Pre-illness to post-recovery:
A Journey.

The lived experience of
Myalgic Encephalomyelitis or
Chronic Fatigue Syndrome
(ME/CFS)

By

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Abstract

This thesis contributes an original perspective to the current Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) literature. The programme of research reported here aimed to provide an account of the whole of the sufferer's journey from prior to the illness through the illness itself and beyond to the recovery period. This is in contrast to much previous literature which focuses just on the period of 'illness'. The present study aims to document the ways in which ME/CFS is formulated as a controversial chronic illness and extend this to consider the 'culture of contention' surrounding claims of 'recovery'. This research adopts a combined theoretical approach of grounded theory and social constructionism. The data set comprises 8 hours of interview data based upon 36 initial interviews and 6 follow-up interviews conducted a year later. Data was analysed using constructivist grounded theory. By adopting this approach it was possible to ensure that findings were firmly grounded in the data whilst also being able to highlight unique features of speech such as the participants' use of financial language to explain how the illness impacts upon their energy levels. The first analytical chapter, *Liminality* proposes that the participants' experiences of being ill with ME/CFS or being in partial or full recovery can be interpreted as liminal because they are continually stranded in between the socially constructed categories of being 'ill' and being 'well'. The *Biographical Disruption* chapter introduces the notion that there is a continual 'balancing act' for the participants to manage as things like trying to improve their health, can cause new, additional disruptions. *Identity and the Self* explores the participants' accounts of being mentally and physically disempowered by ME/CFS as they become unable to participate in even mundane activities. Their descriptions are likened to being held 'under siege'. Finally, *A Longitudinal View* revisits the participants after an interval of a year and provides an insightful exploration the ongoing difficulties that the stigma associated with being ill with ME/CFS continues to cause. Including being unable to talk about either being 'ill' or 'well' and managing concerns that the illness may return. The findings of this research add a new dimension to the chronic illness literature and illustrate some previously undiscovered problems and dilemmas that people with ME/CFS may encounter. It is envisaged that these enhanced understandings will be beneficial to the medical profession and carers as well as people with ME/CFS themselves, their families and support networks.

Acknowledgments

Contents

Chapter 1

Introduction

This chapter provides a brief introduction to ME/CFS, introduces the inspiration and motivation which underlies the formulation of this thesis and provides an outline of the content that follows.

In attempting to provide a definition of ME/CFS, it is important at the outset to note that the syndrome is steeped in a history of controversy and intrigue. It is known as the illness of many names (Bell, 1991) as its aetiology, specifically whether the illness is physiological or psychological, remains unclear and this lack of clarity has led to many different diagnostic propositions. Although the debate over the origins of ME/CFS is not the focus of this thesis it nonetheless informs the participants' perception the illness and their experiences of it.

Myalgic Encephalomyelitis (ME) or Chronic Fatigue Syndrome (CFS) is classified as a debilitating chronic illness and sufferers report experiencing an array of unspecific, seemingly innocuous symptoms including: 'persistent physical and mental fatigue that does not go away with sleep or rest (after mental or physical activity that was previously manageable without feeling fatigued), muscle and joint pain, painful glands in the neck or armpits, a sore throat and headaches, forgetfulness, memory loss, confusion or difficulty concentrating, sleep disturbances (waking up feeling tired or un-rested/having trouble getting to sleep), flu-like symptoms, and dizziness' (BUPA, 2012; ME Action UK, 2012; NHS Choices, 2012). The symptoms are recognised as constantly fluctuating, however the reason for the diversity in the type and severity of symptoms that sufferers experience is unclear (Jason, Richman, Rademaker, Jordan, Plioplys, Taylor & McCready, 1999; Meeus, van Eupen, van Baarle, De Boek, Luyckx, Kos & Nijs, 2011). This in turn causes problems for diagnosis as the symptoms are so diverse there is no definitive medical test to confirm a diagnosis of ME/CFS; instead physicians rely on a diagnosis of exclusion (National Institute of Clinical Excellence (NICE), 2012). This involves the physician testing for any other medical conditions

which may fit the symptoms in order to eliminate them and when there is no other explanation, ME/CFS may be proposed instead.

As there is no clear aetiology for ME/CFS and it has 'medically unexplained symptoms' (MUS), it falls into the category of being a contested illness along with other conditions such as Morgellons (Savely & Striker, 2010), Multiple Chemical Sensitivity and Gulf War Syndrome (Jones & Wessely, 2004). The impact of being labelled as a chronic illness is discussed in more detail below. However, for people with ME/CFS (pwME/CFS), this categorisation does not reflect the level of pain and distress that they can experience, as noted above. The extent of suffering that pwME/CFS experience has been described as being debilitating (Goudsmit, Stouten & Howes, 2009; Hammond, 2002,) and more disabling than Multiple Sclerosis (MS), mononucleosis, Acute Myocardial Infarction (MI) and type II diabetes (Komaroff, Fagioli, Doolittle, Gandek, Gleit & Guerriero et al, 1996). The level of suffering that has been observed and described aligns the subjective *experience* of having the illness with other, more serious conditions.

The incongruity between how ME/CFS is categorised as an illness and the level of suffering that is described by people suffering is directly related to the controversy and debate that surrounds the condition. As I shall discuss in Chapter 2, the historical context of ME/CFS is important as the same controversy informs current medical and lay perceptions of the illness as well as influencing participants' experiences.

My choice of research topic is based on personal experience which began in November of 2001, when my husband, Adrian, collapsed at work and was hospitalised because he was unable to walk, talk or co-ordinate himself in any way. At the time he was advised that he had 'probably' suffered a stroke. It wasn't until several months of extremely poor health and many medical appointments later that he was finally given a diagnosis of ME (Myalgic Encephalomyelitis) by the hospital. Whilst not having a diagnosis was an incredibly stressful time filled with uncertainty and concerns about what *could be* wrong, receiving a diagnosis of ME introduced its own series of problems as we found ourselves plunged into a world of controversy populated by doubts, scepticism and disbelief. Although ME presented some physical difficulties for Adrian, most notably constant fatigue and relentless pain, which

became unbearable at times, he talked about finding the psychological impact of the illness hardest to manage. In a relatively short space of time he lost his job, independence, income, social life and most of his friends which was utterly devastating. Moreover, he felt that he was powerless to do anything about the illness and subsequently get his life back as there was no medical help available. Information in the public domain was difficult to navigate and he felt unable to explain to people "I'm ill, I have ME" because of the negative reactions that he had so far experienced from other people. It was a very trying and difficult situation and one that became the catalyst for this research. As I made connections with the ME community and started conducting interviews, during the course of this research, I discovered that this situation was far from unique.

What was interesting about talking to people with ME was the emergence of a pattern. In order to facilitate any form of conversation about ME, as newcomer to the group, I had to explain my personal experience of it *before* people would talk to me about theirs. Over the course of the research this pattern was replicated in one to one communications as well and most surprisingly also amongst people who described themselves as 'recovered'. It seems that having ME was not treated as 'common knowledge', rather it comprised information which was imparted to the chosen few, who were deemed to be capable of understanding without judgment. Once this obstacle was overcome I listened to countless stories from people whose lives had been cast into complete disarray because their illness had caused a series of problems and dilemmas. ME, I discovered, was troublesome for people, not only because of the problems associated with being ill, but because people affected by it found it difficult to talk openly about their experiences for fear of being stigmatised. It was this that provided the starting point for this thesis. Put simply, I wanted to know, *Why*? What social systems were in play to cause this situation?

Throughout the research process I interacted and consulted with members of the ME/CFS community and listened carefully to the issues that they highlighted as being important and relevant to their lives, illness and needs. At the same time I interrogated chronic illness literature and information relating to ME/CFS to discover that some of what people were describing was represented differently or was indeed missing from the literature. As Chapter 3 explains I used this information to inform the development of my research

questions, thus ensuring that they addressed gaps in the literature and represented issues of importance to the participants

One of the first things that I address in the following literature review chapter is the confusion surrounding the name of the condition. In this chapter I have referred to it as ME, purely because most of my participants talked about having 'ME' rather than having either Chronic Fatigue Syndrome (CFS) or having ME/CFS. As I explain, the names go beyond being a label for the illness; they each have a very different meaning and significance not only for the person with the illness but for the medical profession as well. Throughout the thesis I refer to 'ME/CFS', as the medical profession express a preference for the latter term and this hybrid has become a compromise in the UK.

When I began my literature review I found that there was an extensive amount of information about ME/CFS distributed across the domains of medicine, science, social science, nursing, employment, complementary medicine and ME/CFS charity and support group literature amongst others. The literature covers a diverse range of topics ranging from potential neurological implications and possible viable treatment options on one end of the scale, through to advice on welfare and self-management strategies on the other. It quickly became apparent that in any arena ME/CFS is divisive, as even within the medical and scientific literature there were opposing views both on what ME/CFS actually is (i.e. physical/psychological) and the best way of treating it, which made the task both interesting and daunting. In fact as I suggest in the literature review it seemed that for every argument that was proposed about ME/CFS there was an equal and opposite counter argument. The second striking thing was that there was relatively little research in the social science arena in comparison with other areas. Finally there was very little literature at all that looked at 'recovery' instead of 'illness' although there was some limited documentation of it in the ME/CFS literature.

I was primarily interested in what has been termed the 'experience of illness', the 'insider perspective' (Conrad, 1987) or 'the patients view' (Armstrong, 1984) and, therefore, I also reviewed literature pertaining to the subjective view of illness. I included research that looked at other contested illnesses such as fibromyalgia, morgellons and seasonal affective

disorder because I was interested in building up an overall picture of what living with a contested illness was like. I also reviewed the chronic illness literature, ranging from rheumatoid arthritis to cancer, which allowed me to gather an insight into the patient perspective of what living with an uncontested chronic illness may be like. Gathering this information was invaluable, because it enabled me to develop extensive background knowledge of how *people* managed being chronically ill, regardless of the medical complaint. I also referred to information disseminated from ME/CFS support groups, which was varied and interesting as it ranged from information and advice about illness management strategies, to medical and scientific research into ME/CFS from other countries. Overall, there was an extensive and diverse range of literature to review that has helped to frame this research and inform the theoretical framework.

The scale of the literature review and the diverse nature of the material meant that it produced many interesting topics that I would have liked to have pursued further in the literature and explored within my own data. However, it transpired that although undoubtedly interesting, much of this earlier reading was not very relevant to my theoretical approach or analytical topic and had to be left out of the final thesis.

Accounts of ME/CFS are stories that unfold in a particular way depending on who is telling the tale. ME/CFS is a controversial illness and one that is difficult for sufferers and people in recovery to talk about, and it also makes, normal, everyday conversations with other people problematic too. My analytical interest here is understanding how people talk about and manage their experiences of this controversial and often stigmatised illness. Therefore I examine some of the difficulties, challenges and dilemmas that pwME/CFS encounter during their pre-illness to post-recovery journey.

Drawing on my review of the academic literature and the body of anecdotal knowledge that I had gathered from my interactions with pwME/CFS, I was drawn towards using constructivist grounded theory (CGT) (Charmaz 2000; 2006) in order to examine the participants' experiences. Constructivist grounded theory is the ideal approach to exploring how people experience both illness and recovery from ME/CFS as it presents a flexible framework within which it is possible to look at how people construct events across the data

set as a whole. This approach also allows for in-depth exploration of interesting or unique features that arise from individual accounts. As the title "Pre-illness to post-recovery" suggests, I am adopting the position that ME/CFS is a journey and this medley of methods does not impose any expectations onto the participant. Instead it allows the participant to focus on issues that are relevant to them and salient to their experience of 'illness' or 'recovery' and these methods provide a way by which the meaning of these experiences can be understood.

I have organised my four analytical chapters in a way that reflects the journey from pre-illness through to post-recovery. They are divided into four themes which illustrate different points in this journey, as it seems to be the clearest way of presenting the data.

1.1 Thesis Overview

The participants are men and women who have received a medical diagnosis of Myalgic Encephalomyelitis (ME) or Chronic Fatigue Syndrome (CFS) in the UK and who volunteered to talk to me about their experiences. The thesis is divided into the following chapters:

Chapter 2 reviews the ME/CFS literature relevant to this thesis and provides an insight into the cultural context which shapes how participants construct their experiences. In order to illustrate how ME/CFS has become synonymous with being a contested illness, I outline what I call the 'culture of contention', as well as providing some brief historical context. The 'culture of contention' is so called because all aspects of ME/CFS from what the illness actually is (i.e. psychological or physical) are hotly debated, even within the same disciplines. For example, the medical profession present opposing views about whether ME/CFS can be regarded as a psychological or medical condition which has led to the illness being referred to as both Myalgic Encephalomyelitis and Chronic Fatigue Syndrome ME/CFS. I discuss how this background of debate and contention has shaped the construction of the illness and led to an aura of confusion for people who are affected by it. I also discuss ME/CFS in relation to the general chronic illness literature and explain how citing it in this category can also be contentious as chronic illnesses are constructed as being lifelong conditions which people are not expected to recover from and yet it seems that recovery is possible amongst people

with ME/CFS (pwME/CFS). Finally, I also discuss the construction of 'recovery' and what this means in a medical sense and also in areas where, like ME/CFS, claims of recovery cannot be medically verified, such as mental health and alcoholism. I illustrate that the tensions that I outline form the basis for the scepticism and disbelief that surround the condition and make it something that is very difficult for people to talk about. So this chapter reviews the way researchers have studied how people construct troublesome and sensitive issues.

Chapter 3 introduces my chosen theoretical and analytical approach. The research draws upon two theoretical paradigms which are social constructionism and grounded theory and analysis is informed by constructivist grounded theory. I emphasise how these seemingly opposing paradigms and approaches can be merged to the benefit of the data set. This chapter also describes the process of finding participants and how I selected and presented data for analysis.

Chapter 4 is the first of four analytical chapters which discusses the patients' experiences in the context of 'liminality', which is the concept of being 'betwixt and between' two social categories, which are in this case 'health and 'illness'. I illustrate that the notion of being liminal is fitting, for the contradictory way that ME/CFS, as an illness is constructed within the literature. It lies in a limbo state between being a psychological and a physical illness and is classed as a chronic illness, yet presents a dichotomy because recovery is deemed possible. Liminality is also fitting for the way that participants talk about their experiences at various points of their pre-illness to post-recovery journey. The chapter is divided into four themes which look specifically at certain points in the patient experience such as, diagnosis, early illness experience, the on-going stage and recovery. One of the interesting features I explore here is how participants at each stage frame their experiences in a manner that can be construed as 'liminal' and I focus on the language they use and the context that they draw on in order to do this.

