations involved "radically rethinking how my life was going to go". Before she fell ill she "had become quite material [...] I was focused on being able to make money" as a result of growing up in a lower socio-economic group and wanting to support her sister and her parents in retirement. While this is not simply the classic, selfish economic actor within neoliberal capitalism, the pervasiveness of materialistic thought still drove her conceptions of care and kinship relations. Additionally, Alexandra told me she had always made long-term plans, which CFS/ME had subsequently disrupted: "I *had* a twenty year plan of what I was going to [do], and how old everyone else in my family was going to be, so what their needs were going to be". Supporting her family monetarily had become the primary way "that made me feel [pause] like that's how I had value in my family". However, as a result of her CFS/ME, "I've had to sort of dig deep and try and find something else, some other reason for them to like me!" After pausing to think, Alexandra clarified that developing CFS/ME had led to the reassessment of other aspects of her life and material things really meant:

> Doing my M.A., and then my PhD, you know how it can be; you can get so caught up in your studies... [I] just realised [...] [that] they're all kind of made up things! Money is made up, money is really a gross piece of plastic: It's just that we pretend it's something awesome. And how we pretend, like CEOs, how we pretend that an hour of their time is somehow so much more awesome than an hour of the time of a cleaning lady. Um, but really, it's actually the same. [...] I feel like I was heading down a track of doing things because I thought society expected me to, or... [trails off, stops] And I actually did just want to have a holiday after I finished my PhD, but [...] they were kind of... pushing me into this job, and then, I got it, and they were like, "Oh, this is so great!" And I remember crying after my job interview, because I was worried that they would give me the job! And that I'd have to move to [this city] instead of having a holiday!

At this point, she laughed again before her tone turned far more serious:

> I don't think I would do that again. I think my priorities have really changed now. And I really hope that I one day get better from this... even if I don't, it was kind of like a... I feel like I could have [pauses] wasted my life for not appreciating life for what it is, like, just basic things like breathing. Eating. Being able to walk around the house, which I can now do.

Giddens (1991) points out that 'fateful moments' intensify the reflexive work invested in one's self-identity. Yet he also argues that sickness is often socially sequestered from everyday life. Within the "popular culture" of Western advanced, liberal democracies, "blemishes, illnesses that cannot be rapidly cured and especially grave infirmities that suggest disability or death are banished from everyday life" (DelVecchio Good et al. 1992:205). My participants recognised this cultural banishment (See Chapter Two and Four), for as Stuart Hall notes, those who are marginalised or sequestered are often keenly aware of "the spheres of ideological domination and coercion" that cause their marginalisation (1974:271). As a result of this awareness, my participants reflexively reworked this banishment in order to sustain their new self-identities. By critiquing the capitalist nature of the current world, my participants were able to make sense of the new connections between themselves and wider social and cultural values (Williams 1984). This critique was visible at one moment during my interview with Nicolette and Eva, where Nicolette simultaneously made a point of addressing Eva as well, rather than me exclusively:

> When you haven't got the energy you learn to simplify your life. And manage yourself. I know that's, at least I said to Eva that when you get better, in the future, you may well always have to manage yourself in the future, [but] you will know about stress and you will know how to manage yourself. And you won't get burnt out at a later stage because... Hun, you will [have] an awareness about it – that we're not Amazons. You know, and that we are human. And so if we push ourselves so hard and we're so much of a - in society, aren't we, we must be busy jobbing! So you're forced to take a step back in life, and look at – you appreciate the simpler things in life a lot more.

Both Nicolette and Alexandra question the nature of neoliberal individualisation and work environments in Western nation-states such as New Zealand. This is not to say that my participants completely rejected work as a whole. For example, Nicolette explained how valuable her part-time teaching job was. She was proud that she had not been questioned about her health status at work, which she took to mean that, despite being unwell, she was still able to successfully teach. Additionally, Alexandra told me how excited she was to have recently finished a book review for an academic journal. Rather, my participants had *shifted the emphasis* they placed on work

through reframing it as valuable for 'personal satisfaction' instead of whether they 'achieved' or not in the wider capitalist world. By framing their engagement with work as psychologically satisfactory (Rose 1996) and their self-identities as predominantly positive and authentic in and of themselves (Elliott 2003), my participants rejected the materialistic capitalist conceptions of work through a culturally legitimate narrative for both themselves and others (Charmaz 1999).

The Fragility of the Realigned Self

Despite these efforts, my participants sometimes divulged the difficult nature of this identity work. I argue that these admissions reveal the way that narrative reconstructions about such vital matters as one's self-identity can be fragile when one is in the borderlands of social and cultural legitimacy. This most often occurred when my participants reflected on their old goals and plans for the future. All of my participants bar one stressed that they would prefer to be better, or at least, less ill than they currently were. My participants therefore recognised that they were, I argue, in a long-term liminal position, where there was a final 'step' to be taken: reintegration into society as a healthy individual. The participant who claimed she no longer invested much energy into getting completely well again argued that this was because

> [Being ill] is quite a big part of my identity. Not necessarily, M.E. specific, but I have a chronic illness. It's something that [pauses] affects numerous areas of my life. I think if I actually did get completely well, it would be weird to lose that bit. [...]Now that I'm feeling better than I was, I'm sort of considering re-phrasing it, you know, "I have had this illness for a long time, but I seem to be getting better" or something, just because it's changing. I might have sort of plateaued; I might be stuck at [only] five [really good] days a month. But, I'll just keep going on that drug, and [pauses] I'm just not really motivated to get much better. Why? [laughs] I'm not interested in travel, I suppose I could dance more often, but um... yeah, I think I'm sort of... comfortable.

However, this participant was unique amongst my participants in several ways. Her CFS/ME had significantly improved over the last several years and she had adjusted her engagement with markers of middle-class, capitalist

achievement. While she claimed she was not 'interested in travel' or a high-powered job, she was also the only participant whose economic position had improved since falling ill. She had purchased a house on the outskirts of the city because she was "always been good at saving". She rented out her purchased home to cover the mortgage while she alternatively house-sat for others for long periods of time or rented much cheaper bedsits in the city. Secondly, her new future plan to purchase another house was not affected by whether she was well or not, because she planned to draw on the value of her current house to do so. For others, however, it is important to note that rejecting or adjusting one's engagement with common markers of success was not always easy, and the narrative critique of capitalism could not always be utilised. This difficult reveals the way in which my participants felt pressured to balance the dual projects of securing their self-identity while negotiating the expectations of economic and personal achievement in late modernity. Noah's frustration with his current abilities versus his previous expectations for the future exemplifies these two conflicting demands.

> I've got a lot of things I'm interested in, and that I want to do… and that I try to do. And I've never been bored once. I can honestly say that. Because I'm either too tired to do anything and I have to sleep, or I'm busy reading something, or listening to something, or watching something, or playing with something, or riding a [motor]bike, or firing a gun. [Laughs] You know, there is always something to do. […] You gotta live as much as you can while you can. But it's like, going through a race with your shoelaces tied together. You can only get so far, [and] then you fall over. But I would like to think that I could pick up a bit of steam and achieve something. And I just get really pissed off that I'm about on a quarter of the average wage. I should be able to own my own home, have a nice new car, have a beach house, have a family, do whatever I want to, go overseas for a holiday… You know, that's what I should - everyone should be able to do that sort of shit. Can I? No! And why? Because I've got fucking M.E.! [Laughs, then sighs] It's a limitation. Uh, [but] you either get bitter and twisted about it, or you, you deal with what you've got. And I choose to deal with what I've got.

Noah shows how prevalent and difficult the pressures of late modernity can be on someone who is unwell. He illustrates the expectation and desire to be able to self-direct and control his life, to do 'whatever I want to' which, as Giddens argued, is a significant goal for individuals within high modernity (1991. Beck

and Beck-Gernsheim 2001, Elliott 2003, Rose 1996). However, I argue that these desires have to be managed, for otherwise one's self-identity could be under serious threat or disrupted once again (Snow and Anderson 1987). One cannot risk 'get[ting] bitter and twisted' that they cannot live the life they had previously planned, for it would upset their representations to both themselves and others that their realigned self-identities were "true" and authentic (Desjarlais 1994, Elliott 2003). Above all else, my participants had to reinforce the realignment of their self-identities through claims that they were living an authentic, 'real' and satisfactory version of their selves with its new limitations, to 'choose to deal with what I've got', even if it was within a long-term liminal state (Charmaz 1999, Elliott 1998, 2003; Giddens 1991; Rose 1996, 2007).

Negotiating the Realigned Self within Personal Relationships

Once my participants stabilised their transformed, realigned self-identities, they also had to rework their relationships with family and friends. The reworking of important relationships was the most difficult aspect to manage in the changing nature of my participants' self-identities. This difficulty often arose when either party could or did not meet the roles and duties the other expected from the relationship (Dickson, Knussen and Flowers 2007, Snow and Anderson 1987). This is due to what I call *the perspectival nature of liminality*. While my participants had reaffirmed their new self-identities and normalised their experience as long-term liminal, their family and friends often still did not know where to place CFS/ME and their expectations of my participants at all. Snow and Anderson have argued that the more intimate a relationship, the more likely it is that individuals will be challenged over claims about the 'truth' of their new values, roles and self-identity if it is not congruent with the way in which the individual was previously "known" (1987:1367). My participants were forced to assert themselves within these relationships to try and both challenge and recreate

their families and friends' views of their self-identity to socially legitimise their new state.

My participants tried to do this through actively asserting their own knowledge about how the condition was understood. Seeing oneself as knowledgeable reaffirmed my participants' realigned self-identities within their interpersonal relationships. My participants (re)constructed the questions or doubts of family members as illustrative of their lack of knowledge about both the experience of CFS/ME and CFS/ME itself. Nicolette stressed this was the case with her relationship with her mother:

> My mother has a really clean house. And it's like, you know, she'll always make comments and stuff? And [so I said], "Don't you understand that I don't have the energy to do it? If I do that, I cannot work. If I do that, I can't cook dinner". You know, "don't you know" - [she was] always critical, rather than accepting. That was really hard. And that was a change. [...][It has] taken a lot to get rid of those attitudes. Um, but when Eva got sick, then the help was more, and we went to a herbalist. Who was really, really helpful, and recommended by a friend of my Mum's, who had M.E. So it was sort of like [my family were] getting better, at helping us.

One particular breakthrough for Eva, Nicolette and Eva's maternal grandparents occurred after a fight between Eva and her mother. Eva had lived with her grandparents for a short time, and both her grandparents and herself gained a greater understanding of each other's experiences with illness: "they began to see what it [CFS/ME] was like for me, and I saw what it was like for them, with their arthritis [...] like I'd always nap when they would nap, you know what I mean?" Moments such as what Nicolette and Eva experienced illustrate an interpersonal realignment of the way in which CFS/ME is understood. In these situations, family members were also able to establish that my participants were "really" sick, and the sharpness of their liminal perspective was subdued. As a result, a mutual agreement over the sufferer's changed roles and abilities within a familial context could be reached.

The realignment of families and friends' views with my participants' views of themselves was also achieved through strategic justifications for their inability to fulfil certain roles or tasks. Emily told me that when she first came

to study at university she lived in a hall of residence. She admitted that she had, at first, found it difficult to balance her needs for health with the expectations of her new friends who lived in the hall. She was unable to study at the same times as her peers. Furthermore, the level of her fatigue at this stage of her life required her to be in bed earlier than most of her peer group in this residential situation. However, she had been able to explain what she was afraid would be seen as "boring" by her peers – that she could not stay up late - as necessary "for health, because health is the most important thing". This explanation was immediately understandable for Emily's healthy friends, arguably because it fits within the cultural, "public narrative" (Barker 2002) that promotes the responsibilised, health-seeking subject (Rose 1996). Alexandra also developed different, positive techniques to frame CFS/ME in her explanations over why she was unable to do certain tasks. When she first became unwell, her parents had trouble understanding both what CFS/ME was and its impact on her life. However, Alexandra's "big breakthrough was when I told them it was like a rechargeable battery that doesn't hold a charge. And they suddenly kind of got it, and they understood the basis of what I'm feeling". She was also highly aware of the way in which CFS/ME could be viewed as disruptively liminal, so became very particular in the way that she explained her CFS/ME to others.

> I realised some of it is the vocabulary that we use. Like I'll say, "I can't be bothered doing that right now." And then I realise I'm saying [something] that's not true. And so I try and make myself say, "I'm trying to conserve my energy level right now, so I'm choosing not to do that". It's better. And instead of just saying, "Oh, I'm tired." Everybody is tired! You know, I've noticed that everyone just goes, "Oh, so am I!" and I'm thinking, "Not like me, you're not!" So now I just say, "I feel fatigued".

Both Emily and Alexandra recognised and reworked shared, cultural narratives about the value of health and the meanings of common language terms. Emily utilised the cultural pressure everyone faces to 'quest for health' in order to rationalise her withdrawal from social settings. Alexandra recognised that terms such as 'tired' more immediately relate to what the healthy can experience, rather than the debilitating fatigue that caused her to be housebound for six months. Therefore, my participants realised that it was extremely important to control the way in which CFS/ME was discussed. This

strategic use of language meant that my participants were able to exert greater influence over their family and friends conceptions of CFS/ME, which could readjust the views of family and friends with their own (see Chapter Five).