Chapter 5 builds upon the theme of liminality by exploring how participants account for the impact that ME/CFS has upon their lives. I loosely draw upon the concept of biographical disruption, but focus upon how the participants talk about how disruption affects their lives at four different stages of the pre-illness to post-recovery journey. Of particular interest

here, is how the notion of biographical disruption seems to be a feature of both pre-illness and post-illness experience. I also draw attention to the language that people use to illustrate how and why they consider their lives to have changed.

Chapter 6 further builds on Chapters 4 and 5 and focuses on how the participants describe the impact that having ME/CFS has upon their sense of self. The analysis examines how people reconcile becoming ill with their sense of 'who they are' and how they construct this differently at different stages of their illness experience. In particular, I look at the language they use when they talk about these challenges and focus on the way that this changes at different stages of the journey.

Chapter 7, the final analytical chapter, is slightly different to the others as it draws on the longitudinal element of this research which focuses on how the participants' lives have changed one year later. This chapter focuses on how the participants talk about changes in their lives over the past year and I illustrate salient points by drawing on the similarities and differences with the previous three themes.

Chapter 8, the final chapter of the thesis, summarises the findings of the analytical chapters. I discuss how these findings can contribute to our overall understanding of how people experience ME/CFS, and draw together how the participants talk about the problems they face at different stages of the pre-illness to post recovery journey. I discuss how my chosen analytical approach can reveal how participants themselves construct stages of illness, such as being partially or fully recovered and I suggest that with each stage on the journey, participants are faced with different dilemmas that they have to manage. Finally, I will discuss how extending research beyond the 'illness experience' can reveal different ways of understanding the far reaching effects of ME/CFS, useful not only for those affected but for those who are involved in their care. In addition looking at a contested chronic illness, such as ME/CFS in terms of the whole pre-illness to post-recovery journey promised to add a new and exciting dimension to the chronic illness literature. It represents an area of research that to date has been neglected, but can provide a valuable insight into how people perceive and manage the different stages of chronic illness.

Chapter 2:

A review of the Literature
Introduction

2.1 Introduction

This chapter aims to provide a historical introduction to ME/CFS and present some background to contextualise the extensive controversy that shrouds the illness. It will explain how this appears to influence every aspect of it, causing debates about everything from aetiology through to the best treatment options. As this controversy is so widespread it is suggested that ME/CFS sits within 'a culture of contention' which has a bearing on how ME/CFS is perceived and as a consequence can lead to stigma[1] and scepticism from other people. The chapter also reveals that ME/CFS has a precarious standing within the chronic illness literature because both medical and lay circles suggest that it is possible to 'recover' from ME/CFS (e.g. Bell & Bell, 2010; Knoop, Bleijenberg, Glielissen, van de Meer & White, 2007). This means that ME/CFS is incongruent with the notion that chronic illnesses are lifelong conditions.

Therefore, as the literature review will suggest, pwME/CFS experience some similarities with people with other chronic illnesses, some similarities with sufferers of contested illnesses, as well as some similarities people with medically verifiable illnesses where 'recovery' is possible.

The literature review provides an overview of the socially constructed categories of 'health' and 'illness' as well as outlining how ME/CFS is constructed as both a 'chronic' and 'contested' illness.

2.2 What is in a name? A historical view

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[1] Stigma is defined as a socially discrediting feature of the body or character (Goffman, 1963)

One of the most noticeable things about this illness is the dual name of Myalgic Encephalomyelitis and Chronic Fatigue Syndrome (ME/CFS). It is unusual for illnesses to be referred to by two separate names and to the author's knowledge, ME/CFS is the only condition, contested or otherwise, to be consistently known in this way. The issue for ME/CFS is that the name of ME or CFS or ME/CFS denotes much more than merely a label as each has become suffused with meaning and assumptions about the illness. This is particularly problematic because, from the way they are historically constructed, Myalgic Encephalomyelitis and Chronic Fatigue Syndrome can be perceived as being *separate* and distinct conditions which have little or no correlation to each other. However, at the same time they are commonly regarded as being one and the same illness when they are referred to as ME/CFS.

The medically unexplained symptoms of ME/CFS encapsulate a historical conceptual problem which has led to the illness being given many names and descriptions over the years in an attempt to quantify and address it. Some authors suggest that there are similarities between ME/CFS and neurasthenia which was prevalent in the 1900s (Greenberg, 1990). However, the illness has also been entwined in medical arguments and linked with a range of viruses which have led to claims that the illness is physiological in nature (e.g. Acheson, 1959; Lombardi, Ruscetti, Das Gupta, Pfost, Hagen, Peterson et al, 2009).

2.2:1 Myalgic Encephalomyelitis (ME)

It seems that symptoms resembling ME/CFS have been occurring in the western world throughout the 20th and 21st centuries and they have been conceptualised in different ways, which has led to ME/CFS becoming known as 'the illness of many names' (Bell, 1991)[2]. Although individual cases were reported, typically the illness has been described as occurring in 'outbreaks', and affecting large numbers of people over a period of time. Outbreaks are

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[2] Known names include Icelandic Disease, Chronic Epstein Barr Virus Syndrome, Royal Free Disease, Post Viral Chronic Fatigue Syndrome, Poliomyelitis, Chronic Fatigue Syndrome, Myalgic Encephalomyelitis and most recently Myalgic Encephalopathy. In the UK the names Myalgic Encephalomyelitis and Chronic Fatigue Syndrome are most commonly used.

often considered to centre around an institution of some type and have been documented as happening throughout different parts of the world[3]. Arguably the most influential of these occurred at the Royal Free Hospital in London in 1955, when there was an 'outbreak' of a mystery flu like illness with accompanying inexplicable symptoms (Ramsey, 1957).

At the Royal Free Hospital it was documented that over a three month period in 1955, 292 people, including staff and patients, contracted a flu like illness with additional symptoms such as malaise, headache, low-grade fever, sore throat, nausea, severe depression, emotional lability, neck, back, limb and chest pain, dizziness and vertigo in almost all cases. Many also displayed the following: tender lymph nodes, enlarged liver, lymphnadenopathy, muscle twitches and spasms and sensory loss (Ramsay & O'Sullivan, 1956). Although these symptoms are ambiguous and could be considered indicative of a number of immune dysfunctions, attending medical physicians Ramsay & O'Sullivan (1956) cited them as evidence of the Central Nervous System, cranial nerve, brainstem and spinal cord being involved in the presentation of the illness. Ramsay (1957) coined the name Benign Myalgic Encephalomyelitis to describe the illness as it translates as *Myalgic,* meaning muscles, *Encephalo*, meaning brain and *Myelitis* meaning swelling of the spinal cord. Similar 'outbreaks'[4] reportedly occurred in the London area at around the same period of time (Hill, Cheetham & Wallis, 1959) and medical tests at these locations were considered to further support the medical findings of the Royal Free Hospital. There was a consensus in the UK and in other countries that the illness symptoms patients displayed could be logically explained by a biological or neurological condition as they appeared to mirror the symptoms of polio which was prevalent at the time (Acheson, 1959). In 1969, the World Health Organisation classified Myalgic Encephalomyelitis under 'diseases of the central nervous system' (ICD- 10; G93.3) along with post viral fatigue syndrome.

This event plays a significant part in the history of ME/CFS and in the social construction of the illness as it heralded the name 'ME' and seems to represent the stage at which these

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[3] 1934 Los Angeles County Hospital, USA (Gilliam, 1938); 1939 Harefield Sanatorium, Middlesex England; 1939 St. Gallen, Switzerland; 1949 Adelaide, Australia; 1952 Copenhagen, Denmark; 1954 Seward, Alaska; 1955 Dalston, Cumbria. – Information taken from Hyde (2010).
[4] Addlington Hospital, London (Hill, Cheetham & Wallis, 1959) and unspecified area of North London (Ramsay 1957).

innocuous symptoms were connected with a medical phenomenon. It appears that many other viruses have been implicated and later discredited as being contributory factors to ME. These have included the 'Coxsackie B virus' (Bell, McCartney & Riding 1988), Epstein-Barr virus (Zbinden, Kurer, Altwegg & Weber, 1996) and Parvovirus (Heegaard & Brown, 2002). Although the relevance of these findings to ME are heavily disputed they seem to have reinforced an association between the innocuous symptoms of ME and other illnesses which have a medical basis. This may explain why the label of ME appears to be synonymous with a conviction that the illness has a physiological basis (Horton-Salway, 2007), as it draws on this historical context whereby the ME is associated with something medically tangible. This is seen to directly oppose the label of Chronic Fatigue Syndrome.

2.2:2 Chronic Fatigue Syndrome (CFS)

In the absence of a satisfactory medical explanation for the illness, McEvedy and Beard (1970) proposed a psychological one. They argued that the 'outbreak' at the Royal Free Hospital and some of the others which were documented throughout the world, were actually cases of conversion disorder or mass hysteria, rather than being an organic medical phenomenon. They suggested that *some* of the described symptoms could be explained by features of mass hysteria, specifically fainting, nausea, malaise, abdominal pain, headaches, convulsions, tremors and hyperventilation. However, they failed to account for the remainder of unexplained symptoms such as lymphadenopathy and fever which do not present with mass hysteria and yet were consistent across all of the outbreaks (Compston, 1978). Nonetheless, this psychological explanation came to be regarded as being highly plausible and similarities were noted between CFS and neurasthenia (Greenberg, 1990; Wessely, 1999). This was a further landmark event for ME/CFS, because it marks the point at which it became intrinsically linked with being a psychological condition. Some members of the medical profession also expressed continuing concerns about labelling the illness as 'ME' because there was a lack of physiological evidence to support the name. In 1998 it was proposed that the name 'Chronic Fatigue Syndrome' was a more appropriate label for the symptoms that people described on the basis that fatigue was the most consistent and durable symptom experienced by patients (Holmes, Kaplan, Gentz, Komaroff, Schonberger,

Strauss et al 1988). In the early 1990s the World Health Organisation classified Chronic Fatigue Syndrome under 'Symptoms, signs and ill-defined conditions' (ICD 9 780.1).

Although the name of Chronic Fatigue Syndrome was readily adopted by the medical profession, the diagnostic guidelines themselves were criticised for not being specific enough to distinguish between CFS and other psychological conditions where fatigue may be a factor, such as depression (Jason, Torres-Harding, Jurgens & Helgerson, 2004). Therefore the guidelines were reviewed and amended and two alternative versions of the diagnostic guidelines were generated[5], although these were also criticised as they did not specify that the fatigue had to be of a 'new and different type which was not alleviated by rest' and thus people presenting with illnesses similar to ME/CFS were being inadvertently included in the patient group. The Fukuda diagnostic guidelines were developed to address these problems and this set of diagnostic criteria remains the most commonly used (Fukuda, Straus, Hickie, Sharpe, Dobbins & Kamaroff, 1994) and forms the basis of the NICE (2007) guidelines for CFS. Yet it seems that the criteria attract some of the same concerns about differentiating between people with CFS and people with fatigue caused by other psychological disorders such as depression and anxiety disorders, or fatigue stemming from medical issues such as after surgery or head injury (Jason, Richman, Friedberg, Wagner, Taylor & Jordan, 1997).

The term CFS has therefore been intrinsically linked with suggestions that the illness is of psychological origin, and this perception may be bolstered by research that asserts that ME/CFS does not independently exist and is merely a manifestation of depression (Ray, 1991), a severe form of fatigue (McCrone, Darbishire, Ridsdale & Seed, 2003; Wessely, Chalder, Hirsch, Wallace &Wright, 1997) or a different manifestation of somatic syndromes (Wessley, Nimnuan & Sharpe, 1999).

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[5] The versions were: 'The Australian version' (Lloyd, Hickie & Boughton, Spencer & Wakefield (1990) and The 'Oxford Criteria' (Sharpe, Archard, Banatvala, Borysiewicz, Clare & David at al, 1991).

2.2:3 'Yuppie Flu'

The media perception of the illness as 'Yuppie flu' in the 1980's also seems to have left an indelible mark on the way the illness is perceived. The term 'Yuppie' emerged at around the same time as the economic boom in the financial sector in the 1980s. It was a derivative of 'Yup' (young urban professional) and was applied to young professionals who were considered to be ambitious and 'go-getting', often commanding high salaries in newly created executive professional roles (Hammond, 1986). The term was essentially derogatory and people in this social category were considered to have undesirable characteristics which included being driven by personal greed and having a self-indulgent, frivolous lifestyle (Hammond, 1986). 'Yuppie flu' was represented as an inconsequential illness which was only prolific amongst this minority[6], who were generally considered to have bought it upon themselves from the lifestyle they had.

ME became associated with the label of 'yuppie flu' and was considered to be a self-inflicted illness with no medical merit which affected a few people in prestigious positions. The term 'yuppie' fell out of favour in the recession of the late 1980's and early 1990's, and 'yuppie flu' was later renounced as being unsuitable for use in relation to ME/CFS, even so it is often still used when articles about ME/CFS appear in the media (for example see Daily Mail, 23/02/2013).

Thus, the media have played a crucial part in setting the scene for pwME/CFS being perceived as being of dubious moral character, having undesirable characteristics and possibly a poor work ethic. In other words it seems that some of the stigma associated with this illness stems from this widespread social representation of what ME/CFS is and the portrayal of an ME sufferer. Moreover, as the term 'yuppie-flu' is still attached to stories of ME/CFS in the media, these perceptions may continue to persist today (Horton-Salway, 2004).

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[6] They were a minority because the position of 'executive' was relatively rare in companies at that time.

2.2:4 What is in a name? A Summary

The acronym of ME/CFS implies that there is parity between the two conditions. However, as indicated above (see 2.2:1 & 2.2:2) they signify opposing perspectives about the origins of the illness. The debate over whether the illness is primarily physiological or psychological in nature has caused 'a battleground of confusion' (Huibers & Wessely, 2006) amongst medical professionals, academics, ME/CFS support groups and lay people.

This on-going debate has practical implications for the treatment and management of the condition as key information such as the prevalence[7] of the illness, appropriate treatment, duration and prognosis become difficult to determine. The physiological/psychological debate is too extensive to outline in its entirety here and the emphasis of this thesis is not to present one view as being 'correct', but to illustrate that the disparities form a 'culture of contention' around ME/CFS. It is this body of knowledge with the uncertainty, scepticism and controversy that people draw upon when they talk about the condition.

The apparent conceptual distinction between ME and CFS has been noted in the social science literature and Mary Horton-Salway (2004) suggested that pwME/CFS prefer the term ME because it is regarded as being 'less psychological' than a diagnosis of CFS. It has also been proposed that sufferers perceive a diagnosis of CFS to undermine the *physical* suffering that they encounter and this diagnosis also overemphasises the symptom of fatigue (Whitehead, 2004). Overall the term CFS is disliked by patient groups, because it is believed to carry a level of stigma, and it is thought to be more likely to invite the implication that the illness is 'all in the head'.

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[7]For example, the prevalence rate of ME/CFS in the UK is unclear. The National Task Force (NTF, 1997) estimated it at 1.7 million, whereas the National Institute of Clinical Excellence (NICE, 2007) reported 240,000, other estimates of 250,000 (The ME Association, 2009) and 298,000 (The Daily Telegraph, 2008) have also been reported. These discrepancies may be due to the use of multiple different diagnostic criteria as discussed above or inadequate medical record keeping which has led to estimates being based on extrapolations from other countries (NICE, 2007). Also complicating the issue is a lack of clarity over whether these figures include children.

However, insisting on a diagnosis of ME is also problematic as sufferers who do this are regarded as being illness fixated, medicalising[8] and troublesome (Raine, Carter, Senski & Black, 2004; Tamm & Soderlund, 1994). Furthermore the sufferers' apparent refusal to accept a psychological explanation for their illness can be regarded as failing to take responsibility for it and this is argued to be indicative of poor prognosis for recovery (Martin, Chalder, Rief & Braehler, 2007; Van Geelen Sinnema, Hermans, Kuis, 2007)[9]. In addition the label of ME is associated with the 'yuppie flu' and the negative, stigmatic assumptions that are associated with this term (see section 2.2:3).

2.3 The Social Representation of 'Health' and 'Illness'

One way of making sense of these co-existing and sometimes conflicting formulations of the problem is to consider them in the light of earlier research on the topic of social representations. Social representations of health and illness draw upon a system of shared ideas, values and practices which are usually specific to an individual's culture or social group. Moscovici (1961) argues that social representations provide a 'framework' which enables people to understand the world around them through a socially negotiated communicative process of 'anchoring' and 'objectifying'. Any new concept goes through the anchoring process, whereby it is placed into the context of things that it is similar to, thus providing the group with a basis for talking about it. Through this communication objectifying occurs, as the concept is attributed characteristics of its own that may differ from what is already known and it is at this point that a social representation is formed. Moscovici further argues that everything, including concepts of health and illness, are constructed in the social realm and that people draw upon the social representations that they create.

It is recognised that the social construction of illness can be perceived both as a physical reality and a socially constructed event (Brown, 1995).That is to say that whilst the presence

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[8] Medicalising in this sense refers to being adamant that the symptoms they experience must have a medical basis

[9] It should also be noted that pwME/CFS are considered to possess personality traits such as 'action-prone-ness' (Van Houdenhove, Bruyninckx & Luyten, 2006) and 'perfectionism' (Arpin-Cribbie & Cribbie, 2007) which are argued to make them susceptible to ME/CFS in the first place and have a negative impact on their ability to manage their illness well.

of an illness can be medically discovered, the act of naming and describing it becomes a socially constructed event (Bury, 1991). The broad concepts of 'health' and 'illness' are also seen as being socially constructed and Herzlich (1973) argues that lay people often perceive health and illness distinctly differently. In Herzlich's study, ill health amongst lay people was represented as an unavoidable consequence of modern living which they deemed to be unhealthy in a variety of ways. For instance they perceived themselves to be at greater risk of accidents or exposure to bacteria, as well as illnesses caused by the stressful, time-pressured nature of modern living.

Herzlich (1973) identified three specific lay representations of illness which were: illness as a destroyer, illness as a liberator and illness as an occupation. For people who attribute meaning to their lives through being busy and active, illness is often construed as destructive because it causes a disruption to their day-to-day activities and longer-term biography (see section 2.8)[10]. However, somewhat conversely, for those who are burdened by responsibility or overcommitted in their obligations Herzlich notes that illness can be regarded as a liberator because it provides a legitimate means of being released from these obligations. This concept has also been interpreted as liberation of the 'self' for some people as their identity becomes enhanced when they talk of fighting the illness which Murray (2000) interpreted as liberation of their former subdued selves. Finally, for some, illness would become an occupation as they immersed themselves in finding information or trialling solutions and remedies in an attempt to improve their health.

Herzlich (1973) also highlighted the importance of how 'health' as a concept is socially represented and found that, unlike illness, being 'healthy' was considered to be within the person's control. Being healthy was deemed to be dependent on personal attributes, such as strength of character and exercising self-control (by not smoking, drinking or overindulging for instance). These personal attributes could be drawn upon as resources to defend against the threat of ill health that is believed to exist within society. Subsequent research has supported the finding that people view illness as an external event and health as an internal attribute (Blaxter, 1990; Murray, 1997; Williams, 1983). Furthermore, Herzlich found that

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[10] Also see Chapter 5 which investigates the participants' accounts of biographical disruption in relation to ME/CFS.

there were three specific representations of health amongst lay people: the absence of illness or disease, having health in reserve and health as an equilibrium.

Health as the absence of disease originates from the biomedical view of illness, which simply infers that in the absence of biological evidence to the contrary health must prevail (Murray, 1990). Health in reserve suggests that people are equipped with the strength to take part in life activities, but also that they are able to 'store' good health and keep it in reserve for future occasions when the demands of society threaten to cause ill health. Finally, people stated that establishing an equilibrium whereby they are happy and relaxed in life and enjoying strong, positive relationships, as being a sign of good health.

More recently, Flick (2000) has identified that lay people perceive 'health as a lifestyle', which reflects the societal change towards public engagement in 'healthier' behaviours. These behaviours may include self-examination, self-medication and commitment to a 'healthy' diet (for example, eating five portions of fruit and vegetables a day) and exercise programs which lay people become increasingly involved in (Hughner& Kleine, 2004). Thus, social representations of what it is to be 'ill' or 'healthy' change along with biomedical information or trends in healthcare.

Representations of health, as well as illness are relevant to this thesis, because ME/CFS as a contested illness falls between the socially mandated categories of being ill and being well. These definitions are argued to be specifically relevant to ME/CFS because neither claims to be 'ill' or claims to be 'well' can be medically verified. This means that these categories are socially defined and this process would draw upon representations of what it means to be 'healthy' or 'well'.

2.4 To be 'diseased', 'ill' or 'sick

A social constructionist approach to illness is concerned with the conceptual social distinction between different categories of illness (Eisenberg, 1977). Berger & Luckmann (1967) argue that reality is entirely 'socially constructed', including the arbitrary categories

of 'disease', 'illness' and 'sickness'. Radley (1994) notes the distinction between how different illnesses are conceptualised. He argues that a 'disease' denotes a biomedical physical entity that clinicians are able to discover as 'symptoms' and relate to concepts that can be explored within the biomedical framework. An 'illness' on the other hand refers to the subjective experience of being unwell and is 'discoverable' through sufferers' accounts of illness, but it has a lesser status than 'a disease'. Sickness is considered to be a socially negotiated condition which is applied to people who are deemed to be ill by others. Matters such as the right of the 'sick' person to be excused from social obligations, in other words their access to the 'sick role', is also negotiated (Parsons, 1951)[11].

ME/CFS is classed as a 'syndrome' by the medical profession which infers that the eclectic and unspecific symptoms have been given a label and this is tolerated, but not necessarily accepted, as an illness in the medical arena (Huibers & Wessely 2006). However it also falls into the category of being a chronic illness as well as a controversial and contested one.

2.5 The social construction of chronic illness categories and ME/CFS

Illnesses are labelled as being either 'acute' or 'chronic', terms which are regarded as being 'value laden' because they infer something about the type of illness and how it should be managed (Brown, 1995; Clarke, 1994). Chronic illnesses are so called because they are considered to be lifelong conditions whereby the emphasis is on managing to live with the condition rather than harbouring expectations of a medical 'cure' (Albisser, Hodel, Albisser & Wanner, 2002). Medically acceptable examples of this type of chronic illness include Rheumatoid Arthritis (Bury, 1982), Epilepsy (Scrambler & Hopkins, 1986) and diabetes

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[11]The 'sick role' as proposed by Parsons (1951) indicates that there is a social response to ill health as it implies that there is a theoretical distinction between the physical experience of being unwell and the social expectations that accompany it (Hunter, 1996). Parsons argues that behaviour which would normally be regarded as 'deviant', such as not carrying out one's social duties, is deemed to be socially acceptable and excusable when there is a medically sanctioned reason. The 'sick role' therefore implies that an ill person is not personally accountable for becoming unwell and can be legitimately excused from their obligations, but it also proposes they have a intimated responsibility to recover and commence normal duties as expediently as possible. The medical profession are charged with the task of maintaining social order by policing who is able to access the sick role and deciding how long for.

(Yawn, 2001). Chronic illnesses that are not regarded as being medically acceptable are said to be 'contested'.

Contested illnesses are regarded as being a theoretical link between social constructionism and medicalisation, whereby a biomedical meaning is applied to a range of medically unspecified symptoms (Bird, 2010). Brown (1995) suggests that CFS falls into this category as it is not accepted by many in the medical profession, yet has been given a medical definition.

From a social constructionist perspective it is argued that historical, cultural and environmental influences determine what phenomena become defined as an 'illness' and how it can be addressed (Bury, 1986). It is argued that illnesses with medically unexplained symptoms, like ME/CFS, are a product of the modern social environment (Zavestoski, Brown, McCormick, Mayer, D'Ottave & Lucove, 2004). It is proposed that ME/CFS is a cultural phenomenon which arises as a consequence of the fast pace and demanding schedule of everyday life (Huibers& Wessely, 2006). For this reason it is has been likened to other conditions such as hysteria (Hacking, 1998) and neurasthenia (Greenberg, 1990) which inspired similar debates and controversy in the late 1800s. In fact, as previously suggested there are similarities with neurasthenia, most notably the debate over whether the illness is physiological or psychological in nature (Friedberg & Jason, 1998).

As previously mentioned, by dint of being considered a 'contested illness' ME/CFS shares a social category with other illnesses such as Gulf War Syndrome (Jones & Wessley, 2004) and this range of illnesses are often referred to as 'functional somatic syndromes' and share some constructive features. Firstly, they are considered to have a dubious medical standing, in that medical tests cannot determine a reason for the symptoms that the person experiences. Some of these symptoms are common in the general population, particularly pain and fatigue (Barsky & Boras, 1999) which makes it difficult to isolate them as being indicative of a distinct medical problem. Secondly, the majority of sufferers and those who present with pain and fatigue are considered to be women (Mayou & Farmer, 2002), as is the case with ME/CFS as women are argued to account for two thirds of sufferers (Hart

&Grace, 2000). This is problematic because it also, inadvertently, forges links with the illness of 'hysteria' (Bohr, 1995).

Thirdly, the way that the participants articulate the severity and extent of their subjective experience of suffering with ME/CFS is not reflected in the response from the medical profession who consider it to be of low medical importance (Conrad & Stults, 2008). Finally, people with contested chronic illnesses strive to obtain a medical verification for their pain and suffering but in the absence of any biomedical markers this is often futile. Horton-Salway (2004) describes interaction between ME/CFS sufferers and the medical profession as a 'micro-political struggle' (term borrowed from Banks & Prior 2001, cited in Horton-Salway, 2004) as pwME/CFS attempted to assert their subjective experience and prevent it being undermined. The incongruity between the subjective experience and the medical view often leads to people with contested illnesses, including ME/CFS, incurring real or perceived accusations of 'malingering' (Asbring, 2001).

Diagnosis of contested illnesses is tentative and difficult for people to obtain simply because of the nature of the condition. Dumit (2006) describes diagnosis of these conditions as "illnesses you have to fight to get". It has been claimed for instance that 'Fibromyalgia' is not the diagnosis of a discrete condition but rather represents a way to refer to a collection of medically unspecified symptoms (da Silva, 2004). In the same way CFS has been described as a 'concept' rather than a distinct medical entity and concerns have been raised about validating it with any label at all label (Huibers & Wesseley, 2006). This argument suggests that a diagnosis of ME/CFS provides meaning for the individual's pain and suffering by validating the illness and allows pwME/CFS access to medical care and other services (i.e. welfare) and reduces any stigma (Asbring & Narvanen, 2003). However, it is also proposed that diagnosing ME/CFS reinforces the sufferer's pessimistic illness beliefs, encourages them to engage with the sick role and becomes a self-fulfilling prophecy whereby the person focuses on their symptoms and continually validates that they are 'ill' (Asbring & Narvanen, 2003).

There are differences between how people's actions are perceived by the medical profession depending on whether they have medically accepted chronic illnesses or contested ones. For instance it is noted that people with chronic illnesses are likely to find their own way of managing their illness over time and that these strategies may contradict previous 'medical' advice but this is largely expected and accepted by the medical profession (Patterson & Thorne, 2000). In contrast pwME/CFS who seek help from support groups or make efforts to improve their health themselves using Complementary or Alternative Medicines or Therapies (CAMTs) are considered to be deluded and engaging in behaviours which increases the duration of their suffering (Huibers & Wessely, 2006). Likewise support groups are considered to be 'crucial in the search for legitimacy' as people are able to share their experiences with others in an environment whereby their experiences are deemed to be legitimate (Barker, 2008). However, for pwME/CFS there is an argument to suggest that joining a self-help group may be harmful as it will lead to further identification with and validation for the MUS and reinforce concerns about being 'ill' with ME/CFS (Huibers & Wessely, 2006).