However, in some situations, my participants could not make their new values and sense of self-identity understandable for their family and friends in a mutually satisfactory way. Some participants reached the point where they rejected the views of their family and friends in order to protect the narrative work they had invested in the Realigned Self and to prevent a return to the personally liminal state of the Disrupted Self. Rosalind cast her brother and father as "idiots" because "I'll be talking about my friend who they've met, who has got M.E., and they'll say, 'Oh, can we stop talking about sick people?' and that drives me nuts! 'Right! Okay! You just asked how she was, that's why I was telling you'". Noah explained that his brother had joked that, just because their father had passed away before retirement age, it did not give him the right to claim "his [father's] pension as well". Noah asserted that this brother "thinks I'm an asshole, so the opinion is returned". He went on to explain that his family often misclassified him as simply lazy or unfit.

> They all think that I should just get there and get much more exercise and get fit. And if I get fit that I won't have these problems. They just don't see that… if I try to do what they can do to get fit, it would kill me. I have to do things slowly and for a short time.
>
> **LB:** *do you think that's because people don't know much about it [CFS/ME]?*
>
> Oh, people, they don't want to know. If they really wanted to know, there is plenty of information on the Internet. But I haven't met any of my family, or friends, […] none, not a single one of them has put a minute of effort into looking on the Internet into what M.E. is about. Not one of them.

Noah's extract illustrates two important points: it shows how his family and friends still grappled with the problem of where to 'place' their view of him: his physical abilities defied easy categorisation and he fell outside and 'betwixt and between' our typical expectations of the human body. However, Noah's view of himself had been normalised into a long-term, but stabilised liminal state. Therefore, in order for my participants to prevent a second disruption to their self-identities, my participants viewed the critiques of their family as

both outright wrong, ignorant, lazy or symptomatic of an unwillingness to understand. Melissa, too, faced a situation where she had to behave in this way with respect to her dietary choices at a family picnic.

> Of course I take my own food, and they were having a picnic. And then my sister-in-law said, "oh, do you want some fruit?" And I said, "No, sorry, I can't have fruit" "Oh, it's good sugar" and I said, "No, I can't have sugar" [pauses]"But it's good sugar!" [frustrated laugh] "I can't have sugar, it feeds my yeast" and then that shut her up. But I don't feel like I should have to say that? Because it's like, we're having lunch... [laughs] I don't want to be going into my health conditions, just accept "No, thanks" but she just... Just pushes and pushes it. It just gets very stressful.

What is apparent here is that while a confrontation was required in order to make her point, it is understandably not a situation in which Melissa wanted to be. Thus, while Melissa was able to assert herself in this situation, the negative emotional effects of such conflicts highlight the difficulty and fragility of the realigned self and the instant work required to maintain it. Melissa explained that ever since her mother passed away, she had become the figure who was expected to keep their family together, as her brother and sister-in-law did not get on very well with her father. She explained that despite her new sense of self-identity, it was still stressful and tiring having to constantly defend herself to her family; especially her father, who she claimed "didn't deal with illness very well". Here, Melissa felt she was in a double bind: firstly, that her family still expected her to fulfil feminine roles as the only daughter in the family, and secondly, that the extent of disability that her CFS/ME caused was still doubted. Such experiences illustrate the way that liminality works in differing lights and degrees: while my participants had formed new self-identities, these new claims about their self-identities and the differing expectations around role uptake were still very much outside of or difficult to fit within the categories of others.

Conclusion

In this chapter I have shown that the initial disruption of the person with CFS/ME's self-identity was often a temporary experience. My participants reflexively worked to reconstruct a new sense of self-identity, which I have called the Realigned Self. They achieved this through prioritising their own health, renegotiating their side of relationships with work, family and wider social structures, and legitimising these through claims that the way they were behaving now was the most authentic version of themselves.

However, such constructions were not always easy. A focus on materialism and the drive toward status (Kleinman 1992) are so entrenched within cultural ideals of achievement that when my participants reflected on these, it often threatened the work that they had put into their reconstructions of themselves. This reveals the way in which my participants still struggled with their ongoing position as socially and culturally liminal. However, my participants were primarily able to overcome this through constructing the changes in their self-identity and relationship to employment as ultimately for the betterment of the self (Elliott 2003).

Finally, my participants also faced questioning and judgment from family and friends. This illustrates what I have called the perspectival nature of liminality, where an individual can be seen as chaotically liminal, even when they have shifted into a more normalised stage of liminality. My participants therefore either sought to realign their friends and families' views with that of their own or, if this did not work, they rejected them. This illustrates how difficult it can be to manage interpersonal relationships when one is on the borderlands of social and cultural legitimacy. As I show in the following chapter, this view was not limited to that of their friends and family. Doctors too had their own way of viewing my participants as suspect.

CHAPTER FOUR:

THE REALIGNED SELF WITHIN MEDICINE

Introduction

Because my participants remained unwell with CFS/ME after they had reworked and realigned their self-identities, they still had to engage with biomedicine in order to legitimise their claims about their ill health. However, like in Chapter Three, the claims my participants made about their illness, treatments or moral selves were not always accepted by biomedical and alternative practitioners. My participants came to see themselves as the most knowledgeable about their specific form of CFS/ME, which authorised and supported the developments in their self-identities; if they had not done this work, they faced the threat of their self-identities crumbling once again. They cast doctors as either lacking knowledge or deliberately obstructive when their views clashed with their own. Like in Chapter Three, this clash is illustrative of the way in which there are perspectival aspects to liminality: doctors could not categorise them within the normal conceptions of illness, patients and the body, and sometimes doubted my participants' presentations of themselves. While this could potentially have threatened their sense of self-identity, they reworked this through constructing their own experiences and knowledge as the most valuable for their situation.

In this chapter, I draw on theories of doubt within medicine and knowledge (Brown, Kroll-Smith and Gunter 2000, Giddens 1991, Kilshaw 2009) and the responsibilised patient in contemporary western cultures (Rabinow 1992, Rose 1996, 2007). I use these to illustrate the way in which my participants forged their own understanding of what their health treatments should be, even when these clashed with what their doctors expected of them. By acting as responsibilised, active patients, my participants justified their behaviour around healthcare choices and their view of themselves as the most knowledgeable about their condition.

Biomedicine and Doctor-Patient Relationships

Over the course of the 19th and 20th century, the social and cultural importance of biomedicine increased exponentially (DelVecchio Good 2010, Lupton 2003), to the point where the knowledge-claims of biomedicine and biomedical practitioners are expected to form a cornerstone of both our present lives and our plans for the future (Rose 2007). The authoritative status of biomedicine is due, in part, to the claim that it represents knowledge of "the natural order" of all bodies and pathologies, which is due to "the cumulative results of experimental efforts" where the resulting categories of pathologies are 'truth' rather than opinion or "essentially cultural" (Good 1994:3). The claim that science and biomedicine are 'rational' is the highest peak at which knowledge is valued within Western nation-states, such as New Zealand, since the Enlightenment (Gordon 1988, Kleinman 2010). By extension, biomedical practitioners also enjoy a status whereby their "knowledgeable" position is typically unthreatened, and the information they impart is truthful, helpful and healing.

Within the doctor-patient relationship, the patient has had a very specific role. Parsons (1991) argued that "being sick" is a socially sanctioned category whereby individuals are temporarily relieved of their duties as a member of a family, community and society at large. However, the sick individual is required to desire to get well and return to these familial, social and cultural roles through seeking competent medical care from trained professionals. The expectation that the patient will seek 'health' has arguably intensified over the last two decades due to what Rose calls the 'responsibilisation' of the individual (1996, 2007). Yet, how exactly one meets such requirements becomes extremely problematic when the illness, disorder or disease in question is not only difficult or impossible to cure, but also lacks consensus over what exactly the illness is in the first place (Johnston, DeLuca and Natelson 1999. See Chapter Five). If one cannot meet the requirements of the sick role then, as discussed in Chapter Two, the relationship between a

patient and their doctor, as well as other familial or social relationships, can be jeopardised.

Previous research into the experiences of people with CFS/ME has revealed how often the doctor-patient relationship is fraught. In one of the first anthropological investigations of CFS/ME, Ware (1992) found that the doctor-patient relationship was marked by *delegitimisation*, which she, following Kleinman, defined as "the experience of having one's perceptions and definitions of illness systematically denied" (1992:347). This experience was strikingly similar for Cooper's (1997) participants, who faced "problems of miscommunication, dismissal and disbelief", and limited to no access to a "legitimate sick role status" (1997:186). As recently as 2003, Åsbring and Närvänen found that people with CFS/ME still faced scrutiny over whether they were "really" sick or "merely simulating the problems for some other purpose" because general practitioners' preferred "objective" symptoms over the "subjective" (2003:714). Cases such as the above are common within the international literature about the medical encounter, CFS/ME and other contested conditions (Barker 2002, Garro 1992, Kleinman, 1992; Jackson 1992, 2005; Shriver and Waskul 2006, Werner and Malterud 2003). Research conducted in New Zealand into CFS/ME often reflects these experiences. Both Barker (1991) and Horne (1990) found that New Zealanders' with CFS/ME faced problems of recognition, difficulty in diagnosis and delegitimisation from doctors for whom, at that time, the most popular view of aetiology was "that hysteria is the cause of M.E. outbreaks" (Barker 1991:2). However, as I will illustrate, my participants found ways in which to limit or protect themselves from this delegitimisation. They were able to reduce the effect of doctors' statements, demands and questioning as the chaos of the 'Disrupted' Self subsided, and they began to realign their sense of self-identity.

I argue here that the Realigned Self was predominantly supported through constructing their own knowledge as more valuable than their doctors', which could be dismissed or avoided by a series of strategic moves such as avoiding specific practitioners, terminating the relationship (or, in some cases, not continuing it past an initial "vetting" visit), or by constructing the views of the doctor as ignorant, lacking knowledge or, quite simply, wrong.

'They Don't Know': The Realigned Self as Knowledgeable

My participants reduced the effects that the tensions in the doctor-patient relationship could have on their self-identities by reconstructing their health-care professionals as *lacking* knowledge. This construction ranged from casting their doctors as simply unaware of what CFS/ME is really like, through to what was understood as wilful, in some cases aggressive, ignorance over the aetiology and treatment possibilities for CFS/ME. This recasting is possible today as a result of the way in which knowledge and biomedicine are viewed in late modernity. As Giddens argued, everything is now "open to revision", medicine and "science depend, not on the accumulation of truths but on the methodological principle of doubt" (1991:21). This is supported by a growing, wide-spread public distrust of some scientific and medical claims, which Brown, Kroll-Smith and Gunter argue is a result of the increasingly obvious "lag between the rapid changes taking place in the environment and the limited capacity of experts and their systems for making coherent sense of the changes" (2000:16). As a result of these changes, one's own experience has increasingly become a source for making claims about the truth (Desjarlais 1994). As my participants realised how unknown the aetiology of CFS/ME really is, they also realised that medical experts and authorities cannot claim to know *the* truth, only *a* truth. Furthermore, because we are expected to take responsibility for our own health and sickness (Rose 1996), "people are no longer content to accept the truth claims of scientific knowledge" when they clash with personal understandings of truth (Kilshaw 2009:43). By seeing their understanding of the truth as the correct truth, my participants legitimised their realigned self-identities and the way in which they engaged with biomedical and alternative health practitioners.

People with CFS/ME arguably have even more room for choice around which forms of knowledge to accept and reject. In a very real sense, *doctors do not know*. The lack of consensus around aetiology and treatment within the medical research community (See Chapters Five and Six) means that most

general practitioners are not prepared to take a definite stance on the aetiology of CFS/ME. Emily made this point very clear. When she fell ill with CFS/ME for the second time in her mid-teens, she had several appointments with her doctor to try and diagnose her condition. Much to the frustration of them both, her doctor was "at his wit's end" as her symptoms lacked a clear causation. As he explained, "I don't want to diagnose you with [CFS/ME] again, but that's all I can see". His reluctance over diagnosis was not due to a disbelief in the condition, but rather, as she recalled, "when I diagnose you, there is nothing that I can do". Participants such as Emily ended up in the somewhat contradictory situation, similar to what Fortun recognised for people with Gulf War Syndrome, where they both desired explanations and are called upon to take responsibility for their condition "couple[d] with a keen awareness that [their condition] defies the possibility of expert comprehension" (cited in Kilshaw 2009:44). As my participants became aware of this, they increasingly relied on their own research and understanding of CFS/ME and questioned the views of others.