The experience of being ill with a medically sanctioned chronic condition is recognised as being difficult and disruptive, not only to a person's life but to their sense of identity as well (Bury, 1986; Charmaz, 1991). It involves managing the physical repercussions of becoming ill and alongside maintaining the appearance of a socially acceptable 'public face' (Charmaz, 1991) as well as privately managing the psychological repercussions of becoming ill (Corbin & Strauss, 1988). This situation is exacerbated for people with a contested illness such as ME/CFS because they have the added complications outlined above which are specific to having a medically contested condition. ME/CFS it seems is in an unusual position as it falls between being a medically sanctioned and medically contested illness and illness management strategies that are deemed to be appropriate for other chronic illnesses are regarded as being inappropriate for pwME/CFS. In other words the experience of being ill with ME/CFS could be described as liminal because it falls 'betwixt and between' that is, being in one social category or the other (Turner, 1967).

For ME/CFS the position of being a contested chronic illness is further exemplified because 'recovery' has been documented as being possible (see Bell & Bell, 2010) and is referred to both in the medical literature (see Deale, Chalder, Marks, &Wessely, 1997) and amongst pwME/CFS themselves (see Whitehead, 2006). However in these cases recovery seems to be merely 'reported' as a functional status of health, and consequently little is known about what this means to recoverees themselves or indeed how *they* construct the state of being recovered.

2.6 Recovery from ME/CFS

Recovery from ME/CFS has been reported following trials of Cognitive Behavioural Therapy (CBT) and/or Graded Exercise Therapy (Knoop, Stulemeijer, Prins, Van De Meer & Bleijenberg, 2007). The findings have been debated[12] over their inclusion criteria (Reid, Chalder, Cleare, Hotopf, Wesseley, 2000) and outcome measures (Taylor, Jason, Richman, Toress-Harding, King & Song, 2003). The outcome measures are particularly important here because they relate to how the concept of 'recovery' is accessed. As there is no definitive medical test to verify that a person no longer has ME/CFS, 'recovery' has to be assessed using other criteria. It is notable that CBT trials measure 'recovery' differently with many focusing on a reduction in fatigue as evidence of success, however many patients do not regard fatigue as the main symptom (Taylor et al, 2003). There is also very little longitudinal information about how long the 'recovery' state persists for after the course of CBT has finished[13].

Other research suggests that the prognosis for pwME/CFS is bleak with only small percentages of people becoming fully or partially recovered (Bonner, Ron, Chalder, Butler, & Wessely, 1994; Buchwald, Pearlman, Umali, Schmaling & Katon, 1996; Clark, Katon, Russo, Kith, Sintay & Buchwald, 1995; Vercoulen, Swanink, Fennis, Galama, van der Meer &

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[12]CBT has also been heavily criticised by ME/ CFS support groups and some medical professionals (see Cheney, 1999) as they claim that it is detrimental to the health of ME/CFS sufferers (Action for ME,2010,). This debate is connected to concerns over the ME/CFS inclusion criteria specified by the Fukuda guidelines as it is proposed that CBT is successful for people with fatigue caused by other factors.

[13] Subjective accounts of feeling 'well' have also been taken as being evidence of recovery by the UK Blood Services Standing Advisory Committee as up until 1/11/2010 people who claimed to feel 'well' were able to donate blood.

Bleijenberg, 1996).As with the medical research there are inconsistencies with these findings because of variations in the time between follow-ups and the criteria that is employed to measure 'functional status' amongst the participant groups. It is noteworthy that all of the above studies employed different quantitative questionnaires, including the Hospital Anxiety and Depression questionnaire (Zigmund & Snaith, 1983) and the Beck Depression Inventory (Beck, Ward, Medelson, Mock & Erbaurgh, 1961). Research within the ME/CFS community found that some group members define themselves as being fully or partially 'recovered', but their claims bear little relation to their physical abilities. Instead people who defined themselves as being 'ill' with ME/CFS were often more physically capable of activity than people who were claiming a recovery (Bell& Bell, 2010).

The lack of consistency in approaches to gathering information about 'recovery' means that information is scant and inconsistent. Therefore there is no definitive information about what constitutes recovery, how a state of recovery is achieved and how durable it is over time.

What is quite clearly absent from this research are the participants' subjective accounts of what being 'recovered' *means* to them and this is an important gap in the literature surrounding ME/CFS and chronic illness and this is something this thesis begins to examine. As there is no definitive test for 'recovery' from ME/CFS and it seems to be a state defined by individuals themselves the experience aligns itself with reports of recovery from illnesses such as 'mental health conditions' or 'alcoholism'.

In the case of mental health conditions 'recovery' is becoming a popular and common concept (Starnino, 2009), although one that is beset with conceptual problems because it is difficult to definitively define (Onken, Craig, Ridgway, Ralph & Cook, 2007). The trend towards recovery seems to have arisen through the efforts of former mental health patients who, disillusioned by the mental health care system, which they saw as oppressive and stigmatising, distanced themselves from formal care (Jacobson & Curtis, 2000). Instead they convened away from the medical arena and became politically motivated to challenge the stigmatisation that they felt the label of being 'mentally ill' and the medical profession

bestowed on them. More recently 'recovery' is seen as collaboration between medical professionals and the ill person, whereby the 'patient' is consulted on all aspects of the treatment and also receives help to enhance the social aspects of their lives (Corrigan, 2003). Being able to engage with 'normal' activities such as working and socialising is termed a 'practical recovery' and is argued to be beneficial to sufferers' overall wellbeing as well as their mental health (Jacobson, 2003).

Another interesting perspective to recovery which is of interest here is how 'recovery' from alcoholism is conceptualised within the support group setting of 'Alcoholics Anonymous' (AA) 12 step program (Hoffman, 2003). Hoffman points out that one of the first things that potential new AA members learn is that there is a 'right' way to construct their account of themselves as an 'alcoholic'. They are encouraged to adopt the same format as current members, which involves clearly identifying oneself as 'being an alcoholic'; doing so is regarded as showing a commitment to being a group member and a measure of suitability for the 12 step program. Support groups were made up of what Hoffman calls 'rank and file' members who were ascribed statuses in the group based upon the length of their sobriety, which in turn made them experienced veterans of the 12 step program. One of the main things that Hoffman noted was the expectation amongst the group that in order to be successful a person would be on the 12 steps program for life, even if they remained sober. People leaving the group to recommence 'normal' lives, including resuming their prior social roles, created a tension, particularly if they claimed to be able to drink in a 'normal way'. Hoffman claimed that because their ability to do this violated the group assumption of 'once an alcoholic, always an alcoholic' the leavers were deemed to be failures and were dealt with in one of two ways. In one way other group members were advised that the leaver would most certainly fail and end up as an alcoholic again or it was advised that the person has never really been an alcoholic in the first place and their claim to have been is discredited, which suggests that amongst the support group, recovery from alcoholism was conceptualised in a certain way.

These accounts of recovery are relevant to ME/CFS because many of the anecdotal stories of recovery from pwME/CFS involve self-management, CAMTS, support groups and strained

relationships with other people. Both of the above illnesses are invisible and incur levels of stigma which is similar to that experienced by people with ME/CFS.

2.7 Liminality

It is proposed that because it is a contested chronic illness ME/CFS falls between the social categories of being ill and being well (Brown, 1995) which implies that it has a liminal status.

Liminality has been well documented in terms of anthropology, where Turner (1965; 1967) described it as a transitional 'limbo' state between culturally recognised social categories. Turner (1965) and Van Gennep (1909/1960), studied liminality from a religious and cultural perspective and regarded it as being a challenging but ultimately positive experience. The liminal state is identified as the period when the person is neither in one category or another. Adolescence provides a good example of this whereby the person is no longer a child but not an adult either. Turner noted that people in such a transitional period were ostracised from their social group and became isolated and solitary. This period of enforced isolation allowed individuals to renew themselves or grow and develop in a spiritual way before becoming accepted back into a new social category (i.e. as an adult) once again. Sometimes transitions from one social category to another are acknowledged and managed by a religious ceremony or ritual, an example may be moving from being 'single' to becoming 'married'.

Other ways of defining liminality suggest that being 'in limbo' between two social categories incurs stigmatic and negative connotations. Douglas (1976) for example uses the terms 'matter out of place' or 'category mixing' and argues that phenomena failing to fit into a pre-defined social category are treated as pollution or waste and incur negative stigmatic connotations. Gluckman & Gluckman (1977) point out phenomena that are acceptable in one social category are perceived as being out of place or liminal in another.[14] Jackson (2005) argues that a phenomenon that has the ability to transcend between social

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[14]Human material, such as bodily fluids, hair and clippings once detached from the body become out of place as they are regarded as unhygienic, dirty and undesirable. He explains this as the phenomena transcending the boundaries between being 'part of me' and 'not part of me' once removed from the body.

categories is also regarded in a negative or derogatory way by society[15]. The negative connotations attached to being able to transcend categories, it is argued, also apply to humans and people suffering from a contested illness such as chronic pain, hypochondriacs and malingerers who may be regarded by society in a similar way (Jackson, 2005).

The concept of liminality, it is argued, also applies to those diagnosed with chronic Illnesses such as cancer (Little, Jordens, Paul, Montgomery & Philipson, 1998). Most patients diagnosed with, or suspecting that they may have, such an illness are immediately placed in a state of limbo between life and death (Sibbett, 2006). Furthermore confirmation of such an illness often warrants immediate treatment and patients report feeling a loss of autonomy throughout this process. The treatment or consequences of the treatment can lead to changes to the body or mental state that has been defined as being the person being neither in one category nor another (Navron & Morag, 2003).

Therefore in contrast to the view of liminality as a transitional state (Turner, 1965) and as the ability to shift between boundaries (Jackson, 2005) it is proposed that for people with chronic illnesses liminality is sustained and can continue throughout their lifespan, even after a 'recovery' has been confirmed (Little, Jordens, Paul, Montgomery & Philipson, et al 1998).

Liminality seems to encapsulate the position of ME/CFS as it fits into the neither/nor category because it is a contested illness.

2.8 Biographical Disruption and Chronic Illness

Bury (1982) introduced the concept of biological disruption to explain the disruptive effects of chronic illness to both an individual's life course and the explanatory frameworks that they utilise to understand life experiences. Becoming chronically ill, he argues, causes previously taken for granted assumptions about participating in current or future life events

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[15]Creatures that are tabooed by society such as vermin, who can occupy space inhabited by humans and amphibious creatures are examples of this.

to become questionable which represents a need for their biography to be re-addressed. The disruption caused by illness can affect mundane, routine aspects of life and cause the individuals to readdress their self-perception (Bury, 1982) in light of changes imposed on them by the illness. Aging presents an example of this as ill people often report feeling prematurely old because their abilities are restricted and are more akin to what may be expected of an older person. This represents a shift from the expected trajectory of aging (Singer, 1974), and the anticipated subjective experience where a steady age related decrease in activity would be expected. It is in this sense that a disruption of the past-present-future continuum occurs as the subjective feeling does not accord with actual chronological age.

Bury (1982) argued that lay people glean information about illness and appropriate illness behaviour from the medical profession and that being provided with a diagnosis gives the individual a legitimate basis for illness behaviour. Receiving a diagnosis however did not always result in the patient's expectations of treatment or cure being met. In turn this led to the view that medical knowledge was somehow incomplete and prompted the utilisation of other resources to bridge this gap. Due to the contested nature of conditions people with medically unverifiable illnesses, such as ME/CFS may encounter this and turn to complementary and alternative medicines (CAMs) in order to enhance their understanding and management of their condition. However as already noted, for pwME/CFS decisions to do this may be perceived as being detrimental to overall health (Huibers & Wessley, 2006).

Efforts to manage or control chronic illness also causes a disruption as the emphasis for this is increasingly placed with the ill person and their families (Kerr, Heisler, Krein, Kabeto, Langa, Weir & Piette 2007) and treatment typically occurs outside of a hospital setting (Gately, Rogers & Sanders 2007). There are several barriers to this self-management, of which, being unable to participate in recommended diet and exercise plans (Krein, Heisler, Piette, Makki, & Kerr, 2005) due to physical capability or lack of economic resources is one. However even if this obstacle were to be overcome other issues such as poor communication with the medical profession and a lack of knowledge or social support make illness management difficult (Jarent, Friederichs-Fitzwater & Moore, 2005).

Therefore Bury (1982) argued that becoming chronically ill and attempts to manage or control the effects of the illness caused a disruption to the biography of the person's life. However this view has been challenged in recent years as it is argued that it cannot be assumed that disruption is the typical response to becoming chronically ill (Williams, 2000). Instead it is proposed that several factors mediate any disruption, these include age, co-morbid conditions, life experience and the number of 'normal crises' that they have encountered (Pound, Gompertz, & Ebrahim 1998; Williams, 2000). Revising the concept in respect of these factors has resulted in the original theory being adapted and enhanced to include: biographical flow (Faircloth, Boylstein, Rittman, Young, & Gubrium 2004), biographical reinforcement, biographical continuity (Williams, 2000), and biological abruption (Locock, Ziebland & Dumelow 2009).

Age is considered to be a considerable mediator in determining the potential disruption caused by becoming chronically ill. Older people may view the illness as an expected and anticipated consequence of the aging process and therefore assimilate the illness into their life experience, resulting in biographical flow (Faircloth, Boylstein, Rittman, Young, & Gubrium2010). Younger people on the other hand are considered less likely to adopt this approach and view new illness as being extremely disruptive to their biography (Bury, 1986).

People also assess the amount of potential disruption that the illness may cause by comparing it to other co-morbid conditions that they may already have. If the patient regards the latest diagnosis as less troublesome than pre-existing conditions the level of disruption is unchanged and there is biographical continuity (Bury, 1986). Again this may also be more relevant for older people as aging is associated with experiencing multiple chronic conditions. People also place becoming ill in the context of their life experience so far and compare the disruptive effect of becoming ill to these experiences. The number of 'normal crises'[16] (Pound, Gompertz, & Ebrahim, 1998) that they have experienced mediates the perception of disruption. Ciambrone (2001) presents an example of this where women who experienced difficult lives characterised by financial hardship, drug use and domestic

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[16] Pound Gompertz & Ebrahim (1988) refer to disruptive events such as bereavements, house moves, loss of employment etc. It is assumed that older people would have experienced more of these events.

violence perceived their diagnosis of HIV/AIDS as less disruptive to their everyday life than the previous life conditions they experienced.

For some individuals, becoming ill with certain illnesses can result in biographical reinforcement whereby the illnesses reinforces elements of a person's identity. In Carricabura & Pierret's (1995) study homosexual men found that their diagnosis of HIV/AIDS epitomised their struggles with their identity and the political battle for recognition that had ensued.

Locock, Ziebland & Dumelow (2009) introduced biographical abruption to describe the experiences of people with severe forms of Motor Neurone Disease (MND) which are associated with low life expectancy. These patients, she argued, experienced a particular form of disruption which she termed 'abruption', where normal life comes to an abrupt and sudden halt and the usual perspective of 'life will never get better' (Frank, 1995) is replaced with 'life not happening'. For people with different forms of MND, which allow a longer life expectancy, the level of biographical disruption the illness caused was mediated by the severity of specific symptoms that an individual incurred and the value that they placed on certain activities. One participant for example viewed loss of speech as less disruptive than may be imagined because he was still able to indulge his love of driving.

Williams (2000) presents a further interesting perspective after noting that participant narratives describe chronic illness as occurring at a time of life upheaval and change. Therefore Williams proposes that biographical disruption may cause chronic illness. He also suggests that the modern western approach to self-driven healthcare, where people are increasingly encouraged to self-manage their health, both in terms of adopting 'healthy' habits and behaviours and self-monitoring the body for any changes which could be suggestive of illness or disease, is taxing. This approach to healthcare means that individuals are obliged to adopt a stance of constant reflexivity towards their health and they become 'lay experts' in health issues. Self-managing in this way creates a 'worried well' where people become obsessive about health matters and adhere to suggested behaviours which, Williams argues, in themselves actually has a disruptive effect on people's biographies.

Ciambrone (2001) also argued that it is assumed, by the medical profession and other people that becoming ill causes *the* major biographical disruption for the person concerned and they focus their attention on problems associated with the person's illness. Any other concerns that the ill person had about normal things which they found problematic and difficult to deal with (such as parenting problems for instance) were treated as being 'normal' crises and trivialised by others. Ciambrone found that participants found this assumption of the illness being the most disruptive and difficult problem in their life very upsetting because it did not reflect how *they* felt.

Biographical disruption is not merely constructed as a *response* to illness but instead is mediated by a person's identity and life experience which makes it a very individual concept. It is proposed that a number of factors including social status, life experience and age (Williams, 2000) combine to create an individual response to becoming ill which can include biographical flow, biographical continuity and biographical reinforcement. Ill people tend to rate the impact of disruption they encounter by their ability to 'cope' with the constraints of their illness and by maintaining their participation in everyday life events (Bury, 1991).

2.9 Identity and Chronic Illness

One of the ways that it is possible to understand the lived experience of a chronic illness is by understanding the impact that it has upon a person's sense of identity. Research suggests that becoming chronically illness poses a disruption to a person's sense of identity and overall has a negative influence, at least initially, on their sense of self (Charmaz, 1983; Karp, 1996).

It is argued that the 'sick role' (Parsons, 1951) implies that ill people should behave in a certain way. Being defined as 'sick' and being excused from 'normal' duties obligated the individual to act responsibly in so far as consulting medical professionals and becoming well as quickly as possible (Lawton, 2003). Therefore it was anticipated that ill people would assume the identity of 'patient' and submit themselves to the medical profession (Crossley,

1998, Lawton, 2003). In other words the identity of the ill person and the consequences that becoming ill would have upon their sense of self was not considered (Kelly & Field, 1996).

It has already been noted (see section 2.3) that social representations of concepts or phenomena are negotiated and agreed within a group setting and that they form a constituent part of the group's social identity, which in turn has a psychological effect on an individual's sense of self (Charmaz, 1987). People are often simultaneously part of multiple social groups where they have something in common with other people; examples may include being a student, wife, child, hockey player, academic, mechanic, asthmatic and so on. In effect people have multiple social identities which inform an overall 'self' (Charmaz, 1987). The self can also be understood as an ongoing consecutively ordered narrative of life events, which illustrates 'who I really am', and provides a way for people to communicate the 'story of oneself' to others (Williams, 1983; Frank, 1995).

For the purposes of this thesis Charmaz's explanation of the 'self' as a constantly evolving social construct is adopted as it has been utilised in similar studies of identity and chronic illness (e.g. Charmaz, 1991). Identity on the other hand refers to the different identities that people exhibit in different social situations (Charmaz, 2006). Charmaz (1983) proposes that chronically ill people experience a 'loss of self' when they become ill as they become unable to engage in activities that they were doing before. Although she notes that their identity is renegotiated within the context of being ill for the most part her participants talked about a loss of identity and feeling constrained by the confines of their illness.

Charmaz (1987) proposes that people with progressive chronic illnesses have a hierarchy of preferred identities, which concur with the degenerative nature of the condition. This five stage hierarchy includes the 'supernormal self', 'restored self', 'reconstructed self', 'contingent self' and 'salvaged self'.

Charmaz (1987) proposed that the 'supernormal self' was someone the ill person aspired to be in the unlikely event of making a full recovery. It depicted becoming a supremely capable person who accomplished things to levels in excess of what may be considered 'ordinary'

for an able bodied person. Some older people, Charmaz noted, were able to instigate a partially supernormal identity in some areas of their lives and did so in order to be societally valued and to circumvent any of the connotations of slowing down which are associated with the aging process. In cases where a 'supernormal self' was realised to be unrealistic people hankered towards a 'restored self', whereby they were able to resume life as it was before. Charmaz states that the 'restructured self' was a complex area and proposed three sub-categories. The 'entrenched self' refers to people who wanted to return to the life precisely the same as it was before, practicing precisely the same behaviours and habits as they always had. The 'developing self' is a restored self who looks towards developing new ways of doing things rather than being reliant on previous ways. The 'assumed self' is a self-concept which stems from long standing social relationships and the persons place in the social world which they assume will continue despite their health. If a 'restored self' in any capacity was also deemed to be unlikely then people looked towards a 'reconstructed self' which utilised elements of their previous identity and allowed them to be as similar to their pre-illness selves as possible. Where the future of a person's health was uncertain, people talked about a 'contingent self', because the future of the self was dependent on health status. Finally Charmaz proposed that people who became physically dependent on others retained a 'salvaged self' whereby they hung on to a small facet of their previous identity.

Charmaz makes the point that changes in peoples' physical condition resulted in changes to their sense of self and as their illness progressed and they became unable to do things that they used to do their self-concept also altered. Whilst the descending linear trajectory proposed by Charmaz (1987) above may be appropriate for some degenerative conditions Yoshida (1993) offers a more fluid description of identity changes instead, arguing that sufferers of traumatic spinal cord injury were able to move swiftly between five identity categories in a manner that was reminiscent of a swinging pendulum. Here movement is perpetuated by the subjective personal experience of loss, sustainment, integration, continuity and development and did not necessarily occur in any specific order.

The first of these categories 'the former self' is similar to 'the restored self' which Charmaz (1987) proposes above. It refers to a desire to be as one was before the injury, and includes

retaining 'core' aspects of the self, allowing the ill person to establish continuity by continuing to do the things that they have always done.

The 'disabled identity' occurs at an opposite point on the pendulum and is associated with the disabled person having unrealistic expectations of how intuitive other people will be to their changed physical needs and how much assistance they will receive from others in their day to day living. Yoshida also notes that a 'supernormal identity' also exists, although this differs from Charmaz's description as it has two meanings. Firstly, it refers to people engaging in activities, such as horse riding, which may be considered as out of the ordinary for people who have spinal injuries and defies societal expectations of the type of activities that disabled people may do. Secondly, people who have unrealistic expectations of their capabilities and steadfastly refuse any assistance from other people are also banded under this category.

Yoshida's next category 'the disabled aspect as an aspect of the total self' occurs once people begin to assimilate their disablement into their concept of 'who they are'. In a practical sense instead of trying to return to a former self, people may make accommodations for their illness by, for instance, retraining in a different type of work.

The final category, 'the middle self' refers to a central category which the pendulum naturally settles upon when it is not swinging and represents the individual reaching equilibrium. In this category people became increasingly positive and typically accept their disability, and any consequences such as obligatory dependency on others for personal needs. They also demonstrated an acceptance of having a position in a larger social group or society of disabled people.

Charmaz (1987) and Yoshida (1993) present changes to identity as either hierarchal or fluid in nature, but there are some similarities with categories such as 'former' and 'restored' identities and the 'supernormal identity', which feature in other research too. It is interesting that Charmaz (1987) based the preferred identities upon people with progressive chronic illnesses, as it may suggest that identity changes are spurred by changes

in the physical condition. Yoshida's research, on the other hand was based upon people who incurred a sudden long term injury which meant that they effectively became immediately detached from their former identities and had to struggle to try and return to their previous selves.

A further way of understanding the lived experience and understanding the impact of illness upon identity and the self is proposed by Frank (1995) who identified three identity related responses: restitution, chaos and quest. The restitution narrative is usually generated as an initial response to illness and supposes that the ill person will expediently endeavour to overcome the effects of illness and return to good health (Frank, 1995). This is reminiscent of Parsons's (1951) traditional sick role which proposes that responsibility for recovery from illness and resuming societal duties, such as working, lies with the individual. The focus of this narrative is usually upon the action taken towards recovery rather than the illness itself.

The restitution narrative appears to accord with Charmaz's (1987) 'restored identity' and Yoshida's (1993) 'former identity', whereby people are expressing a desire to return to their previous selves. Interestingly though, Frank (1995) claims that this particular narrative is rarely found in relation to chronic illness. The chaos narrative is one of hopelessness and despair as people perceive themselves to be entirely at the mercy of an illness that they have no control over. Unlike the previous category, people focus solely on the disabling effects of the illness and presume that this situation will continue for the rest of their lives. The disabling effects refer to being unable to participate in life as one did before, for example being unable to work, socialise, look after oneself and so on. Again this category is similar to Yoshida's (1993) category of 'disablement as the total identity', which is explained above as people became defined purely by their condition. The quest narrative occurs when people accept their illness and perhaps deduce that the illness experience has a deeper meaning for them personally. When this occurs people may re-evaluate their lives or infer some religious significance from their experience which alters their view of life.

Thus there are similarities in the accounts of how people with progressive chronic illnesses (Charmaz, 1987; Frank, 1995) or chronic disablement (Yoshida, 1993) perceive it impacts upon their identity. Therefore these definitions are of interest to exploring the experience of ME/CFS and are therefore referred to throughout this thesis.

2.10 ME/CFS: A literature review

The literature surrounding ME/CFS is extensive and diverse not least because there is no clear aetiology and medical opinion is divided as to whether ME/CFS is a physiological or psychological condition. Therefore information about ME/CFS appears in a variety of different arenas within medical, academic, social science and holistic literature presenting a very complicated picture.

It is important to note that there is a distinction between Chronic Fatigue and Chronic Fatigue Syndrome which had to be carefully observed whilst searching for appropriate articles. Chronic Fatigue appears to refer to fatigue associated with an event such as a head injury or surgery and is expected to improve as the physical injury heals. Chronic Fatigue Syndrome, on the other hand, is used in conjunction with ME and refers to medically unexplainable fatigue of unknown origins and outcome. As already noted the similarity between these terms causes some confusion and therefore the search criterion used for this research was *Chronic Fatigue Syndrome*.

2.11 The search and selection process

The literature informing the conception of this research came from a variety of different sources including self-help groups (membership newsletters, magazines, websites), articles in the media, items from ME/CFS conferences, publications such as 'Nursing Times' and 'New Scientist' and a wide variety of academic literature. Whilst information from all sources was used to form an understanding of the context of ME/CFS, the literature presented below

is drawn from the academic arena as it has the most direct bearing upon the theoretical perspective of this thesis.

The literature review process involved interrogating several academic databases[17]for appropriate and relevant research articles dated up until March 2013 using terms such as 'Chronic Fatigue Syndrome', Myalgic Encephalomyelitis and Myalgic Encephalopathy[18]. The initial search criteria yielded a high return of results initially which had limited relevance to the theoretical context of this project. Therefore the selections were further refined using additional search terms such as 'social', 'psychological' and 'qualitative'. The remaining literature was then screened for relevance by reading the abstract and applying the exclusion criteria[19]. Other terms such as 'recovery' and 'treatment' were also employed in the searches, however, typically these yielded articles that focused on medical interventions with limited relevance to psychological or social factors subsequently these were disregarded.

Therefore 14 studies were selected as relevant to exploring the subjective experience of ME/CFS and these are reviewed below[20].

2.12 ME/CFS:A review of relevant literature

As previously mentioned (see section 2.10) chronic research in the social sciences to date has focused on exploring issues such as biographical disruption and identity in relation to medically legitimate chronic illnesses. Therefore there is scant literature covering these topics in relation to being ill with ME/CFS or being in recovery from it. Salient ME/CFS literature relating to the topics of interest covered by this thesis is presented below.

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[17]These databases included Academic Search Premier (ESBCO host), Applied Social Sciences Index and Abstracts (ASSIA), CINAHL, COPAC, Emerald Full Text, Europe Pubmed Central, International Bibliography of Social Sciences (IBSS), Ingenta Connect, PSYCarticles, PsycINFO, Science direct, Scopus and the Science Citation Index.

[18] The term Myalgic Encephalomyelitis (ME) rarely appears without also being referred to as CFS within the same piece of literature, therefore an exploratory search revealed that articles mentioning ME are included by default when searching for CFS. Also searching for CFS specifically limited confusing ME/CFS with Chronic Fatigue, Fibromyalgia, post viral fatigue syndrome etc.

[19] Research that; focused on 'Chronic Fatigue' rather than Chronic Fatigue Syndrome; was written from a medical perspective; was older than 1996, and that looked at ME/CFS alongside another medical condition were excluded from this literature review

[20] A table of relevant studies can be found in Appendix A

A study by Clements, Sharpe, Simkin, Borrill & Hawton (1997) set out to understand how ME/CFS is perceived by sufferers and others and to seek a qualitative explanation for why a large number of ME/CFS sufferers appear to suggest that their illness is physiological on questionnaires. Further exploration revealed that the majority of their sample (66) believed that their illness was initially caused by a virus such as flu. However, it was also ascertained that half of the participants also believed that stress contributed to their illness. Interestingly it was also noted that the participants made a clear distinction between their 'symptoms' and their 'illness'. They conveyed a belief that controlling symptoms was possible through managing periods of activity and rest but there was no way to control the illness itself. The study also began to explore how pwME/CFS seek to manage their illness and noted that many draw on an extensive range of information including complementary and alternative medicine (CAM), self-help group literature and media articles. In contrast it seems that medical information was regarded as being of less relevant their quest to get better.