Constructing doctors as lacking knowledge could occur at any point in seeking health-care, including finding and "vetting" doctors. When Melissa first developed CFS/ME, she had been living in another New Zealand city. She had repeatedly visited the Accident and Emergency at the hospital there because she suffered from extreme dizziness and did not know what this meant. Eventually, she saw a nationally recognised expert on CFS/ME who was diagnosed and referred her to a local doctor. Once Melissa returned to her home city after living away for ten years, however, she had to search for a new doctor who was both sympathetic to her condition and shared her own view of CFS/ME.

> I tried my family doctor, who I used to see when I was a kid. My most important question was, "Do you believe M.E. is a physical illness?" And of course, he said "no". But he said, "but I'd be willing to learn more about it". So he didn't know anything about it, but he already believed - obviously he didn't know anything about it! Because he believed it was not a physical illness. So, that kind of made my mind up pretty quickly there, [Laughs] that I'm not going to be going back to him. He did the usual thing, he ordered blood tests, which are useless, and of course they came back clear.

Melissa could see this doctor's views on CFS/ME as incorrect not just through his denial of CFS/ME as a physical illness, but also through what she saw as clumsy attempts to treat her. One of the factors that make CFS/ME so hard to diagnose is that there are no biophysical markers to be found through blood testing[10] (Reeves et al. 2003). Because her doctor knew Melissa had already received a diagnosis of CFS/ME, Melissa saw these blood tests as pointless due to her knowledge that blood tests do not reveal anything about CFS/ME. Even her current doctor, who she had found through the support group, was "not as thorough" as she would like. In fact, as a result of her own research – through books from both the lay and medical sphere and the Internet – Melissa felt she was more informed about the treatment options for CFS/ME than this 'sympathetic' doctor. As she explained:

> I've read so many books on it, [and] I'm kind of saying [to my doctor], "Well, what about this?" and she goes, "Oh, yeah... that's something you could do!" [laughs] it should be the other way! [Laughs] She's had some good tips, but most of them I've already known.

Here, Melissa is, in a very real sense, embracing the idealised requirement that one should take responsibility for one's health which Rose has argued is part of the 'techniques' of government in advanced liberal democracies (1996, 2007). It is further enabled by the consumerist approach to health care in New Zealand (Hyde 2005) where one is expected to choose which sort of health-care and general practitioner is the most appropriate for the individual (see Lupton 2003). What is most interesting about this, though, is that Melissa's health-seeking behaviour was on her terms, rather than her doctors. This conception of one's own knowledge is possible due to cultural link between personal experience and authenticity in Western thought (Desjarlais 1994). Viewing the self in this way helped Melissa support her realigned self-identity, where she is *right* about her condition. Alexandra's experience was similar when she realised that her knowledge of CFS/ME outweighed her doctor's knowledge. Alexandra first received a diagnosis of post-viral fatigue syndrome (PVFS), and as her illness experience became far more chronic than PVFS, she

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[10] Good argued that biomedical practitioners are trained to rely on the physical aspects of the body, such as blood, to diagnose patients (1994). Furthermore, bodily substances are increasingly important in the search for answers as medicine now most often operates on the molecular levels of the body (Rose 2007).

began her own research on the Internet and discovered the link between PVFS and CFS/ME. Her suspicion that her PVFS had moved into CFS/ME was confirmed by a neurologist, who agreed that she may have CFS/ME. However, trying to get finalised answers from her general practitioner was far more difficult. Alexandra explained that she would be:

> Always trying to get explanations, like, is this pins and needles, circulation, or is this nerves? And the Doctor would be like, 'Well, I don't know'. And I'd ask, "What causes my mysterious headaches?" 'Oh, headaches are caused by a range of things.' He didn't seem to know… you know, there are lots of different theories of the aetiology of it, but he didn't seem to be familiar with any of them. Like I would say, "Some people think it is the mitochondria" but he was like, "Really?!" [Laughs]

Here, Alexandra's doctor illustrates the way in which my participants were still seen as disruptively liminal by their doctors. They could not provide any specific answers over where participants such as Alexandra were within the biomedical milieu, for they themselves were uncertain. Alexandra went so far as to provide her doctor with literature on CFS/ME, a clear transformation of the normal doctor-patient information exchange. She told me that "I ended up getting the Canadian – a summary of the Canadian Consensus document[11] […] and sending it to him, and getting him to read it". Her motivation behind giving him this information was "so that I could make sure he was doing all the tests like he was supposed to do". Through movements such as this, my participants reaffirmed their suspicion that they were more knowledgeable than their doctors, which justified the claims that they made about their aetiology.

Attempts to inform doctors in this way, however, were not always successful. Participants who tried providing information to their doctors were often met with dismissal or outright hostility, arguably due to what doctors perceived as an attempt to subvert the normal power structure of the doctor-patient relationship (Wright and Morgan 1990). This illustrates the way in which my participants defied explanation through both their CFS/ME and the altered "patient" role they adopted. When Noah first fell ill, he was frustrated

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[11] Carruthers et al. (2003), a recent explanation of CFS/ME developed for biomedical practitioners. All of my participants were very active in engaging with recent discussions of CFS/ME within the academic medical sphere and several were aware of this specific document.

that his doctor tried to diagnose him with depression. He argued that his "physical condition was not dependent on his mental condition" and that, regardless, he did not feel "depressed". Both Noah and Melissa illustrate the importance of defining CFS/ME as a physical condition. Physical conditions hold more legitimacy within biomedicine because they can be "found" within the material aspects of the body and cannot be dismissed as a 'fault' of personality or the mind (Good 1994). The struggle to define CFS/ME as an organic, physical condition is thus a "struggle over knowledge … [and] *whose* scientific knowledge [is] deemed legitimate" (Kilshaw 2009:54). Noah's experience illustrates this, especially as he began researching the condition himself. One transformative moment was when Noah found a book on Chronic Fatigue Immune Dysfunction Syndrome[12] by David Bell (1988), one of the first major CFS/ME researchers. While Noah felt the condition he "describe[d was] something very, very unusual", he suddenly realised he met all the symptoms:

> I sort of looked at it, right, bing, bing, bing, every single one. It was like, man, he was talking about me! I hadn't heard anyone describe anything like this. So I thought, wow, this is new information. So I took the book to my G.P., and I said, "there, this is what I've got. Here." And he said, "Yeah, ah, I'm not going to read that", he said. "I've got ten minutes to deal with patients, and that's it. I'll decide what you have".

This doctor's reaction not only reveals the lack of time available per patient in the New Zealand healthcare system, it also illustrates the varied diversity of truth-claims within individual realms of knowledge. As Giddens (1991) and Bauman (1992) have pointed out, increases in knowledge-claims leads to increased specialisation. Specialisation is paradoxical: while it provides greater depth to spheres of knowledge, it is hard to disseminate to both the public and others within a broader knowledge-field; as Bauman states, "partial knowledge belongs to partial experts" (1992:22). While Bell's (1988) book was authoritative for Noah, his doctor could dismiss it by falling back on both his traditional role as the authority figure within the medical encounter and the "methodological principle of doubt" that enables different authorities to suspect each other's claims (Giddens 1991:21).

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[12] Alternative name for CFS/ME. See Chapter Four for further discussion around the problems of 'naming', and Chapter Five for the importance of the immune system for my participants.

While such dismissals of one's views had the potential to threaten my participants' constructions of CFS/ME and the self, Noah viewed his doctor as ignorant and uncaring. This was especially the case when Noah begrudgingly took Prozac because "I got sick to death of him badgering me every time I went to see him", which, unfortunately, was fairly regularly due to severe asthma. Yet Prozac caused Noah to experience uncomfortable digestive problems and dramatically increased in his liver enzymes. When this increase was revealed through a blood test, Noah's doctor "accused me of being a secret drinker [because] he figured, 'I've only seen this in cases of alcoholics'". This was despite the fact that, as Noah told his doctor and sheepishly laughed as he explained it to me, he cannot drink alcohol as a result of his CFS/ME: "if I have one beer, that's it, I go to sleep". Consequently, while my participants were open to engaging with the differing knowledge-claims surrounding CFS/ME, they almost immediately cast their doctors as uninformed when their claims clashed with their own experience. This work served to protect my participants from the way they were cast as unfixable liminal beings by their doctors. A similar situation occurred with Nicolette and Eva. Nicolette constructed a perceived lack of respect from her doctors as a misunderstanding of who she really was, a lack of knowledge about other people with CFS/ME and the condition itself. This was especially the case when Eva became sick too:

> The attitude [of doctors] changed and it became [pauses] more of a suspicion, about the fact that we both had it. Eh, darling? And I'd had it for quite a while. I even had one doctor who was a really lovely doctor when I first came here, and [...] she saw me and she said to me, "Aren't you over that yet?!" She said, "Oh! You're supposed to be over it in two years!" I could have hit her! Because she was wonderful, and I was like... "Okay, so you accepted I had M.E. at the time... but you had a time limit on it. That in two years, I had to be... better, because that's what you've been *taught*, by some silly... senior doctor, that that's the "latest research", that, [...] "Yes, we agree it exists, and we agree it's real, but in two years, you should be over it" When in fact, there are a lot of people around who have had it ten years. Some have had it twenty years.

The problems that Noah, Nicolette and Eva experienced here illustrate a number of points. Firstly, it shows the tenuous nature of trust in authorities within the contemporary world (Brown, Kroll-Smith and Gunter 2000, Giddens 1991). Secondly, even though the most culturally legitimate

authorities on our bodies - biomedical practitioners - sometimes dismissed my participants' experiences and ideas, they still framed their own knowledge as correct within the quest for health. It illustrates how my participants assumed responsibility for their condition and life direction, even when it clashed with the authorities who were expected to provide support in this process (Rose 1996). Seeing the self as knowledgeable is therefore intrinsic for the realigning of my participants' self-identities, for it meant they could continue forward in their reworked goals and life directions even if they were seen as liminal or wrong by others.

Fighting Back: Realigning the Self within the Doctor-Patient Relationship

The way that my participants conceptualised themselves and CFS/ME often sharply contrasted with the views of health practitioners. This once again illustrates the perspectival quality of liminality: while my participants had stabilised their self-identities, felt sure of their understanding of CFS/ME, and had moved into a long-term liminal state, doctors were still almost completely unsure of how to classify them. My participants therefore sometimes endeavoured to change these views to legitimise their own claims that they made about their CFS/ME. One clear example of the 'Realigned Self' is visible in an interaction with Nicolette and a CFS/ME specialist. She explained she had been at the hospital in this instance to discuss menorrhagia. Though an intern had told her that she was "a few points away" from being anaemic because she had "bled for two years", Nicolette felt her doctors had not paid sufficient attention to this problem. As she recounted this part of her experience with sickness, Nicolette's ambivalence toward medical professionals became starkly obvious. She had laughed sadly, saying she suspected the dismissal of her concerns around potential menorrhagia was because she was seen as "just another woman with an issue with blood, you know, like in the Bible". However, upon this particular visit, she also happened to run into the CFS/ME specialist in a hall way:

I grabbed him and I said to him, [spoken quickly] "Tell me, what the latest thing is for M.E. that will help" so I kind of got him out of his usual context of an appointment, you know, and he said, "Gabapentin[13]", he said, "it's the latest thing". And so, I kind of got him, because when I went to see him next time, I said to him, "I want gabapentin!" [laughs] And then when he protested a little bit, because of the fact that, you know, "Oh, are you sure you're bad enough, da da da, and you have to have this, and you have to have that first, da da da" I said, "*you* told *me,* that was the best thing, and the latest thing, and the most important discovery for M.E. – I want it" So but, you know, I had to fight for it. I had to be smart. I had to know, you know, what to do.

What is acutely apparent in this instance is that Nicolette was highly aware that she had to 'fight for it', be 'smart' and 'know what to do' to get her desired treatments. She had internalised the requirement to take responsibility for one's condition, even if it meant defying the relationship with her doctor: a relationship which typically gives the sick person legitimacy within wider social and cultural contexts (Parsons 1991). One could go so far as to argue that, in this situation, Nicolette held the upper hand. She had utilised her doctor's words to her own advantage, and his protests were reduced to a series of "da da das" that indicate how invalid and ineffective they were in determining the outcome of the consultation. Other participants also made specific demands for particular medications. For example, the first time Rosalind did this was when she heard about an expensive medication a friend of her mother's was on, who claimed it had relieved her of almost all her CFS/ME symptoms. Rosalind travelled an extensive distance to see a nationally recognised expert on CFS/ME for the express purpose of trying to get a prescription for this medication.

I wasn't just sort of, 'what do you reckon?' I was, 'this is what I want' [because] […] it's off label or something, [treating CFS/ME] is not what it's really for. There are probably doctors that would only want to do what it's supposed to be for. […] that's what I was up to.

When this medication failed, Rosalind continued to demand specific medications. She told me that she really liked the doctor who she had been seeing since the beginning of her CFS/ME because "I get the national [CFS/ME Society] magazine, and things will come up and I'll say to the

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[13] Gabapentin. Originally developed to treat epilepsy, gabapentin has also proved useful for treating neuropathic pain and fibromyalgia (Moore et al. 2011).

doctor, "Oh, can I try this?" and they'll give me some and off I go". Like Rosalind, Anna had also reached a point where she felt able to frame appointments with doctors on her terms. Anna often travelled between her hometown and another New Zealand city, visiting doctors in both locations. She had expressly told her second doctor not to send her notes to her core general practitioner because he might think "I'm being a bit funny". She explained that she "could not be bothered" telling her primary doctor about her second doctor at this point, rather, she planned to "tell him eventually". While Anna was somewhat concerned that her second doctor "thinks she can make me better by her usual standards",

> I am very direct with her [...] but I think she can handle that. But I think I'm a bit odd because I'm not scared, you know, she's quite officious... But um, it's pretty equal footing there, and I get my money's worth out of her! Because I just go and load her with questions. She'll say, "oh, we're running out of time!" and I'll say "great [...] I'm just going to ask you some more questions!" [laughs] She can charge me an extra bit.

It is clear that when moving into the realigned phase, my participants were highly motivated to both prove that their doctors were sometimes less knowledgeable than them about their form of CFS/ME, and to also, almost aggressively, construct the relationship on their own terms. In his essay 'Making Up People', Ian Hacking (1986) argued that for most marginalised groups, the definition of what or who someone "is" is formed from above; however, there is the opportunity for that definition to be reworked "from below". This reworking was visible with my participants. Furthermore, the argument that they are the most knowledgeable about their experience of CFS/ME is supported through the culturally salient idea that one should be true or authentic to one's self – as Giddens states, "the authentic person is one who knows herself and is able to reveal that knowledge to the other, discursively and in the behavioural sphere" (1991:186-187. See also Desjarlais 1994). By reconstructing their relationships with their doctors through the prioritising of their own knowledge, my participants felt justified – realigned – in their claims to say what the real experience of CFS/ME is.

My participants were also willing to experiment with alternative medicine in their search for health. As Nicolette argued, biomedical

practitioners often failed to provide adequate care or treatment: "we realised we had to go outside of the box, outside of conventional medicine, because it was not doing anything, there was nothing they could do". Once again, my participants engaged with alternative health practitioners on their own terms, confronting, negotiating and managing these relationships with the same assertive approach. My participants prioritised their own knowledge over that of alternative health-care providers, were highly aware of these practitioners' limitations and were willing to confront them when their views contradicted their own. Even though Nicolette explained that she and Eva were willing to experiment with seeing a 'Chinese herbalist', the herbalist had told her

> That in three months she'd have me well. And I was like, "What?! What!" The woman that my mother knew [who had CFS/ME] had gone to her, [and] she did get better in three months! She only works part time and she is kind of retiree age, you know, so obviously [the herbalist] used that as a gauge, 'oh, she's got M.E. too', you know? And I couldn't believe it when she said that to me! I said, "you seriously did not say that to me", three months! But you know, she was wonderful in other ways, […] but not enough to be completely better. And in the end I just think she kind of thought that, you know, that she couldn't do any more for us and she'd like us off her books.

Nicolette was able to use the high variability in responses to different treatments for people with CFS/ME to question the legitimacy of her herbalist's overall knowledge and her ability to treat her own form of CFS/ME. Rosalind also did this with an acupuncturist. When she went to her second appointment with him, he had asked her which way her body had been positioned for the first session. She explained that at this point, she was immediately unimpressed with him, as "surely that would be something that he would know and would be important?!" Thus, while Barker (1991) suggested that people with CFS/ME in New Zealand have little choice but to embrace alternative medicine when biomedicine fails them, my participants show that it is not quite this simple. Rather, my participants were highly assertive in constructing their relationships with health practitioners on their own terms, whether these practitioners were from a biomedical background or otherwise.

Conclusion

This chapter illustrated the way in which my participants' engaged with both biomedical and alternative health practitioners after they began to realign their self-identities. My participants primarily constructed themselves as the most knowledgeable about their CFS/ME by drawing on specific medical research and their own experiences. However, both my participants and their claims were not always accepted by their doctors. My participants therefore recognised that they were difficult to place within the standard rubric of biomedical understanding. While such delegitimation can be damaging, my participants instead constructed themselves as the only ones who were *really* knowledgeable about their own condition, which supported the work they had put into realigning their self-identities and protected them from the threat of a second biographical disruption. As I show in the following chapter, one of the ways this was achieved was through constructing and controlling the aetiology of CFS/ME.

CHAPTER FIVE: CFS/ME AND THE CONSTRUCTION OF AETIOLOGY

Introduction

Over the course of their CFS/ME, my participants developed complex and nuanced understandings of what CFS/ME meant for them. Despite an absence of definite proof for the aetiology of CFS/ME, they used this lack of evidence as a flexible site whereby their claims about the aetiology of CFS/ME could be established. This was primarily achieved by selecting specific, preferred medical explanations and authorising these with their physical experiences. I argue that my participants' use of aetiology was a strategic form of narrative work that primarily supported the *public* presentations of their realigned selves. It justified their claim that they are the most knowledgeable about the condition to others, which reaffirmed their decisions to accept or reject particular social roles. My participants also used the debates around the name of CFS/ME in a similar way; their choices were used to authorise their claim to others that they were "really" sick and to control the way in which others saw them and their condition. These explanations legitimised my participants' new self-identities to others through the presentation of themselves as acting responsibly for 'health'.

Here, I draw on theories of illness narratives (Williams 1984) and narratives of the self (Charmaz 1999, Snow and Anderson 1987) to show the way that my participants constructed flexible, complex understandings of CFS/ME out of its unknown aetiology. I also draw on theories of the responsibilised patient (Rose 1996, 2007) and authenticity (Desjarlais 1994, Giddens 1991) to show how my participants could fit their flexible interpretations of CFS/ME within culturally legitimate frameworks in order to reaffirm their sense of self.

The Aetiologies of CFS/ME

The aetiology of CFS/ME has been the object of consistent debate since the first case definition of CFS/ME was developed (Holmes et al. 1988). Over the last several decades, the leading biophysical theories have focussed on a possible immunological[14], neurological[15] or viral basis[16] for CFS/ME. The most recent example of this debate was the proposed link between CFS/ME and the Xenotropic Murine Leukemia Virus (XMRV)-related virus, which was found in 68 out of 101 of CFS/ME patients (67 percent) compared to 8 out of 218 (3.7 percent) healthy controls (Lombardi et al. 2009). This was the sharpest difference between CFS/ME sufferers and a control group in the CFS/ME literature to date, which medical researchers and patients alike immediately hailed as the 'holy grail' of the CFS/ME debate. However, a series of attempts to replicate the Lombardi et al. study failed (Groom et al. 2010, Switzer et al. 2010) and the authors partially retraced their results after discovering a selection of sample contaminations (Silverman et al. 2011). Finally, *Science* retracted the article in late 2011 due to "lost confidence in the report and the validity of its conclusions" (Alberts 2011:1636). The case of the XMRV-related virus mirrors the other debates around CFS/ME, where inconsistencies and frustrations have flourished. As early as the late 1980s, researchers questioned the biophysical theories of CFS/ME, proposing instead that it is psychosomatic depression (Abbey and Garfunkle 1991) or a personality disorder (Millon et. al. 1989). Patient advocacy groups and sufferers', on the other hand, have insisted that CFS/ME is a physical rather than 'mental' or psychosomatic disorder (CFIDS Association of America 2011). The far-ranging nature of this debate is illustrative of the escalating knowledge-claims from a variety of authorities in the contemporary world (Giddens 1991). Furthermore, the increased specialisation within areas of

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[14]Bansal et al. (2012), Caligiuri et al. (1987), Klimas et al. (1990), Lorusso et al. (2009). Both Lyall et al. (2003) and Mihrshahi and Beirman (2005) argue this research is often biased and the methods within such studies flawed.

[15]Costa, Tannock and Brostoff (1995), Lange et al. (2009), Nijs et al. (2012). However, Wojcik, Armstrong and Kanaan (2011a, 2011b) argue this evidence is insufficient.

[16]Kerr (2008), Zhang et al. (2010). Lindh et al. 1996 were unable to find proof of entroviruses affecting CFS/ME sufferers in Sweden.

expertise has made it harder to stabilise the 'facts' about CFS/ME and disseminate this information across the field (Bauman 1992, Giddens 1991, Kilshaw 2009).

The controversies around CFS/ME is exacerbated by the variety of case definitions[17] available for medical researchers, practitioners, patient groups and individuals to use. Early case definitions include the 1988 Centre for Disease Control (CDC) Case Definition (see Holmes et al. 1988); the 1990 Australian Case Definition (Lloyd et al. 1990) and the 1991 Oxford Case Definition (Sharpe et al. 1991). The 1994 CDC Case Definition (Fukuda et al. 1994) is currently the most internationally recognised definition; however, its applicability in general use has been questioned because it was designed as an epidemiological research rather than clinical practice tool (see Jason et al. 2001, 2004 and Sullivan et al. 2002). Patient-favoured definitions include the 2003 Canadian Consensus Definition (Carruthers et al. 2003), which was cited by two of my participants; and the recent 2011 Myalgic Encephalomyelitis International Consensus Criteria (Carruthers et al. 2011). Many people at the support group I attended were excited about this 2011 consensus, especially the recommendation that CFS/ME should be called 'M.E.' alone.[18] The variety of different case definitions is problematic because they are essentially opinions, rather than developed through systematic, empirical evidence. This "creates a degree of confusion as the differing definitions place inconsistent emphasis on particular CFS symptoms and features" (Christley et al. 2012:27). The issues listed here are only a mere sample[19] of these debates for researchers, medical practitioners and patient communities, which has resulted in a field marked by a multitude of different definitions, symptomologies, and explanations, and no conclusive answers.

Establishing the Realigned Self through Aetiology

[17] Case Definitions are created when an aetiology cannot be found. These are typically the result of expert opinion and location-specific samples of sufferers. Differing case definitions develop as a result of which symptoms are most present in these samples and ideologically driven conceptions of illness (Christley et al. 2012).

[18] This definition has been criticised because there is still no sufficient evidence that CFS/ME is caused by a fault in the brain stem (van der Meer and Lloyd 2012).

[19] A search on the 20th of May, 2012 for "Chronic Fatigue Syndrome Aetiology" of Victoria University of Wellington's database 'Te Waharoa' returned 4,563 results; the same search of PubMed's database returned 2,459 results.

Despite these contestations, my participants constructed specific meanings for their CFS/ME. While this lack of specificity could be disruptive (See Chapter Two), My participants realised that this could be reworked as a flexible site to establish their own claims for CFS/ME. I argue that these claims were a necessary form of narrative work which drew on culturally legitimate explanations of illness and the body to publically affirm the Realigned Self. As Williams (1984) argued, aetiology explanations are not simply descriptive; rather, they are "an attempt to establish points of reference between body, self and society and to reconstruct a sense of order from the fragmentation produced by chronic illness" (1984:177). My participants' explanations about the aetiology of CFS/ME authorised their public claims that *they* were the most knowledgeable about CFS/ME, rather than doctors (see Chapter Four), which legitimated their claims about the 'real' experience of CFS/ME.

All of my participants sought to assert the construction of their self-identity to others through vehemently rejecting any suggestion that their CFS/ME could be a mental rather than physical condition. When they discussed depression, it was seen as either part of the symptoms of CFS/ME or a natural *result* of being unwell; depression was never constructed as the 'cause'. Rather, my participants thought of themselves as not so much depressed, but "*oppressed* and frustrated by the condition", as Nicolette suggested. These passionate appeals to CFS/ME's physical nature can be seen as an attempt to avoid the stigmatisation of mental illnesses (Kirmayer 1988, 1992). As Brown et al. note, when biomedical explanations emphasise stress or depression as the most likely aetiology of a contested condition, sufferers are more likely to be questioned, because it "taps public stigma concerning stress as a cause of physical health problems" (2000:246). On the other hand, established organic conditions are 'physical'– they can be located and seen by the eye, tests, and other medical tools of diagnosis (Good 1994, Gordon 1988, Rose 2007). Therefore, appeals to the physical nature of CFS/ME are important on three counts: firstly, they help legitimise my participants' claims that they were 'really' sick and not at fault for their condition while secondly,

avoiding the stigma "often associated with 'purely' mental illnesses" (Kirmayer 1988:65). Finally, this construction meant my participants represent their CFS/ME as "somewhere" within biomedical and cultural classifications of illness. This reduced the way that others saw my participants as unknowable, which enabled a realignment of others' views with my participants' views of themselves.

My participants intertwined highly scientific language with common, cultural narratives of medical conditions in order to represent CFS/ME as a physical disorder. For example, Noah's suspected

> the problem is actually inside the brain, because the brain controls most of the autonomous functions, and those are where all the problems are with M.E. Like pressure regulation, if you get up too quickly you get dizzy. And you can't get your pressure, temperature regulated properly, and your energy is not properly regulated. So there's a combination of your brain stem problems, [and] it's mostly from your mid brain downwards. And your adrenal glands, well, the ones that have been tested, people have shrunken adrenal glands, with reduced function[ing]. It's not a one site problem. It's a bit like asthma. Where it's not your lungs that [are] short, so much of air... it's every single cell in your body [that] is short of air.