This research is important because it explores the subjective reasoning behind sufferers' claims that their illness is physiological rather than psychological; an issue that is extremely relevant to the subjective experience of suffering with ME/CFS. It also provides an insight into how pwME/CFS perceive their illness by exploring their beliefs about why they became ill thus adding valuable contextual information to the body of existing quantitative research.

However there are also a number of shortcomings with this research which limit the extent of its application to the wider ME/CFS community. Firstly the interviews are described as being open ended and as being 'conducted quickly' due to time constraints and the high volume of participants (66). This description suggests that the main benefit of using open ended interviews (i.e. to encourage full, open and honest dialogue) may have been negated by attempts to conduct them within narrow time constraints. Secondly, participants were recruited from an 'infectious diseases' clinic where they were receiving treatment for their ME/CFS. It is possible that being treated in a medical setting had some bearing on participants' assertions that their illness is physiological. Finally, the research also relied on retrospective accounts of life events prior to becoming ill, which may harbour inaccuracies due to the delay in recall.

Asbring (2000) looked at the disruption that illness caused to the lives of 25 women diagnosed with *either* CFS (12) or Fibromyalgia (FM) (13). The findings suggested that participants faced an initial disruption to all areas of their life (e.g. employment, financial, social) although participants with CFS reported experiencing a greater degree of biographical disruption than people with FM. Over time both groups were able to negate some of the negative repercussions of being ill by finding new ways to do things or immersing themselves in alternative, more manageable things (e.g. finding new hobbies). Asbring found that adapting to changes imposed by illness involved a perceived change in identity for the participants. Making this transition took time and people reported a subjective feeling of having two identities, of being 'ill' and being 'well' until they became fully integrated a new way of life and a changed identity. It was also noted that participants reported experiencing some positive effects from becoming ill, such as becoming more aware of the beauty of nature and by delighting in simple pleasures. However the author proposes that the in-house treatment program the participants were undertaking, which encourage pro-activeness and positivity may have contributed to this finding. Although this research is valuable the clear distinction that Asbring makes between CFS and FM presents some cause for concern as both illnesses have similar symptoms therefore it is unclear how participants can be divided so neatly. Despite these similarities a diagnosis of FM implies that sufferers experience more physical symptoms with a greater emphasis on joint and muscle pain (NHS, 2013). This distinction between FM and CFS is important because it may make the FM appear more credible to both suffers themselves and others which in turn may elicit more practical help or referral for prompt medical treatment.

Overall it seems that people with FM and CFS go through similar processes of adapting to a different and new type of life once they become ill, yet this research also suggests that this process is more difficult for pwCFS. The study falls short of providing any explanation for the perceived difference in experience between the two conditions even though both sets of participants were on the same hospital based treatment program.

Horton-Salway's (2001) research highlights how pwME/CFS construct their individual accounts of being ill and particularly focuses on talk about their pre-illness lives to

demonstrate this. The single participant of the study[21] talked about having a frenetic pre-illness lifestyle and Horton-Salway suggests that this could be a way of countering a defence against any claim of ME/CFS being psychosomatic. It is also argued that by portraying themselves as active and busy her participant may be suggesting that ME/CFS is an involuntary response to the stressful pressurised demands of modern life. It also seems that emphasising such a lifestyle may inadvertently resonate with descriptions of ME/CFS being akin to 'yuppie flu'[22]. Although Horton–Salway brings key debates and perspectives to the fore there is an important flaw in her research. Interviewing one pwME/CFS in the presence of a partner/carer (albeit with the consent of both parties) may lead to constrained responses or avoidance of some topics for reasons of embarrassment or for fear of insulting the feelings of the other person. It may also be that the partner/carer subjective experience is different and therefore the way that the 'typical CFS story' unfolds is different to how a pwME/CFS on their own may choose to talk about their experiences.

Clarke and James (2003) focus upon changes to the 'self' amongst pwME/CFS finding that participants' talked about losing their identity when they became ill with a debilitating flu-like condition[23]. They found that as sufferers managed this process they 'rejected their old values and selves in favour of establishing new selves'. Clarke and James propose that this change occurs because of some of the difficulties associated with suffering with a discredited condition such as ME/CFS. Clarke and James argue that some of the problems that pwME/CFS experience arise because ME/CFS does not have a clear legitimising discourse from the medical profession which has a direct impact upon the experience of sufferers'. They suggest that pwME/CFS will often struggle to obtain a diagnosis, medical care and welfare benefits because of the contentious nature of their condition. These problems, Clarke and James argue, coincide with other consequences of becoming ill such as, losing employment, relationships and ability to partake in leisure activities and this combination leads pwME/CFS to reject all aspects of their previous self. PwME/CFS are then able to create a new radical self that can be perceived as legitimate by others. Although this study offers a valuable insight into how pwME/CFS may come to terms with their identity once

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[21] One person with ME/CFS was interviewed along with her partner/carer who did not have ME/CFS

[22] Specifically as a self inflicted illness of the young and upwardly mobile. Horton Salway draws on Wessely (in Ware, 1993) for this point.

[23] It is frequently found that ME/CFS sufferers talk about a 'flu-like illness preceding the onset of their ME/CFS see Chapter 4 theme 1.

they have ME/CFS it has the limitation of only selecting participants from local support groups. This may have an impact on the research as people in a group may have adopted an accepted and established way of talking about their illness amongst themselves.

Soderlund & Malterud (2005) also investigated people's perceptions of how and why they became ill with ME/CFS. They recruited 8 women through a CFS support group although, in an attempt to minimise the possibility of group members establishing a 'normal way' to describe their illness, they selected pwME/CFS who claimed to have minimal involvement with group activities and events. The research found that the participants attributed becoming ill as a consequence of their previous busy lifestyle. Interestingly they also suggested that being 'busy' was complicit with their gender implying that women experience greater demands on their time and resources in comparison to men. The participants' also expressed an opinion that this apparent gender related difference in the use of resources may explain why the majority of ME/CFS sufferers are female. It is notable that all of the participants in this research were female and therefore the authors were unable to compare how gender is perceived to influence the subjective experience of ME/CFS for men and women.

Whitehead's (2006) research moves away from trying to establish perceptions of aetiology and towards a greater understanding of how sufferers' manage and understand different stages of the illness experience. Whitehead proposes that pwME/CFS are on a trajectory that has three distinct phases; acute, medium and longer term. The acute stage she argues encompasses severe biographical disruption to life and identity as people moved from highly-active pre-illness lives to being much less active once they became ill. This stage is consistent with identity changes which, drawing on Yoshida's (1993) terms, are defined as disability of the total self, disability as part of the social self and the supernormal self. The medium term stage was described as being one of experimentation whereby sufferers attempted to find new ways of doing things that they did before they became ill. Whitehead, like Gray & Fossey (2003) also notes that receiving a diagnosis is crucial to the process of addressing the effect that the illness has upon identity. In the longer term Whitehead proposes that a new self emerges for the majority of sufferers, but maintains that this does not involve a complete rejection of any former selves as other research (Clarke and James, 2003) have suggested. Instead it appears that sufferers retain some elements of their

former-selves and a 'new' identity is formed from there which is consistent with research in CFS arena (Asbring, 2001) and research involving people with other chronic illnesses (Charmaz 1983). Whitehead suggests that drawing the participant sample from a geographical location where there is NHS provision for the treatment of ME/CFS may have influenced the responses of some of her participants. This research is longitudinal yet Whitehead does not offer any insight into how this approach informed her findings in the paper. She also fails to discuss the findings within themselves, instead preferring to immediately intersperse them within previous findings relating to ME/CFS and chronic illness literature in general that focuses on identity. Furthermore it is noted in passing that one participant considers themselves to be recovered in the second data collection but their contribution to the themes is not sufficiently explained.

Whitehead (2006b) is a response to Clarke and James's (2003) findings that pwME/CFS reject their former identities and adopt radicalised new ones and it also elaborates upon the findings of Whitehead's (2006a) paper. The previous findings, it is explained resonate with Frank's (1995) notion of quest and exploring the experiences of pwME/CFS using Franks typology may indicate if and how people arrive at a radicalised new self. Whitehead recruited 17 participants and found that in the majority of cases narratives followed the trajectory of chaos, quest and restitution. The research suggests that the initial phase of illness brings with it emotional responses of frustration, anger and often depression which are further exacerbated by the economic and social losses that are associated with becoming ill. Whitehead argues that some sufferers rejected their former identity, not out of what she terms resentment (as Clarke and James suggest) but after they make a pragmatic and realistic assessment of their changed capabilities. Interestingly Whitehead points out differences in perceived experience between ME/CFS and other medically verifiable conditions such as breast cancer or HIV. She suggests that differences in how the illnesses themselves are perceived and understood may explain the differences in identity reconstruction between sufferers medically verified illnesses and pwME/CFS. Whitehead focuses on two specific subjective experiences of ME/CFS. Firstly she suggests that pwME/CFS are constantly reminded of their ill health through the unrelenting, constant presence of symptoms and do not therefore get an opportunity to distance themselves from it as people with other illnesses might. Secondly she posits that pwME/CFS do not receive a

prognosis like people with other medical conditions would and it is suggested that because of this pwME/CFS are unable to access a restitution narrative because they hold little hope of ever recovering. It is suggested that the timing of the interview in relation to the duration and therefore stage of the person's illness has important consequence for findings and Whitehead notes this as an issue in her research. It is noted that Whitehead chooses two chronic illnesses for comparative purposes but draws conclusions from previous research of only one researcher in each field which does not appear robust enough to draw such conclusions from.

Dickson, Knussen & Flowers (2007) research also focused on perceptions of the illness and how this may influence the subjective experience of sufferers. The authors argue that diagnostic delay that pwME/CFS experience contributed significantly to both the delegitimisation of the ME/CFS and the stigma experienced by sufferers. They suggest that the delegitimisation impacts not only on relationships with medical professionals but, more poignantly for sufferers, also on relationships with significant others. The authors draw upon a participants' subjective account of feeling pressurised to present themselves as being either 'ill' or 'well' with no ambiguity as being unclear seems to exacerbate the perceived disbelief of others. The research claims to be rich and insightful yet it offers no exploration of the findings other than commenting that they are compatible with previous quantitative findings, the body of qualitative literature is ignored. It also appears to add little to available literature by failing to further explore the 'new' finding that delegitimisation by significant others is extremely hurtful and difficult to deal with. It should also be noted that half of the participants were recruited from an alternative therapy clinic which may have had an influence upon their perceived feelings of delegitimisation.

In 2008 Dickson, Knussen & Flowers focus on exploring the relationship between ME/CFS and identity. They found, as with other research, that becoming ill is permeated with a sense of loss of agency and physical control of the body which impacts upon identity by restricting access to previous or anticipated future selves. However they argue that the way the participants describe the loss of identity is akin to how people talk about being bereaved. They also found that of having ones illness experience delegitimised by others caused sufferers to begin to have self-doubts over whether they were, perhaps inadvertently, fabricating the illness in order to avoid their work or social obligations. PwME/CFS, the

authors argue, feel detached from their previous selves in a number of ways once they become ill. For one, it seems that their previous identity is challenged as questions such as 'who I am' become difficult to answer because the associated roles (I am a worker, hockey player etc.) become inaccessible. The findings also suggest that people negate some of these problems by 'pretending' to be their old selves when they are in company of others who are unlikely to understand. It was also suggested that acceptance of one's condition and associated limitations was a key component of becoming able to do familiar tasks and roles in a different way as previous research (Asbring, 2001) has also suggested.

One other interesting finding which is commented upon is the excessive use of the pronoun 'you' in the participants' narratives when a first person term would have been more appropriate. The authors' note that this indicates that something else is happening within the narrative but do not speculate as to what this may be.

As well as noting the same limitations of their previous research (drawing participants from an alternative therapy clinic) Dickson, Knussen & Flowers (2008) note that conducting an interview only at a particular point in time is a further flaw. They suggest that a longitudinal approach would be beneficial in order to plot how changes in the illness over a period of time influence sufferers' perceptions of their identity.

Arroll and Senior's (2008) research explores the experiences of 8 ME/CFS sufferers recruited from a self-help group. The research explores different stages of the ME/CFS experience from becoming ill through to the time of the research. The authors demonstrate how participants often respond to becoming ill by searching for answers and solutions to remedy their ill health in alternative domains to the medical profession. They also note that receiving a diagnosis from the medical profession did not represent the end of this quest period, instead it continued as sufferers sought to find ways to improve their health. Limitations noted by the authors include selecting from a self-help group setting, thus excluding pwME/CFS who are too unwell to attend social gatherings. Also by default the authors have included people at different stages of being ill with ME/CFS this is important as experiences may vary according to the length of time one has the illness. It also seems telling that the authors used two self-help groups from the same region in the UK as it is possible that both groups received the same health care provision. It may explain the strong themes that

emerged from their participants' narrative as group members may have an established way to articulate their experiences and tell their ME/CFS story. This research concludes by calling for more research aiming to further explore the lived experience of ME/CFS.

De Carvalho-Leite, Drachler, Killett, Kale, Nacul, McAurthur et al (2011) explored the medical needs of 35 ME/CFS sufferers, recruited via support groups throughout the UK. Through focus groups and semi-structured interviews it was found that participants' expressed a desire for greater support in three main areas; managing symptoms and improving health; practical support for day to day living and social inclusion, and finally; financial support and assistance. The research argues that pwME/CFS claim that accessing support for their illness is difficult as they encounter a number of barriers when trying to access assistance such as medical help or financial support from the welfare system. The authors argue that these barriers are complex involving a combination of medical, social, cultural and professional factors but it seems that these difficulties were exemplified for people in ethnic minority groups. The research presents an interesting insight into the scope and extent of perceived barriers that pwME/CFS report as being relevant to their experience of being ill and provides a much needed account of the lived experience. It also highlights issues such as ethnicity and health equity which have a considerable impact on people's individual experiences of ME/CFS.