Barker (2002) argues that personal narratives are most justified when they draw on and connect with cultural, public narratives. For this reason, Kilshaw's (2009) British Gulf War veterans, like those with CFS/ME, had a complicated relationship with medical discourses; they often dismissed mainstream medical knowledge-claims about their condition, but they also recognised that claims that are framed by medical discourses are more legitimate. As Nicolette argued, having "nothing to say to impress" others both destabilised my participants' self-identities and enabled others to continually classify them as disruptively liminal. On the other hand, when my participants' utilised specialist medical language, it supported their claim that they were the most knowledgeable about their personal experience of CFS/ME. This is visible in the way that Noah intertwined specialised knowledge of the body (shrunken adrenal glands) with a common ailment (asthma) in his explanation of CFS/ME. Asthma is a particularly useful symbol because it is widely recognised within public narratives of ill-health as a serious, chronic condition – especially in New Zealand, where it is the third

most common specific-cause of disability (Holt and Beasley 2001:1). Alexandra also intertwined specialised and 'common sense' medical knowledge in her explanation of aetiology:

> I have two theories. One theory is that Chronic Fatigue is actually like bi-polar disorder, irritable bowel syndrome, and things like that, in that it's actually a catch-all term that's being used on several closely related illnesses. Because it seems to be that some people have very different...
>
> **LB:** *Experiences?*
>
> Yeah. And I kind of like the mitochrondrial, the ATP[20] production problem theory. Because... partly because, all my life I have had a condition, that if I didn't have enough carbo[hydrates] I would faint. My father had it, and his father had it and so on. But when I got Chronic Fatigue it exacerbated that so badly. [...] So that makes sense to me, because it really clearly interacted with my other energy issues. And it just seems to me that it's quite likely, because that would account for why it just messes with so many different aspects of your body, your whole body relies on energy.

Alexandra's narrative work here utilised conditions that are part of our collective medical consciousness, highly specialised forms of knowledge and, most importantly, her own experiences. According to Robert Desjarlais (1994), cultures with a history of Christian and Romantic thought tend to classify 'experience' as a culturally legitimate form of self-expression. 'Experience' is entwined with the cultural ideal of the individual-as-actor, which has increased in value throughout the 20th and 21st century (Rose 1996:169). Finally, the prevalence of doubt in late modernity means that experience and trust have become increasingly important to our interpretations of knowledge-claims (Giddens 1991). Therefore, when my participants supported their claims about the nature of their experience with medical language, the public presentation of the 'realigned self' was justified through two culturally accepted forms of explanation. Even when my participants felt that they did not completely understand medical

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[20] Adenosine Triphosphate. A coenzyme which is the "principal energy currency of the cell": when operating correctly, it reproduces itself daily, contributes to the functioning of our metabolism and transfers energy within and between cells (Törnroth-Horsefield and Neutze 2008).

explanations, they still took advantage of these to justify their reasoning. For instance, Nicolette explained post-exertion malaise[21] in this way:

> From what I understand, and I don't understand that much, or how everything fits together, but apparently the lactic acid in our muscles [pauses] doesn't go away at the right pace. So like, if you did a workout at the gym, you'd be sore for about an hour – you know, with your sore muscles, but you'd feel good, like, "oh, I've done something good". Whereas what would take you one or two hours to recover from will take us eight. So therefore, whenever we use our muscles, our bodies, we have to... we suffer, and we have to refuel. It's like a car, I think like with petrol, that's how I think of it. If it gets down to empty, we have to [refuel] – and the way that we do that is by resting.

Both Nicolette and Alexandra linked the physical experiences of the body to medical knowledge. As Good has argued, "the body" is "an essential part of the self ... [and] the body as 'physical object' cannot be neatly distinguished from 'states of consciousness'" (1994:116). Viewing oneself as embodied is especially prevalent within the contemporary world, as we increasingly include the body in our conceptualisations of our biographies and self-identities (Giddens 1991). Thus, we can *understand* the claims that Nicolette and Alexandra make: we understand that carbohydrates help with the production of energy, and even if we may not understand lactic acid, we can understand the experiences Nicolette framed it in. Such explanations were both relatable and, therefore, legitimate to the family member or friend, which worked to align their views of each other. Noah did this too when he told me what it is like to have CFS/ME.

> Have you ever got to that, you've gone for a nap, and you've heard some noise so you've jumped up and you've wandered around, but you're not really...you're not quite wide awake, and you're not quite thinking? That's like that, all the time with M.E. They've actually proved that, with MRI studies. There's a gear box with most people, and if you're doing tasks, most people would change from gear one to about four gears, you accelerate, there's more efficient ways of going. But with us, two things happen – one is that we don't change gears. So we can do resting level tasks, but ask us to do more than that, and it's difficult. The other thing that's happening is that, we not only have wake patterns going on, we simultaneously have sleep patterns going on. We have patterns going on that normally only happen in deep sleep. Our brains are not producing the correct patterns a lot of the time.

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[21] Post-exertional malaise: Physical and mental activity can worsen the fatigue which sufferers experience (Fukuda et al. 1994).

The narrative power of experience was also used to supporting the aetiologies constructed by other sufferers, even if it differed from one's own experience of CFS/ME. For example, Rosalind argued for "multiple causes, for different people". While her own CFS/ME was gradual onset with no definitive starting point, one of her friend's CFS/ME was "brought on by pesticides [and] he knows what chemicals are being sprayed in the neighbourhood by which symptoms he's got". I found that the flexibility and lack of consensus around treatments for CFS/ME were also utilised to justify the individual's decision to take or *not* take part in certain medical regimes. My participants legitimised these decisions by drawing on consumer notions of choice and the responsible patient, which is salient within New Zealand health-care (Hyde 2005). When Joan and I discussed the various treatments she had tried, I asked if she had considered replacing the fillings in her teeth. Two of my other participants had done this based on the idea that the mercury in older fillings could leak and poison the body. She explained that she had thought about doing it, but "I decided not to believe that in the end, to be honest". Likewise, Rosalind told me that she considered it worse to "mess with the mercury" by replacing her fillings than the effects of leaving them alone. Rosalind had also justified her decision to not take some of the treatments other sufferers claimed had made them well: she reasoned that these people usually attribute getting well to "whatever [medications] they were trying at the time" but that "some people are just going to get well. It's not necessarily true" that what they were taking had made them better. The way in which my participants chose, or chose not to, engage with treatments is part of a general trend in late modernity: health is now "idealised as self-governed lifestyle choice" and "health, self-identity and consumption are increasingly entwined" (Bunton and Burrows 1995:210). Hyde (2005) and Neuwelt and Crampton (2005) have argued that this is also true of New Zealand medical practices, where the focus "is on the rights of consumers to information, access, [and] choice" (Neuwelt and Crampton 2005:198). By drawing on consumer notions of choice, my participants framed their treatment decisions in a legitimate cultural ideal, even if it meant the rejection of treatment.

Picking and Choosing: the Naming Debate

The official 'name' of CFS/ME has also been under considerable debate. The most popular names for CFS/ME are Chronic Fatigue Syndrome, Myalgic Encephalomyelitis (predominant in the United Kingdom, European countries and New Zealand), and Chronic Fatigue Immune Dysfunction Syndrome (USA). Other names have also been used over the history of CFS/ME. Researchers, sufferers and patient groups (including the support group I attended) have retrospectively pointed to Neurasthenia (Beard 1869) and Da Costa's Syndrome or Effort Syndrome (Da Costa 1871) as historical examples of CFS/ME given the similarities in their symptomologies. Both Beard and Da Costa argued these were physiological conditions (neurological abnormalities in Beard's Neurasthenia, an "irritable heart" in Da Costa's Syndrome) that caused pronounced fatigue, headaches, digestive problems, dizziness and sleep disturbances. These syndromes are utilised to prove that CFS/ME "is not new and probably no more prevalent now than it had been" (Straus 1991:6. Farmer et al. 1995[22]). Other names used throughout the twentieth century include the Royal Free Disease, named after an outbreak of an illness with a similar symptomology to CFS/ME at the Royal Free Hospital in the United Kingdom (Crowley, Nelson and Stovin 1957); Nightingale Disease, due to a suspicion that Florence Nightingale developed CFS/ME after returning from war service (Jason et al. 2002); Iceland Disease, another location-based breakout name; benign polio; and Epidemic Neuromyasthenia (Acheson 1959).

When Acheson recognised the similarities between Myalgic Encephalomyelitis, Iceland Disease and Epidemic Neuromyasthenia, he argued that "the wisdom of naming a disorder, the nature of which at present cannot be proved, and which may be due to more than one agent, is debatable" (1959:590). Despite his warning, "Chronic Fatigue Syndrome" was proposed in 1987 (Buchwald et al. 1987) and in 1988 became the official Centre for Disease Control definition (Holmes et al. 1988). The use of CFS was

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[22] This work found that 97 out of 100 CFS/ME patients met the ICD-10 definition for neurasthenia.

cemented in the internationally utilised Fukuda et al. (1994) case definition. Fukuda et al were *also* concerned that "the name may trivialise this illness" due to the common association of tiredness with 'fatigue' and that 'chronic fatigue' described a symptom, not an aetiology. However, they argued they could not support a name change "without adequate scientific justification" (Fukuda et al. 1994:1957-8). This resulted in a substantial backlash amongst patient advocacy groups. For example, within the United States, the Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) Association of America had advocated for "CFIDS" since the late 1980s in order to reflect the immunological dimension of CFS/ME (CFIDS Association of America 2011). In the United Kingdom, the Royal Colleges of Physicians, Psychiatrists and General Practitioners' report (1996) also recommended that CFS/ME should be known as CFS alone because they found little to no scientific evidence for inflammation of the brain and spinal cord, which the name 'ME' suggests. Patient advocacy groups criticised the report; an editorial in *The Lancet* went so far as to suggest that "psychiatry has won the day for now" because of a perceived lack of attention paid to the biophysical markers of CFS/ME (1996:971). Due to such complaints, a Working Group to the Chief Medical Officer was established to conduct further research, which finally recommended that "CFS/ME" should be adopted as the new terminology within the United Kingdom. The change was justified by the CFS/ME Working Group (2002:20-21) as such:

> For some, the term "fatigue" is problematic and considered demeaning because it is common parlance for the physiological experience of tiredness ... "Myalgic" is similarly inappropriate for those patients with little muscle pain. "Encephalomyelitis", meaning inflammation of the brain and spinal cord, is incorrect because the term implies a pathophysiological process for which no evidence exists. ... The Working Group decided that the most important requirement in terminology is for patients and doctors to agree on a satisfactory term as a means of communication. We recognise that no current terminology is satisfactory, so in line with our original terms of reference, we have used the composite CFS/ME ... acknowledging that CFS is widely used among clinicians and ME among patients and the community.

These debates around naming also proved to be a flexible site for my participants, who picked between terminologies to publically support their

reconstructions of their self-identities. During my interviews, everyone utilised 'M.E' almost exclusively as we talked, yet when asked to explain their preference in terminology, the answers were often complex and nuanced. For example, Alexandra used M.E. throughout her interview, yet when I asked her what name she preferred,

> I don't like any of them. But I think I prefer Chronic Fatigue Immune Deficiency – whatever it is.

> **LB:** *That's more prevalent in the States, isn't it?*

> Yeah, I think so. I just like it because if you say M.E. they just say, "Oh, Tapanui Flu!"[23] and they think they know all about it, and if you say Chronic Fatigue Syndrome... They just think you're tired. Or with M.E., they go, "What is that?! Are you going to die?" Although, my sister hates me calling it the other one [CFIDS] because she thinks it sounds like AIDS. But I think [...] the first time I got it, I *did* appear to have a virus. And the second time I got it... I think I did have... a urinary tract infection. [...] It does seem like your immune system is really caught up in it.

While some participants, such as Alexandra, made their decision over what name they preferred based on symptoms, other participants strategically utilised multiple names. As Dumit (2006) notes, naming and diagnosis are intimately linked to social and institutional legitimacy. Through their selective use of names, my participants legitimised their personal constructions of CFS/ME and had greater control over the way they were viewed by others. Joan had even more flexibility here, because she had a joint diagnosis of CFS/ME and fibromyalgia.

> I think for ordinary folk, I prefer to say M.E. now, because everyone understands now. [...] Fibromyalgia is useful for health professionals who, who would be inclined to not believe it exists. So it probably depends on who I'm talking to, which I accentuate.

> [...]
> Um, Chronic Fatigue, I usually put as well: if I'm explaining to someone in an email I'll put both. Because some people understand Chronic Fatigue quite well. I don't like the Syndrome bit, I think, "Oh God, that looks, that's not a good sound for some

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[23] "Tapanui Flu" was CFS/ME name in New Zealand in the 1980s. Like other location-based names, this name was a result of a CFS/ME breakout in the West Otago town of Tapanui (St George 1996).

people", depending who they are? But I, yeah, I just put [both ME and] CFS now and hope that they understand ME/CFS.

Emily also proved to be highly selective on her name choices dependant on the audience. She was very aware of the way in which making claims about names could be used to support her claim that she was the most knowledgeable about her experience of illness.

> I don't like Chronic Fatigue Syndrome, because as soon as I say that, people just think… you're just really tired all the time, and I hate that, that just like… simplicity of it. Because it's so much more complicated. […]Especially the *Syndrome*? Like I don't even understand that word myself, but it sounds like I have something weird. […] And among all things, that isn't the thing I suffer from the most with it, at the moment, anyway. So sometimes I just use M.E., when I just want to […] make people know that they have no idea, because as soon as you say that, they're just like, "oh, yep" and […] and then I [can] say some symptoms. Or I use adrenal fatigue. I quite like that one. [With] adrenal fatigue, there's different stages of it so Chronic Fatigue is quite high up, but a lot of people suffer from this adrenal fatigue um… and they don't even realise it, because our diets and our lifestyles these days means we're drinking all these caffeinated drinks, and salt, and stuff. Which constantly like, boosts up our adrenal, so then they just flatten out.

Through their naming decisions, both Emily and Joan attempted to enforce that CFS/ME made them unwell, while also attempting to control how they were viewed as sick by others. Further, this work was required in order to support my participants' presentations of where they were classified within the cultural conceptions of illness. "Chronic Fatigue Syndrome" alone was problematic for my participants because they were highly conscious of continually constructing CFS/ME as a physical disorder. Nicolette was also uncomfortable with this name.

> I feel embarrassed saying Chronic Fatigue, because you're sort of talking about a specific symptom, as well. Like sort of, instead of saying arthritis, you say, "Hello, I've got sore, aching joints illness!", you know what I mean? [laughs] You know, and that's much more specific and personal and emotional. You feel like you're admitting it. You know, sort of like you're confessing something, you know, like, "I've got Chronic Fatigue", you know, "Oh, have you now?" You know? [laughs] I don't know, it's just something like that about it. Chronic Fatigue is the New Zealand official term, and the American official term, and the doctors will call it chronic fatigue, they won't call it M.E. But this latest magazine thing says, Canada – the International Board, or

whatever they are, have decided that it's going to be universally known as M.E. Thank god for that, because I felt uncomfortable saying Chronic Fatigue.

As mentioned in Chapter Three, the reconstruction of my participants' self-identity could be fragile. For Nicolette, "Chronic Fatigue" had the potential to reveal this fragility to others, which threatened her established realigned self-identity. However, because she now felt comfortable using 'ME' to explain CFS/ME, she could reaffirm the narrative work she employed to assert her new sense of self-identity. Furthermore, she justified the affirmation through research in the field. In the above quote, Nicolette appears to be citing Carruthers et al. (2011:327), who advocated for the renaming of CFS/ME because ME is "consistent with the neurological classification of ME in the World Health Organization's International Classification of Diseases". This illustrates why sufferers and patient network groups are highly informed – both to 'know' their condition and to use that knowledge to construct scientific, legitimised narratives of CFS/ME and their self-identities. Likewise, Noah referenced specific research and the history of the debates around CFS/ME:

> There was a study done in Chicago[24], where they [had] two groups of people: they labelled one group of people with 'Chronic Fatigue Syndrome', they told them to go and access medical health services and say they have Chronic Fatigue Syndrome [and] see how they were treated. [To] the other group [they] said 'Myalgic Encephalomyelitis, go in there'. The ones who said Myalgic Encephalomyelitis got roughly double the attention and respect then the ones who said Chronic Fatigue. The ones who said Chronic Fatigue were basically, half of them were prescribed Prozac or, dismissed. Well, I've looked into it, and especially on that Hummingbird site[25] you can see that um – there's a lot of information about it there. Myalgic Encephalomyelitis is the name that was given in the 19- 1950s, after the outbreak at the clinic, the London Free Clinic, and it very accurately describes all of the encompassing symptoms of M.E. Whereas Chronic Fatigue Syndrome is really not a diagnosis at all. It's a non-diagnosis.

As Noah told the support group at one meeting, the reason many people preferred 'ME' is because it is listed within the WHO International Classification of Diseases as a neurological condition, which granted

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[24] Jason et al. (2002).
[25] http://www.hfme.org/ - a patient advocacy website.

legitimacy to the claims about the organic nature of CFS/ME. The placement of ME here has been alternatively embraced (Carruthers et al. 2011) and criticised[26] (Wojcik, Armstrong and Kanaan 2011a, 2011b), but could be utilised to argue that CFS/ME is a physical – in this case, brain – disorder.

Conclusion

In this chapter, I have shown the way in which my participants constructed highly complex and nuanced understandings of the aetiology of CFS/ME. My participants did this through constructing their CFS/ME as a physical rather than mental disorder, which are granted differing degrees of legitimacy by both biomedicine and the public. By drawing on publically legitimate understandings of medical discourse, public narratives of illness, and ideas of the responsibilised patient, I argue that my participants formed constructions of CFS/ME that worked to publically legitimise their illness experience. My participants also utilised the varied debate over the 'naming' of CFS/ME to control the way in which CFS/ME was classified and understood by others. This illustrates the way in which my participants recognised that they were still socially and culturally seen as disruptively liminal. However, through their explanations of their aetiology, my participants worked to realign the views of friends and family with their own. However, my participants also needed to build explanations for themselves that narratively made sense of their past experiences, as the following chapter will demonstrate.

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[26] Wojick, Armstrong and Kanann (2011a, 2011b) state that "ME" alone is categorised in the WHO International Classification of Diseases as a neurological condition because it means "inflammation of the brain and spinal cord". They argue that if such a specific condition did exist, this classification is appropriate. However, because ME is popularly used as a stand in for or alongside CFS – to which there is no proof of any such inflammation (see CFS/ME Working Group 2002:20) – it is not appropriate. Carruthers et al. (2011) have attempted to argue that CFS/ME should be called ME alone (again). As is characteristic of the CFS/ME field, they have been criticised for these recommendations (van der Meer and Lloyd 2012).

CHAPTER SIX:

THE IMMUNE SYSTEM AND CFS/ME

Introduction

The immune system is one of the most salient medical symbols in our current cultural domain (Kilshaw 2009, Martin 1994). Out of all the theories for the aetiology of CFS/ME, my participants most preferred the argument that CFS/ME is an immunological dysfunction disorder. In the previous chapter, I examined how general explanations of the aetiology and names of CFS/ME were used to create a public representation of CFS/ME. In this chapter, I argue that explanations around the immune system were used to reaffirm my participants' personalised understanding of CFS/ME. I show how this work both illustrates how my participants recognised that there was a final 'step' to be taken with respect to liminality and reintegration. They were, of course, still ill. I argue that ideas of the immune system were used to form a narrative link between their current health status and any past experiences with illness, which legitimised their current realigned selves by absolving them of blame for the condition.

My participants also linked an immune dysfunction with notions of toxicity. One of the core ways my participants felt that they could affect the level of toxins in their body was through conceptions of diet. This helped my participants to fulfil the expectation within advanced liberal democracies that one should take responsibility for one's health, even if it is a form of action that biomedicine may not advocate. However, like with the previous discussion of aetiology, not all of my participants embraced these ideas. This illustrates the way in which the uncertainty of the aetiology and treatments for CFS/ME is a flexible site: my participants reworked these in order to legitimise their experience while simultaneously affirming other sufferers' experiences, even if it was not their own.

In this chapter, I draw on illness narratives, notions of the responsibilised health subject and theories of toxicity, risk and high modernity to show how my participants negotiated and renegotiated these personal explanations of their illness experience.

Biomedical Explorations of Immunological Failure and CFS/ME

Within popular and medical discourses, the immune system is often constructed as militantly defensive, capable of fighting any intruder that crosses its borders (Martin 1990, 1994 and Weasel 2001). However, people with CFS/ME often dismiss such accounts of the immune system's strength. Since the late 1980s and early 1990s, researchers and sufferers have suspected that an immunological dysfunction may be the cause of CFS/ME (Bansal et al. 2012, Caligiuri et al. 1987, Klimas et al. 1990, Lorusso et al. 2009). Researchers argue that because CFS/ME is "often proceeded by viral infections and a 'flu-like' illness", it may indicate an immune dysfunction which enabled the continued problems of CFS/ME (Lorusso et al. 2009:288). Several of my participants (Melissa, Anna, Alexandra and Noah) used their prior diagnosis of 'post-viral fatigue syndrome' in a similar way, arguing that these viruses had damaged their immune systems to the point of their current health problems.

Once again, however, the medical research of the past decades has resulted in "little consensus on the presence, nature and degree of immune dysfunction in this condition" (Bansal et al. 2012). Systematic reviews of the immunological CFS/ME data have failed to establish a clear pattern of proof within these claims (Lyall et al. 2003, Mihrshahi and Beirman 2005). Lyall et al. went so far as to caution future researchers and patient communities alike "that the CFS literature now contains papers with results to support virtually any conclusion about the nature of the immunological abnormalities [and] traditional reviews without priori definitions and quality ratings may be prone

to bias" (2003:88). The difficulty of this research was illustrated by Pariante (2009), who stated that even in cases that seem to show an immune dysfunction, "we still do not know *why* the immune system is abnormal in these subjects", especially because the viruses that occurred prior to the onset of CFS/ME onset varied substantially across research participants (325). For the CFS/ME research community, the likelihood of an immunological basis continues to be argued back and forth yet, once again, the current medical picture of immunological dysfunction and CFS/ME is hazy.

Tailoring the Immune System to Fit

My participants, however, were very clear about the link between an immune dysfunction and the aetiology of CFS/ME. Such a difference between my participants' and their doctors' knowledge-claims has the potential to threaten the sick individual's sense of self-identity, as biomedical practitioners may blame the patient for their failure to find answers (Kirmayer 1988:58). This blame calls into question the legitimacy of both their illness construction and their morality (Kleinman et al. 2010). As Barker (1991) found, this biomedical world-view extends to the operation of the New Zealand medical system. The doubt from doctors meant her participants wondered, "If you are somehow bringing it on yourself because you're not a coper. That is very damaging indeed" (Barker 1991:39). However, after the initial shock of the Disrupted Self, this damage was not apparent for my participants. While other explanations of the aetiology of CFS/ME were primarily used by my participants to provide justification to others (See Chapter Five), the immune system was used to make sense of CFS/ME largely for themselves. The immune system proved to be a rich tool for my participants to justify their treatment choices, make narrative sense of the development of their CFS/ME and reduce the feeling of blame for their condition.

For some of my participants, an immunological dysfunction was used to both shed light on their current health status and to form a narrative link

between their pre-CFS/ME and current selves. This narrative work legitimises their current health status by making it appear to be part of a coherent, reflexive biography (Good 1994:121. See also Williams 1984). In order to fit CFS/ME within the 'flow' of their biography, they reconstructed and highlighted areas within their past where they felt their systems had been compromised by prior illnesses. In these situations, the immune system was understood to become vulnerable under repeated strain (Kilshaw 2009 and Martin 1994): For example, when Noah worked in a small New Zealand town, he was often sick with different viruses and bronchitis because of the poor climate and insulation in his house. Nicolette believed working full-time with children meant that she had encountered more viruses than others. She told me she had also "never felt one hundred percent after" a serious episode of campylobacter. Nicolette's daughter Eva drew directly on these ideas to explain her own development of CFS/ME:

> In Year Seven [of the New Zealand school system], I had a best friend, and [...] she had really bad eczema, and I got a staphylococcus infection off her, and that's when I got – my immune system got completely hit, it was just [pauses] I had nothing left. But I managed to get over that, but then in Year 9, [pause] I had to go to a court case, because my friend was being [pauses] sexually abused, so I had to be the key witness, and that knocked my system. And I ended up getting, gland – oh, wait, tonsillitis, and um, it was like the worst tonsillitis they'd seen in ages, so they had to take them out. [...] I started getting really bad throat infections and stuff, and then I developed glandular fever, and that lasted for six months. And then I remember waking up, like, I think it was about twelve o'clock in the afternoon, and I was like, "that's the latest I've slept in, in like forever". And it was then I thought something was wrong.

While Eva noted that 'sleeping in' was the first clue that something "was wrong", she had subsequently reworked her past experiences of illness in narrative form to make her CFS/ME appear inevitable and 'logical' after these prior exposures. Other participants, such as Anna, did not have specific 'trigger' viruses that they pointed to – rather, the entirety of their medical history were tied into their narratives of the development of CFS/ME. She told me she had often wondered

> Whether something has compromised my system a bit beforehand. When I look at things like, I'm very, I've always been really strong, but something about the stamina,

if I try and get fitter? So I have got queries about different onset things, like maybe there's been things compromised, like pesticides in the past.

The creation of these narrative links also helped my participants protect the work they had put into their new self-identities by absolving them of the guilt of causation. For example, Melissa linked the concept of a weakened immune system to her family's medical history.