Anderson, Jason & Hlavaty (2014) conducted a follow up study with a small proportion of participants derived from a larger sample of pwME/CFS who participated in a research project a decade earlier. Participants were asked to provide a retrospective account of significant life events in the period of time between the two studies in order to ascertain how these events may have influenced the progression of the persons' illness. Although the life events that people reported varied common features such as the deleterious impact of stress on health conditions, the stigma surrounding ME/CFS and the difficulty with securing medical care and welfare benefits because of this stigma were present. The authors also note one case of 'remit' as a participant's health improved over the period and the participant attributed this to balancing activities and exploring complementary and alternative medicines (CAM). The research identifies a need for greater collaboration between clinicians and pwME/CFS as well as promoting greater understanding of ME/CFS in the wider community. Noted limitations to this study include the possibility of recall bias and

the sample including people who have had ME/CFS for varying lengths of time as well and who report a number of different outcomes. As the authors point out creating subgroups for each of these different groups would allow stronger correlations between life events and the effect they have on their ME/CFS. Although this study highlights the interaction between real life events and ME/CFS the variation between reports of events and effect is too broad to do anything other than indicate a need for further research.

The research reviewed above indicates that being ill with ME/CFS is perceived by sufferers to be an intricate and complicated, personal experience. It seems that, like other chronic illnesses, ME/CFS has a devastating effect upon the identity of sufferers (Clarke & James, 2003; Whitehead, 2006), but as suggested above this can be exemplified by its controversial status (De Carvalho Leite, et al, 2011).

In terms of general chronic illness literature the ME/CFS literature particularly surrounding identity presents an interesting array of similarities and differences. For instance De Carvalho Leite et al's (2011) findings about the barriers that pwME/CFS have to contend with resonates with Anderson & Bury (1988)who argue that when the legitimacy of contested conditions is called into question by others, this also raises questions about the moral integrity of the ill person. Therefore pwME/CFS have to defend themselves against any implications of dishonesty and also protect their identity as a moral person (Horton-Salway, 2001). Research to date suggests that the initial response to ME/CFS is devastation of the identity (Clarke & James, 2003), which accords with the findings of other research into chronic illnesses which has been presented above (Charmaz, 1987; Yoshida, 1993; Frank, 1995). However, reports of how the illness affects identity overall vary between studies.

The above research presents similar findings in terms of the initial loss of self that occurs at the beginning of the illness period and the emergence of a new, positive identity after a period of time (Asbring, 2001; Clarke & James, 2003; Whitehead, 2006). Quite how this occurs though seems open for debate as the research proposes pwME/CFS retain different degrees of attachment to their previous selves and different strategies for constructing 'new' selves. Whitehead (2006) and Clarke &James (2003) speculate that the severity of the loss of self experienced in the beginning of the illness process and the lack of a medical diagnosis

may cause people to reinvent themselves in an attempt to establish some order and meaning to their lives.

However, as all of the above researchers note, their selection of participants from areas with ME/CFS clinics (Whitehead, 2006), participants that were receiving treatment for symptoms from a hospital clinic (Asbring, 2001) or members of support groups (Clarke& James, 2001) may have influenced their findings. Actually being treated in a medical setting for example, goes some way towards negating the stigma associated with the illness, provides a context of meaning and presumably a framework of activities that is presumed to lead towards good health. It is possible that positivity is encouraged in such an environment. Recruiting from self-help groups as Clarke & James (2003) did results in conducting research with people that are confident to provide their story and they may be different to other people who have the illness but may not be part of a group.

It should also be noted that the sample sizes of most of these studies are small and therefore may only reflect the views of a niche proportion of the ME/CFS community.

2.13 The purpose of this research

The above sections have illustrated that ME/CFS is surrounded by a 'culture of contention' because it is a contested illness; because it falls between the categories of being 'ill' and being 'well'; because 'recovery' is deemed possible which undermines its position as a chronic illness, and; because ME/CFS research to date is disparate in its findings relating to important issues such as biographical disruption and identity.

It is clear that whilst there is some literature that addresses the *lived experience* of pwME/CFS, the experience of recovery has yet to be addressed systematically in this way. Where recovery has been studied, this is overwhelmingly in terms of the functionality of recovery, using quantitative tests of capability, rather than establishing what this *means* to pwME/CFS themselves, in other words, rich, contextual information about the longitudinal trajectory of the illness is missing. Despite Anderson et al's (2014) efforts to conduct a long

term follow up we still know comparatively little about the experience and meaning of recovery. Whilst authors such as Clements et al (1997) write of the active strategies by which people attempt to ameliorate their condition we are left with little sense of how this is believed to contribute to change in the condition over time.

This thesis aims to bring to light areas which have been under-explored to date by focusing on the participants' subjective experience from the pre-illness stage through to post-recovery. It differs from previous research to date that focuses on people who are ill with ME/CFS because the participant selection in the present study includes people who are claiming to be fully or partially recovered. It is argued that extending the focal point, which is usually the 'illness' period, to incorporate a longitudinal perspective on the pre-illness and post recovery stages will provide a valuable addition to the current understandings of ME/CFS and chronic illness. Several authors such as Gray and Fossey (2003) point to the sudden change noted in people's accounts between pre-illness activity and the limitations experienced in the illness period. Yet this formulation may well have sequelae for how the experiences of recovery are understood. The thesis will also investigate whether issues that are related to being chronically ill such as biographical disruption and identity can assist in interpreting the participants' experience throughout their journey. In addition the longitudinal chapter (Chapter 7) includes the analysis of participants' accounts after the interval of a year and promises to provide further contextual information about the meaning of 'recovery' and how pwME/CFS manage to consistently achieve this state and maintain a 'normal' life.

This thesis aims to enrich the current literature by adding new and valuable information to present knowledge of both chronic illness and ME/CFS. It is also envisaged that it will provide further insight into how the concept of 'recovery' is constructed by pwME/CFS.

Reviewing the ME/CFS literature alongside consulting members of the ME/CFS community informed the formulation of the following research questions:

- Why do participants focus on their pre-illness life? What meaning does this hold for them?

- How do people experience different stages of the pre-illness to post-recovery journey? How do they define getting better? How do they manage the transitional stages?

- How do people construct the experiences of being in full or partial recovery from ME/CFS? What do these categories mean? How are they formulated?

- How do people address issues of their identity at stages through the pre-illness to post recovery journey? How do they see themselves?

Chapter 3

A Constructivist Grounded Theory Methodology

*Science is nothing but trained and organized common sense, differing from the latter only as a veteran may differ from a raw recruit: and its **methods** differ from those of common sense only as far as the guardsman's cut and thrust differ from the manner in which a savage wields his club.*

Thomas Henry Huxley
(Collected Essays, No.4,'The Method of Zadig')

3.1 Introduction

The previous chapter provided an overview of the extensive, contradictory literature which surrounds ME/CFS and illustrated how the illness is constructed in different ways by the medical profession, social scientists, the media, sufferers and lay people. It also explained how this situation feeds an aura of scepticism and stigma which appears to influence the way that pwME/CFS experience and talk about being ill. Overall it sets the scene for the notion that because of the opposing ways that ME/CFS is constructed it can be a difficult subject for people to talk about.

The body of literature presented in Chapter 2 also examines concepts such as how people live with ME/CFS and manage the consequences to their lives such as changes in their employment status, familial obligations, leisure activities and an individual's overall sense of identity. It is, however, noticeable that this research primarily focuses on difficulties associated with the period of illness with ME/CFS and that sufferers' pre-illness life is only referred to for comparative purposes and post-illness life scarcely at all. Research to date has not considered what the pre-illness life *means* to pwME/CFS and the influence this has on how they manage being ill with ME/CFS. Likewise, there is scant literature about people in recovery from ME/CFS (pirfME/CFS). In addition to this omission from the literature, very little is known about how the concept of 'recovery' is constructed by pwME/CFS themselves.

This means that the picture of the participant experience of ME/CFS is incomplete as important and influential periods of the illness journey have been neglected.

With the controversial nature of ME/CFS and the apparent gaps in the literature in mind it was envisaged that qualitative methods would be most appropriate for this thesis. Adopting a qualitative framework provides a foundation for exploring the subjective meaning of concepts such as recovery. This also addresses a need which is increasingly perceived in the literature. As Anderson, Jason and Hlavaty (2014: 3) say 'there is a need for more longitudinal qualitative research on epidemiological samples of patients with ME/CFS'. The value of qualitative research has been stressed in mapping the patient's journey through treatment and rehabilitation (Beasant, Mills and Crawley, 2014). The suitability of constructivist grounded theory in exploring perceptions of time through the illness course was particularly emphasised by Pemberton and Cox (2014). Accordingly, the qualitative approach adopted here speaks to a number of concerns of contemporary scholars and practitioners and adds depth to the quantitative investigations of life quality, symptomatology and prevalence which have been undertaken elsewhere.

The purpose of this chapter is to introduce the rationale for the chosen theoretical and analytical approach to the data in this thesis, which is based upon constructivist grounded theory (CGT). An account of how the data was collected, processed and analysed will also be provided here.

The chapter begins with a brief account of two theoretical approaches that have influenced the adapted version of CGT used in this thesis. These are: social constructionism, and grounded theory[24]. It then moves on to explain how reconciling these two apparently opposing theoretical positions presents the best way of understanding and interpreting the ME/CFS data in this thesis.

In the final section of the chapter, information will be provided about participant selection, ethical considerations, interview style, data recording, processing and transcribing the interview data, data selection and finally coding and analysis.

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[24] This refers to Grounded theory as a theoretical approach rather than Grounded Theory Method which details a methodological, rigorous approach to the process of data analysis.

3.2 Grounded Theory

Grounded theory in its original form as established by Glaser & Strauss (1967) was devised in order to address criticisms that findings from qualitative research were undermined because they are subjective. The approach was devised to provide a scientific, systematic method of gathering qualitative data that would enable researchers to generate theory which is securely grounded in the participants' experiences (Charmaz, 2000; 2006).

Grounded theory proposes a range of unique features for gathering and analysing data which proponents argue leads to the generation of theory. The processes of data collection and data analysis should be conducted simultaneously and researchers should adopt a both an inductive and deductive approach to the data in order to aid conceptual understanding. Core themes should be identified early within the data analysis process and be strengthened or discarded depending on how they appear in subsequent transcripts. It is also argued that the size of the sample should not be predetermined, but be governed by constant comparative analysis and that sampling is complete once a core theme has reached 'saturation' point. Finally the core categories that emerge from this process are placed into theoretical frameworks (Charmaz, 2006; Corbin & Strauss, 2008; Glaser & Strauss, 1967). Glaser and Strauss's original grounded theory also stipulated that the researcher should not influence the data collection process by engaging with the research literature prior to collecting data and that interaction between the participant and the researcher should be kept to a minimum to negate any bias. This research typically adopts a realist position by arguing that following a strict methodological procedure will result in accessing 'reality'.

The original version of grounded theory has undertaken a number of revisions (Strauss & Corbin 1990; Rennie, Phillips & Quartaro 1988; Charmaz, 1995; Henwood &Pigeon, 1996) which challenge the epistemological view and lean more towards a relativist perspective; however, all of these approaches adopt the grounded theory method (GTM) of collecting and analysing data.

The grounded theory approach has been selected as the most appropriate methodology for this thesis because it allows the development and enhancement of a theoretical foundation

for the experience of suffering with ME/CFS as the current research appears to be contradictory and unclear. As noted in Chapter 2 there appears to be a distinct difference between how sufferers construct their illness as 'ME', a physiological condition and how the medical profession construct it as 'CFS', a condition which does not appear to have a physiological basis. Thus it accords with the view that using grounded theory is appropriate when there is a need to revisit current knowledge in order to explain how changes in the field may call for new theoretical categories (Crooks, 2001; Grbich, 2007). At the same time it is claimed that grounded theory is also considered to be an appropriate form of analysis for data that is potentially novel to the field of research (Skeat & Perry, 2008). Therefore it is an appropriate method not only to enable a new dimension and understanding to be added to the ME/CFS literature, but it also provides a method for exploring the conceptual issues raised by participants themselves. This is particularly valuable in terms of exploring experiences of being 'in recovery' or 'recovered' from ME/CFS, which has received very little attention in the literature to date.

The theoretical approach adopted for this thesis is constructivist grounded theory (CGT) as proposed by Charmaz (2000), which also draws on social constructionism.

3.3 Social Constructionism

Constructivist grounded theory (CGT) as defined by Charmaz (2006, 2009) falls within a social constructionist[25] framework. CGT theory recognises that knowledge is co-constructed through the process of human interaction. Therefore in the research situation data and analyses are regarded as being socially constructed (Charmaz, 2006). Studying the use of language therefore allows an insight into how the participant constructs and experiences their social world.

The social constructionist perspective argues that objective reality does not exist but is constructed by individuals through the process of social interaction, which aims to examine

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[25] The terms constructionism and constructivism are noted to be used interchangeably in academic literature (Dean, 1993). Constructivism argues that knowledge of the world is gleaned through innate internal cognitive processes, whereas constructionism argues that knowledge of the world is created via interaction and social meaning making practices. For the purposes of this research constructionism is used throughout.

how individuals and groups perceive and construct reality. As already discussed in chapter 2, the construction of ME/CFS as an illness is complex and peoples' experiences of suffering from it, being in recovery or having fully recovered from the illness occurs within the social constructions of the condition.

Researchers in the social constructionist domain investigate the social processes that inform individual meaning making and are interested in how these meanings become entrenched into institutional and individual interpretations of reality (Berger & Luckmann, 1967; Gergen & Gergen, 2005). The roots of social constructionism lie in the work of Mead (1934). Although there are many different versions of social constructionism, this thesis focuses on social constructionism as set out in the arena of psychology focusing on authors such as Burr (2003; 2002) and Gergen (1985; 1997).