> My Mum was on antibiotics from when before she was pregnant with me. And then when she was feeding as well. So I was, in my opinion, pretty stuffed before I was born. Because she had, and she had kidney problems and things like that. So I was kind of on the back foot even before I was born. And my brother has poor immune system too.

Melissa was particularly interesting in the way in which she had constructed her medical history. She had created a seven page document that extensively charted her experience of CFS/ME since falling ill in 2003. It also detailed her family's medical history and what she had called "Habits and Medical History" from before she developed CFS/ME. This included her family's incidences of illness, including her brother's cancer and her mother's kidney problems; a recurring pain in her left ankle from approximately ten to fifteen years of age; recurrent back problems since 2000 and Glandular Fever and Chicken Pox as an adult. As she explained in the above quote, this combined multitude of illness was seen to weaken her immune system. These reinterpretations of the past are part of forming a coherent narrative of the self, answering the question, 'why me?' which illness poses (Evans-Pritchard 1937) and reducing the burden of personal responsibility of blame for the development of CFS/ME. Hyde has argued that the core questions of medical practice in New Zealand, much like Western medicine overall, now ask "'what are you doing to cause your illness?' and 'what behaviours or consumption practices do you need to change?'" (2005:236). Such questions are the product of the increasing emphasis on personal responsibility for illness within the 21st century (See Beck and Beck-Gernsheim 2001, Rose 1996, 2007). However, as Beck and Beck-Gernsheim (2001) have argued, the flipside of responsibility is blame: at any time, we can be considered at fault for the conditions that afflict us. While a weakened immune system through viral attacks or one's family history cannot definitively be proven, my participants produced them as

authentically real through their experience and narratives (Desjarlais 1994). For example, eight out of my nine interviewees claimed that their particular CFS/ME had a viral onset, which they interpreted as their immune system failing to respond in the way it was supposed to, explaining why they developed CFS/ME in the first place. Melissa told me that she took the medical history document she had created to doctors' appointments: it helped her answer the question "what are you doing to cause your illness?" (Hyde 2005:236) with "Nothing – see?" Thus, for my participants, the immune system worked to "make a coherent, inclusive system out of the incoherent" (Kilshaw 2009: 97). It was narratively used to frame their CFS/ME as 'logical' as a result of a history of medical conditions and absolve them of the responsibility of causation.

While on the one hand, my participants sought to absolve themselves of the responsibility and blame of causation, on the other, they were compelled to manage the way in which they were responsible for their health overall (Rose 1996, 2007). This illustrates the way in which my participants saw themselves as long-term liminal, as they recognised they still needed to try to become healthy. The notion that one should take responsibility for one's health was directly emphasised by Nicolette, who argued that "I'd worked out it [CFS/ME] was an immune disorder, and that you had to protect your immune system, you had to heal yourself. That's what it was about". Notions of the immune system were also used to make sense of the way in which people with CFS/ME respond differently to different treatments. Noah explained that for any treatment that was found,

> anything that we try, only one third of people [with CFS/ME] respond to it. Unfortunately with M.E., because it's an immune disorder [pauses] it adjusts the immune system to cope with any changes. And it gets - I'm sure it's an adaptive illness, that's one of the traits of retro-viruses. They adapt to the immune system responses. Or any, or even drug attacks.

Likewise, Nicolette drew upon the immune system to explain Eva's digestive problems. She told me that they are

> aware of the effect things like gluten has [...] because when you have a heightened digestive problem because of an immune disorder, then you know that that's

important [...] Eva's back on gluten free now. Because she's just been... feeling lousy again, in her stomach and stuff. But she's been to a gastroenterologist, and they say there is nothing wrong, so I guess that is good that you've got that base like that: there's nothing serious, that they can see. [...] But there's still an intolerance there, you know? Because your whole system is over sensitised, and I think when your immune system goes hay-wire, everything is over sensitised.

What was most important for both Eva and her mother, Nicolette, was that a gluten-free diet provided relief from her digestive problems, even if there were no test markers for proof of intolerance. To see this as an example of Giddens' (1991) suggestion that individuals in late modernity can choose whatever form of medical knowledge they like and reject the other is too simple. Such a decision around one's claims about illness still needs to be legitimised socially and culturally, both for the self and when asserting this to others. My participants legitimised their decisions around healthcare by drawing on their own experience, the prevalent medical symbol of the immune system (Kilshaw 2009 and Martin 1994) combined with the cultural ideals of consumer choice (Bunton and Burrows 1995) and the 'quest for health' (Beck and Beck-Gernsheim 2001) in late modernity. In this way, my participants could dictate the way in which they chose to take responsibility for their health, even if their conception of what taking responsibility meant clashed with conventional biomedical knowledge-claims.

As Martin (1994) has pointed out, different groups – be they medical researchers or lay members – understand the immune system in a variety of complex and flexible ways. Furthermore, as Kilshaw argued, "the idea of the immune system has become so embedded in popular culture that popular notions of one's own vitality and health are often expressed in terms of perceived immune function" (2009:120). The immune system is thus one of the most prevalent symbols for health and ill health today. For my participants, the immune system was as a flexible site to understand how they became sick in the first place and narratively worked to both explain a variety of contributors to their ill health and the way in which people respond to treatments. Like the Realigned Self as a whole, the immune system is constructed on the terms of the individual, reinforcing their self-identities and shedding light on their own CFS/ME experience.

Toxicity, Diet and the Failure of the Immune System

In my participants' narratives, notions of an increased level of toxicity in the body were one of the core explanations for a compromised immune system. 'Toxicity' was understood in a number of ways. Firstly, "modern life", in which one is exposed to many synthetic chemicals, was seen as poisonous, attacking not just the body but also the environment through pollution and pesticides. Secondly, the interior body could become toxic, poisoning the self and the immune system through the production of acid. The participants who believed that toxicity in the body could affect the immune system argued that toxicity could be altered by food intake – it could be either increased through poor food choices, or decreased by following certain, often restrictive diets. For example, Melissa stated that

> Gluten is one of the [big] intolerances to certain foods [that people know about], but another one that people don't realise is sugar, as well. Like everyone knows that you shouldn't eat too many lollies and all that kind of thing, [laughs] but it's actually a poison! It lowers your immune system and stuff. Which is the worst thing for anyone with M.E.

The narrative linking of diet with the failure of the immune system and CFS/ME was one way my participants tried to manage taking personal responsibility for their condition. By embracing diet as a means for controlling symptoms, even if it is a token effort, it works to legitimise my participants as "really" sick and fulfil the expectation that one will aim to get better within the sick role (Parsons 1991). It therefore narratively worked to support my participants' realigned self-identities. The importance of this was visible at the Christmas lunch of the support group. All of the food brought to share was clearly labelled based upon a variety of dietary restrictions. The group's facilitator had made a vegan chocolate cake and apologised several times that it was not gluten free; Charlotte had cooked gluten-free sausages and chicken, for which, she explained, she had travelled across town. Several fruit salads

were provided, one woman had prepared gluten-free scones, and Joan had made what looked like large, puffed crackers that were gluten free. Emily brought raw, vegan miniature cheesecakes and truffles; she had made them so that the group could see that raw, sugar-free foods could be both enjoyable and healthy. In order to participate, I had brought along a vegetarian and gluten-free pasta salad, and several of the group's members thanked me for taking into consideration any dietary requirements that people may have had. Of note here is that, at this particular meeting, nobody else apart from Emily strictly followed the diets represented by the foods that they brought. Rather, the food that was brought was done so out respect for other members, working to reaffirm the shared narrative links between diet, toxicity, the immune system and health. Emily, on the other hand, fully embraced the links between diet toxicity and personal responsibility.

> Your immune system reacts to foods it doesn't like, it sends out bad fighters, which will tire out your system, if it's doing that constantly. [...] When I got sick again, I went and saw the specialist who does Neurolink[27] in [another New Zealand city]. He did a bunch of stuff on me, but then he was like, "you're just really toxic, you need to go and change your diet". [...] He told me I needed to get a juicer, and start juicing, so I did that, and pretty much started getting better straight away. Since then I have been increasing juicing, and [eating] straight, raw foods, or alkalising foods, we call them; so like, foods that [...] your body doesn't have to produce acid to break down. [...] [The] acid in your body, that acid is what diseases and other things feed off. Also, all [of] your organs go into action mode and try and produce all these minerals like magnesium, and calcium, to try and alkalise your body. So then you become deficient. When you eat fruits and vegetables, your body [...] doesn't make the acid and it becomes alkalised.

While participants such as Emily were willing to take on the personal responsibility of the 'quest for health', notions of toxicity also worked as a means for my participants to deflect the responsibility of blame for the development of their CFS/ME. As Martin (1994) has argued, the 'immune system' can be considered a flexible symbol that is interpreted in multiple ways by different parties. For example, the majority of Gulf War Veterans in Kilshaw's (2009) study believed that they had been exposed to toxins during

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[27] Emily explained that Neurolink was like acupuncture, except instead of needles it worked through the pressure the practitioner placed on certain points of the body through touch.

their war service, which had *irreparably* destroyed their immune system. However, I would like to suggest that this conception of the immune system was because Kilshaw's participants were able to place the blame for their conditions at the foot of the government and the Ministry of Defence. Arguing that the immune system cannot be repaired worked in their favour to claim compensation from the British government for their exposures. Kilshaw herself notes that the only veteran who tried to repair his immune system (also, interestingly, through diet) did not believe his illness was a result of his exposure (2009).

My participants, on the other hand, did not have a united, easily visible enemy that could be used to absolve them of guilt for their condition, nor do they have a vested interest in staying unwell. In seeking to narratively reduce their responsibility for causing their CFS/ME, my participants primarily focused on external agents as the reason why their bodies had come to be in a toxic state. This narrative work fits within one of the culturally salient fears of life within a high modern world, where both the industrialised world and damaged environment cannot be trusted (Brown, Kroll-Smith and Gunter 2000). The speaker at the support group meeting on 'the benefits of raw food for your health' utilised these fears in her talk. She argued that when we are born, our bodies and blood are neutral. However, as we get older, the toxicity and acidity of our bodies and blood increases as a result of the 'Western' diet; specifically cooked foods, meats, sugars, refined carbohydrates, caffeine and alcohol. While diet was a major factor in this speaker's arguments about toxicity, she also pointed out the toxic nature of the environment, pharmaceuticals, living in cities, stress and "negative emotions". We can see the changing nature of food and the environment, living in cities, pharmaceuticals, et cetera which this speaker focussed on as hallmarks of the contemporary industrialised world. The contemporary world is filled with the risk of toxins for all of us, not just those with CFS/ME (Beck 1992, Brown et al. 2000, Brown, Kroll-Smith and Gunter 2000, Giddens 1991). My participants utilised these fears during their interviews. For example, Joan explained that her first doctor told her that her CFS/ME was a result of the

> Immune system being affected completely, which was why I had all these weird and wonderful symptoms all at once. Yeah. Um, all the locals, including him, talked about the spraying that was going on for killing weeds and stuff, farmer sprays, in the area. Yeah, that was their kind of way of thinking in that area really.

Joan illustrates the way in which nature in the contemporary world is considered dangerous and poisonous by multiple parties, as her doctor and "the locals" also feared the threat of pesticides and toxins (Brown, Kroll-Smith and Gunter 2000, Beck 1992). Her understanding of toxins therefore fell within a legitimate social narrative, which she embraced in order to reduce the burden of causation for her CFS/ME. Melissa also drew on the threat of modern life as toxic, arguing that the healthy could also be affected:

> People who even are just generally tired, who don't even have M.E. – Can get a lot of the same symptoms? And they generally call it oxidized stress. That's when your body is subjected to too much toxins, and that's just the lifestyle that we live in. You know, Like the environment, and the fumes and everything, and in our foods, and all that kind of stuff. So I think that, for me, that it is definitely a contributor. But I also think it depends on the person.

The view of a toxic, contemporary world is emblematic of increased notions of *risk* in late modernity (Beck 1992, Beck and Beck-Gernsheim 2001, Brown, Kroll-Smith and Gunter 2000, Giddens 1991). The way in which my participants placed themselves alongside the healthy narratively worked to construct themselves as the unfortunate victims to a threat we all must face. Horne illustrates this nicely when she explained that her participants "saw themselves as canaries [down the mineshaft[28]] of society – a warning to the world of its dire and polluted future" (1990: 27-8). As Gregg (1998), a sympathetic doctor, elaborated:

> What if, like those canaries, you were simply the early warning system for this culture? What if your experiences were exposing mounting health risks for everyone? You are, I suspect, at the far end of a continuum that all of us are on to varying degrees.

Constructing the risks posed by modern life as something that *everyone* may have to face reduces the blame that could be placed on an individual for their

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[28] The phrase, "canaries down the mineshaft" is often used in the online presence of CFS/ME sufferers (Gregg, 1998, Little Bird Awake 2011) and in relation to Multiple Chemical Sensitivities (Valkenburg 2009).

CFS/ME. Comments by my participants and patient advocates such as Gregg (1998) suggest that it is, perhaps, only a matter of time before more still fall ill with CFS/ME. It illustrates one of our fears about life in the modern world: that the environment, despite how much we may have been able to master some aspects of it, is beyond our control, or has become damaged as a result of human influence (Brown, Kroll-Smith and Gunter 2000 and Giddens 1991).

It is important to note that notions of toxicity and diet did not work for all of my participants. The flexible approach that my participants used to understand the aetiology of CFS/ME meant that some of my participants could utilise this flexibility to easily rationalise their choice not to participate (See Chapter Five). This decision was justified by falling back on the legitimacy of one's own experience (Desjarlais 1994). This work was clearly visible at the support group meeting where 'the benefits of raw food' was discussed. Throughout the meeting, members of the support group critiqued the speaker's arguments in a number of ways. When the speaker claimed she had 'healed' people with CFS/ME in the past, and could also heal members of this support group, Joan asked her what her timeframe was for 'healing' someone with CFS/ME. The speaker claimed that, dependent on the individual's circumstances, healing could be instant, and occur within a week. This statement resulted in a wave of murmurs from members of the group. Moments before, the group had discussed how they had repeatedly tried and tried different treatments and that there was "no pill, no strategy" that worked for everyone. One woman explained that she had tried lots of different suggested treatment strategies, but felt that these had mostly just "chipped around the outside of the symptoms but never got to the core" of her CFS/ME. Joan continued to push the speaker on her healing claims, stating that while she knew everyone was different, she wanted to know the outlying expected maximum timeframe for this healing. The speaker stated that she believed "in 30 days, I could make someone feel like a new woman or new man through diet and juicing". At this point, the speaker moved on to a different topic but after she had left, Anna and Joan returned to discuss the issues she raised. Anna's voice rose slightly as she exclaimed she was tired of people who argued that they could "guarantee" healing her, as she had had lots of people promise

this without any success, which frustrated both herself and the practitioner (See Chapter Four). Others critiqued her in more subtle ways, without denying the claims she made. For example, twenty minutes before the end of this meeting, one woman removed large, obvious headphones from her bag, placed them over her ears, and shut her eyes for the remainder of the meeting. In another instance, the speaker claimed that one must eat organic food and juice as much as possible. The support group co-ordinator responded, asking "what happens if you don't have the luxury to do all of that? If you have children, or are on a low-income?" to which several other members of the group had murmured agreement. The speaker repeatedly shut down questions such as this by claiming that an organic diet was affordable and did not engage any further along that line of discussion, which led some of the group's members to openly reject her views of the body and the immune system after she left.

My participants also critiqued notions of diet and toxicity during our interviews. Once again, my participants utilised the explanatory power that drawing on one's own experience can provide (Desjarlais 1994) combined with the culturally accepted ideal of consumer choice. For example, Joan had a bad experience with an alternative doctor who put her on a diet low in sugar and wheat; when she did not experience "any benefit whatsoever, I gave it up again". The failure of this diet was reframed as "not eating right", especially as it resulted in significant weight loss. She did, however, point out the benefits of foods without pesticides or additives:

> I noticed at times, my husband was a really keen gardener, and when he was providing all our vegetables, I realised over time I felt better. And I could only tell looking back, when we were living somewhere without a garden, I'd feel really bad and that happened several times. And I thought, that is quite remarkable to notice. Something about fresh, fresh stuff in the garden, with no pesticides and chemicals in it. I can't prove it but it seemed to be more than a coincidence.

Joan illustrates the way in which the individual's own experience is considered the most authentic form of truth when reflecting on toxicity and the effects diet may have on CFS/ME (Desjarlais 1994). Others rationalised never taking part in diet as a treatment by falling back on popular notions or

their own reasoning about nutrition and health. When I asked Alexandra whether she had tried using diet management as a means of controlling her symptoms, she argued that

> for me it's more like, I'm more trying to make sure my body has all the normal components. And having been tested for, my blood has been tested so much, I know that there's nothing missing. [...] Some people want to take massive doses of Vitamin C. on the grounds that it doesn't harm you. But actually, it causes you to have a kidney stone... Yeah, I'm sort of saying to them, "No!" And the thing is, most of the Vitamin C you buy... I was looking at it, and it's got more than the recommended daily amount in it. A lot of them are like, 1000[mg] and you should take 750, really. I just think, "God, what are people doing?!" So I'm trying not to go down that road too – I've also noticed that a lot of people in the, what I've read is that a lot of people with M.E. think that they've got food allergies, and toxins... I don't feel like that at all.

Noah also used notions of what was "normal" to justify his reluctance to use diet as a means to control his symptoms. He said that "you've got to have your vege[tables]" and that he "always do[es] better if I have two eggs for breakfast", but ultimately, Noah felt that once you digest food, "it's all yellow mush inside of you [laughs] it all looks the same". As Noah shows, then, it is clear that my participants utilised common notions around immunity, toxicity and diet in order to support their own position – whether it involved taking part or not taking part. Such variety in the way participants were able to 'play' with these theories to inform their own understanding of causation and treatment is available to people with CFS/ME due to the lack of consensus around the illness itself and its definition.

Conclusion

In this exploration of aetiology, I have shown the way in which my participants utilised notions of the immune system and toxicity in order to create a view of CFS/ME that explained both why they developed CFS/ME in the first place and to deflect any blame of causation that may be levelled at them. Because my participants recognised that they were on the borders of legitimacy with regard to their CFS/ME, they had to develop these

conceptions of CFS/ME in order to sustain the development of their Realigned selves.

Secondly, my participants utilised ideas of the immune system and toxicity to decide the way in which they would – or would not – accept responsibility for dealing with the condition. By presenting themselves as responsible, my participants fit themselves within the expected role of the patient in advanced liberal democracies, even if this involved conceptions of illness and the body which are outside of standard, biomedically accepted definitions.

CHAPTER SEVEN: CONCLUSION

Throughout this thesis, I have shown the way in which the experience of CFS/ME affected my participants' self-identities, their social and cultural roles, and their imagined relationships with family, friends, doctors, and society as a whole. In Chapter Two, I argued that the initial experience of falling ill seriously damaged my participants' ability to draw on their previous markers of self-identity, such as their bodies, their familial and work-related roles and their plans for the future. Furthermore, the experience of being doubted and questioned by family, friends and doctors destabilised my participants' self-identities when both of their expectations of each other fell short. This led to what I called the 'Disrupted Self', where everyone in this situation, my participants, their familial and social networks and their doctors, saw my participants as liminal beings, falling outside and between culturally accepted categories of illness, the sick person and the roles of a person within work, school, friends and family. However, as Chapter Three illustrated, individuals in late modernity constantly work to stabilise their sense of self-identity, even in the face of adversities such as sickness and delegitimisation. I argued that through the process of prioritising their health, reworking their relationship to familial and work-related roles, and critiquing capitalism, my participants worked to realign the self. However, my participants still recognised and felt pressured by the cultural expectations of healthy individuals in advanced liberal democracies. This showed how my participants came to inhabit a long-term, stable liminal state. Here, the importance of framing their self-identities as positive overall was revealed: it legitimised both their rejection of wider cultural goals and the on-going struggle of living a life with disability.

However, as both Chapter Three and Four revealed, these realigned self-identities sometimes conflicted with the way in which CFS/ME and my participants' were remained conceptualised by others. I argued that this

reveals the *perspectival nature of liminality*, where others can cast an individual as chaotically liminal, even when that individual now understands their view of themselves as stabilised again. In order to counter these views, my participants firstly attempted to engage with their families, doctors and friends in order to reformulate their views. This was often successful, and many of my participants felt that others, especially their families, had come to understand their CFS/ME. I argued that this showed a realignment of views, which provided my participants with social recognition for their experience and new constructions of themselves as stabilised long-term liminal beings. In other instances, however, this work was not successful, and my participants were still unable to be categorised both by and within these important relationships. In these instances, my participants cast the other in these relationships as lacking knowledge, both about the "reality" of CFS/ME and their skills, roles and self-identities. I argued that this helped my participants to protect their personal constructions of their Realigned self-identities, for it enabled my participants to prioritise their own experience and reject the view of others.

Despite the contestation around the aetiology of CFS/ME, my participants created highly specific, varied understandings of what the aetiology, trigger and nature of CFS/ME was for them. In Chapter Five, I showed how my participants utilised this contestation as a flexible site in order to create publically justifiable presentations of their CFS/ME. They did this through using specialised medical language in combination with common medical symbols, strategic explanations of symptoms, and finally, through controlling the way in which CFS/ME is named by their family and friends. In Chapter Six, I argued that my participants primarily utilised ideas of the immune system to create personalised narratives of their experience. The failing immune system worked to place CFS/ME as part of a cohesive narrative of the progression of illness. Falling ill with CFS/ME appeared inevitable as a result of their exposures to different viruses either immediately preceding their development of CFS/ME or throughout the entirety of their medical history. The linking of the immune system with notions of toxicity and diet were useful in order to prevent my participants' blaming themselves

for their CFS/ME by constructing themselves as the unfortunate victims of the contemporary world, to which anyone may become a victim. Secondly, the use of diet meant my participants could work toward the expectation within the contemporary world that one will both take responsibility for and attempt to improve one's health (Rose 1996, 2007).

This thesis works to fill a gap in the literature on the experiences of New Zealanders with CFS/ME. While there have been some anthropological explorations of CFS/ME in New Zealand, these works have focussed on visual representations of CFS/ME (Gibbons 2010) and the psychological effects of having CFS/ME (Horne 1990). Other social scientific work has focussed solely on stigmatisation (Barker 1991) or the link between explanations of illness beliefs and coping mechanisms (Moss-Morris, Petrie and Weinman 1996). My work is therefore unique within a New Zealand context by both revealing the way in which my participants' sought to address stigmatisation from others and to build and rebuild their relationships to themselves, to others and to CFS/ME itself. It moves past the exploration of illness beliefs with regard to CFS/ME (Moss-Morris, Petrie and Weinman 1996) to show how my participants created nuanced, strategic explanations of the aetiology in order to morally reaffirm and legitimate the developments in the self-identities to both themselves and others. This work is also the only *ethnographic* study of a CFS/ME support group in New Zealand. There is also an absence of ethnographic literature into CFS/ME support groups internationally (see Bülow and Hydén 2003, Horton-Salway 2004). My thesis therefore shows the way in which people with CFS/ME do not just build narratives for themselves, but built upon and shared narrative explanations about the body, illness, toxicity, diet and health together.

Finally, this work fits within other medical anthropological exploration of liminal experiences and chronic, contested illnesses (see Dumit 2006, Honkasalo 2001, Jackson 1992, 2005, Kleinman et al. 1992). The little published work with regard to liminality and CFS/ME[29] (Dumit 2006) has primarily focussed on the experience of stigmatisation. Jaye and Fitzgerald

[29] Whitehead (2006) argues that the experience of CFS/ME is marked by three phases: "Quest, Chaos and Restitution". While the narratives of her participants' could also be analysed through liminality, she does not apply the concept.

(2012) recently noted that there are multiple liminalities within the narratives of New Zealanders with Occupational Overuse Syndrome. Likewise, my thesis illustrated the way in which there are multiple dimensions, perspectives and degrees of liminality within the narratives of my participants. I hope to contribute to the field of medical anthropological analysis by demonstrating how liminality could also be considered to be both shifting and perspectival. It helps to explain the way in which my participants viewed themselves at different stages of their illness experience *and* the way in which they were seen by others. Finally, the use of liminality to show the way in which my participants were seen by others helped to explain *why* my participants were sometimes stigmatised or doubted; even when they had reworked their sense of self-identity others found them difficult to place within the categories that they relied on to make sense of the world.

Like all works limited by time, this thesis has limitations. Further work could explore the narratives of those who associate with and care for people with CFS/ME in order to gauge the way these groups engage with and understand people with CFS/ME, rather than solely relying on the narratives of those with CFS/ME. Furthermore, it would be interesting to examine how those who have recovered from CFS/ME regard their prior liminal experiences once they are beyond them, and how such chaotic and realigned experiences transform their identities long term. Like Jaye and Fitzgerald (2012), I argue that medical anthropology overall could benefit from further applications of liminalities, especially in ways that reveal the fluidity of viewpoints that determine liminal experiences and stages.

Ultimately, I hope to have provided a detailed ethnographic window into the personal experiences of those who live with and make sense of CFS/ME, and to reveal their daily challenges, strategies and aspirations. It is important to remember that my participants are still sick. None of my participants had recovered at the conclusion of this research project: they all had to face the daily, physical struggle of living with a disability that bestows little in the way in social and cultural legitimacy. As the reality of living with CFS/ME continued onward, so too did the battle to maintain what I have

called their Realigned self-identities. As Nicolette told me at the end of our interview,

> we just keep on; keep on working on self-improvement, and trying to do more [trails off] but respecting our condition as well. […]I hope you get a lot about how we tick, and um, obviously a lot about health! And the human body, the spirit, you know, self-esteem and… And appreciate life. Value what you have.

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