From a social constructionist perspective all knowledge - ranging from 'taken for granted' or 'common sense' deductions to official statistics - arises through a process of social interaction which follows three distinct stages; these are; externalisation, objectification and internalisation. In the first stage of externalisation people begin to interact and form relationships with other people where they negotiate the context and meaning of concepts and phenomena. As a result of these initial interactions social products are generated such as artefacts, rules, guidelines or codes of conduct which provide perceptions with tangible form. These social products themselves become 'objectified', they are no longer recognised as a consequence of perceived reality but infer independent meaning. That is to say that the social product itself becomes a form of reality that can be studied in its own right. The final stage of the process is 'internalisation', where subjective views of the world are cognitively established as representing a reality through the process of socialisation. An important feature of the latter stage involves being given an identity and a place in the social hierarchy (Burr, 1995). Identity in this sense relates to categories such as wife, mother, employee, hockey player etc. and is bestowed upon a person along with the societal expectations of appropriate duties and behaviours that the role carries. Learning about these things occurs within social groups, but is also influenced by representations of what 'should be' which prevail in the media. Thus people gather knowledge about their place in the social world and subsequently an understanding of how they relate to others (Berger & Luckmann, 1967) but there is no objective, definitive base to any concept of reality, it is all socially constructed.

It is recognised that certain types of knowledge command more influence than others, Berger and Luckmann (1967) explain that the complexity of the knowledge generation process leads particular individuals to specialise and become 'experts' in specific areas. A prime example of this is the medical profession, who have gained control, power and influence over how information about 'health' and 'illness' is conveyed and understood within society (Hunter, 1991). The construction of knowledge in this area in particular explains why some conditions such as ME/CFS are regarded as contentious as although illness can be recognised as a form of objective reality which is led by information gleaned by the medical profession, constructing what the illness is (the naming and describing of the illness) becomes a socially constructed event (Bury, 1991; Friedson, 1970). In this case the construction of 'ME' and of 'CFS' can be perceived as being very different, which explains why use of the combined acronym of 'ME/CFS' is regarded as problematic (Horton-Salway, 1998). The medical profession appears to construct ME/CFS as 'CFS' an illness that is not medically serious as it does not seem to have a detectable physiological basis but instead is considered to be more of a psychological complaint. The majority of sufferers seem to oppose the medical view and construct their illness as 'ME', which implies a physiological basis for their pain and suffering and suggests that the underlying cause is not psychological. As Mary Horton-Salway (2008) noted an ME diagnosis is often regarded by sufferers as being less psychological than being diagnosed with CFS, meaning that each condition is constructed in a particular way. As it is clearly a contested condition much of the information about ME/CFS is constructed in the sufferer and lay domains.

Research informed by Social Constructionism has studied the influence of power in society and in relation to health and illness and the dominance of medical discourse (Bury, 1986) and specifically how this relates to ME/CFS (Banks & Prior, 1997; Horton-Salway, 1998). Establishing a convincing narrative is recognised as a crucial element of constructing a version of events that supersedes others and this is achieved either at a macro level, which refers to structures found in organisations (politics, medicine or jurisprudence) for instance or micro level which refers to interaction between individuals (Burr, 2003).

Some social constructionists argue that the most successful versions of events stem from a macro level and people in positions of power and influence (politicians, doctors, lawyers) as they are often able to make their construction of events seem the most plausible (e.g. Burr,

2003; van Dijk, 1983). Within this macro structure and at a micro level is the construction of peoples' identities, sense of self are established and maintained through everyday interactive discourse (Burr, 2003). However, there is also an argument to suggest that accepting this view that macro constructions always dominates over micro constructions fails to account for situations where people can and do influence the balance of power and can instigate social change. In short it calls the question of human agency into question. If, as the social constructionist framework suggests, people are products of a social structure, how can they also choose to act independently and be the instigators of social change?

3.4 Agency vs. Structure within Social Constructionism

In order to address the dichotomy of how people can be shaped by society and also recognised as shaping society, it is necessary to look at the role of structure and agency which causes considerable debate in the social science arena. Agency and structure are difficult to define but broadly speaking agency refers to the actions of people in society acting either individually or as a collective body. Structure, on the other hand refers to large scale social structures or structured activity amongst people such as interaction (Ritzer, 2004). Within the social sciences researchers differ in terms of to what extent human action is perceived to be the consequence of either agency or structure. From one perspective it is argued that people operate under an illusion of freedom, not realising that they constrained within an ideological framework (Foucault 1998). In this context people have been described as 'puppets', as the unwitting bearers of dominant structures. Craib (1984; p 109) argues that "people do not speak but rather they are spoken (by the underlying structure of language), that they do not read books but are 'read' by books. That people do not create societies but are created by societies". In short, people are perceived not as the actors in situations, but as the acted upon. At the other end of the spectrum theorists argue that individual people are the active constructors of events.

In terms of social constructionism, the debate presents a contentious issue in terms of how the relationship between the individual and society (as a structure) is perceived. Burr (2003) argues that the concept of either agency or structure presents problems. If individuals are seen as agents and have created society, through making independent choices and

decisions, the notion of 'society' itself becomes defunct as there is no logical explanation for social order, regimes or processes. On the other hand, perceiving people to be shaped by a structure, such as society, renders any notion of human agency obsolete because any choices or decisions are considered to be a consequence of the social situation and not a conscious choice. The issue of how to define structure and agency is rife through the social science arena and is a dilemma that does not have a satisfactory solution.

Archer (1986) posits that agency and structure are relatively independent concepts yet at the same time they are also interdependent, so without one the other does not exist. For the purposes of this research 'agency' and 'structure' themselves are treated as 'concepts' rather than as definitive statements (Burr, 2003). In line with other theorists agency and structure, for the purposes of this research, are viewed as being simultaneously constructed by the participants during everyday interactions. Studying how participants account for how they go about doing things allows the researcher access to issues affecting 'the self' and how people relate to the world around them (Edwards, 1995; Parker, 1998;Wetherall, 1994).

Therefore, this thesis is not concerned with furthering the structure/agency debate but instead focuses on how participants claim to experience structure and how they describe their own agency within the context of their experience(s) of becoming ill with or recovering from ME/CFS. Of particular interest here is how people talk about agency and structure in relation to a full or partial recovery, as it represents an area which has not yet been fully explored. As described in chapter 2, pwME/CFS are described as being individually active (by way of actively pursuing medical or CAMTs treatments) and also collectively active (in terms of campaigning and lobbying to raise awareness of the illness), which suggests that they are instigating a form of agency by acting against the confines of structure[26]. How participants describe their experiences then becomes the point of interest.

3.5 Language and social constructionism

Language, as the basis of the majority of human interaction, is regarded as an important tool for sharing and generating knowledge as it provides people with a way of constructing and

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[26] Structure in this sense is not defined it may refer to the medical framework that ME/CFS is placed in which suggests that the illness should be viewed in a certain way; the societal structure that pwME/CFS are part of and how becoming or managing the stigma that forms part of having the illness.

communicating meaning. As such language and the study of language becomes a crucial component of understanding how people construct their social world. Burr (2003) argues that language allows people to formulate and express thoughts and concepts and provides a medium through which it is possible to communicate information about their social world. Yet at the same time she ascertains that thoughts and concepts predate the formulation of language and warns against assuming that language constantly clearly and accurately conveys them. In view of this Burr argues that it is prudent to remember that it is possible for the same events and phenomena to be constructed in many different ways depending on the languages that are used and indeed the situation that events or phenomena occur in.

As noted above this thesis adopts the position that people can be viewed as constructing the world around them through applying agency and by interacting whilst also experiencing the world as a form of structure and the way that people talk about events or phenomena reflects this. Gergen & Gergen (1991) argue that through studying language, social constructionism:

> *"…draws attention to the manner in which the conventions of language and other social processes (negotiation, persuasion, power etc.) influence the accounts rendered of the 'objective' world. The emphasis is thus not on the individual mind but on the meanings of people as they collectively generate descriptions and explanations in language"*

> (Gergen & Gergen, 1991; p78)

So the way that people talk about events or phenomena is regarded as being representative of the reality that they are experiencing at the time. Social constructionism posits that verbal communication is awash with meanings, some of which are taken for granted in conversation as they can be easily inferred by the listener without being specifically described[27], yet questioning these assumptions allows for greater understanding of the how the participant constructs their 'objective' world. Studying how people talk about or describe

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[27] Mead (1934) argued this point using the example of a chair, claiming that it would be unnecessary to specifically mention the purpose of a chair in his conversation as the listener would be able to ascertain how the chair is relevant by drawing on shared knowledge of what the object is and how it could be used.

events or phenomena provides an insight into the social or political influences that have tailored their version of 'reality'. The analytical framework of constructivist grounded theory (CGT) focuses on how people talk about and describe events or phenomena.

Within CGT language is active as in the research setting it emerges from the interaction between the researcher and the participant but is also influenced by the temporal, structural and cultural contexts of the environment that that the interaction occurs in. Charmaz (1995) argues that the interactive interview process actively "produces the data" (Charmaz, 1995; p35) and places the researcher in the position of being able to observe and define meaning as it arises. Researchers are charged with 'keeping the data alive' by processing it using an active coding technique which aims to decipher and question the nature of meanings and taken for granted assumptions, which involve paying careful attention to how people are using language.

Social Constructionism is a particularly relevant theoretical framework for this thesis because it makes it possible to investigate how suffering from ME/CFS and being in recovery or recovered from it is socially constructed in medical, social science, sufferer and lay arenas and how this influences the reality that the participants describe. It is particularly interesting in terms of understanding how participants choose to construct the concept of recovery from ME/CFS because the medical profession construct 'chronic' illness as something that is lifelong. So examining the way that the participants construct their recovery and the way they talk about their experiences promises to yield a novel and unique insight into a previously underexplored category.

3.6 Methodological dilemmas of Social Constructionism and Grounded Theory

One of the main contentions associated with combining the theoretical positions of social constructionism and grounded theory relates to where each positions itself on the realism to relativism continuum. Realism and relativism are considered to present two opposing positions. On one hand realism suggests that there is an ultimate truth to be uncovered from the data which tends to align it with a positivist position. Relativism on the other hand takes the view that reality has multiple, simultaneous versions and is opposed to realism. Broadly speaking Social Constructionism is considered to be relativist (although it is possible to adopt a realist position – see two paragraphs below), promoting the notion that 'truth' is socially

constructed and is relative to the social circumstances in which it arises. On the other hand classic grounded theory as proposed by Glaser & Strauss (1967) tends towards a realist position arguing that 'truth' can be accessed through rigorous scientific processing of the data.

Social constructionists, on the other hand, do not deny the existence of an objective reality but argue that all knowledge is given equal credence regardless of its origins (Berger & Luckmann, 1966). Therefore as construction takes place in different contexts it is recognised that people can hold multiple, simultaneous versions of reality. Any influence that the researcher may have on the research process by interacting with the participant is also recognised.

Adopting a strongly relativist position as opposed to a strongly realist one allows the researcher to develop a rapport with the participant and establish a mutual understanding which is important for generating "thick description"[28] data. "Thick description" data is described as being rich, informative and contextual and a key element involves the researcher becoming familiar with the participants social environment and in a position to decipher meanings from participant accounts (Willig, 1991). Sensitive and personal topics such as illness have been noted as being difficult for participants to talk about, therefore adopting a relativist position and building a trusting researcher/participant relationship with the researcher can be extremely beneficial to the research process.

The relativist approach to social constructionism does, however, present some theoretical dilemmas which have been subject to critique. One of these relates to the assertion that all knowledge is treated equally and one interpretation of events cannot take precedence over another, which has also been presented as strength of the approach. However, it presents a dilemma in the sense that *everything* is treated as a social construction that can be subject to enquiry (Lupton, 2001). Furthermore, having multiple constructions and accounts of the same phenomena, which are considered to be equally valid, means that social debates and dilemmas can never be directly addressed or resolved as research presents alternative views that are also open to enquiry.

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[28] "thick description" was coined by Geertz (1973)

In the medical arena the approach has been criticised for being pre-occupied with examining how illness and disease are discursively constructed by the people concerned but at the same time ignoring the central issue of embodiment (Bury, 1986; Williams, 2001). Bury (1986) also points out that it is not possible for social constructionists to make recommendations because, as all knowledge is equal, research findings cannot be judged against other research which means that instigating social action based on findings of research is also not possible. However other theorists argue that rather than being a shortcoming of social constructionism the relativist stance of not adopting a position of truth is a strength. It means that social constructionists are in a position of being able to identify and highlight the social structures and restraints that people are subject to but may not be explicitly aware of. Raising awareness of how these affect everyday interaction can prompt theoretical and practical debates which can, in turn, instigate social change (Nicholson & McLaughlin, 1987). By critically analysing these taken for granted aspects of the participants' social world, researchers can promote the notion of human agency by encouraging people to explore alternative views and perspectives to dominant discourse (Shotter, 1992; Holstein & Gubrium, 2008).

Social constructionism is also perceived as being an oxymoron as, by its own definition, it is itself a social construct which means that it cannot be considered to be superior to any other theoretical framework. Any 'knowledge' is treated as social construction and this means that when conducting any form of analysis the researcher is also constructing a version of reality (Horton-Salway, 1998). In line with Geertz (1979) and Willig (1991) this thesis recognises the value of gathering 'thick description data' which explores the social context that participants allude to when they construct their own version of events.

In order to negate some of the theoretical issues and dilemmas this research adopts a position on the relativism to realism continuum which accords with what Hamersley (1992) terms 'subtle realism' and Charmaz's (1995) claim that constructivist grounded theory adopts a relativist position. This means that the notion of an objective reality which exists independently of human interaction is accepted. However, at the same time it is realised that the researcher has an influence over the research findings by being charged with producing a representation of the reality that the participant is trying to convey, thus it is recognised that this thesis is also a social construction.

Many of the dilemmas raised by the social constructionist framework and classic grounded theory are reconciled by the application of the flexible research approach which is advocated by constructivist grounded theory.

3.7 Constructivist Grounded Theory

The data in this thesis draws mainly upon constructivist grounded theory which was proposed and subsequently revised by Charmaz (2006; 2005; 2004; 2000; 1995; 1990). It should be noted here that Charmaz also refers to constructionist grounded theory (Charmaz, 2008) which describes how social constructionism influences the theoretical framework without offering a reason for the distinction. Therefore in line with other researchers (Mills, 2006) it is supposed here that the terms are used interchangeably by Charmaz but for the purposes of clarity this thesis refers to constructionist grounded theory.

Charmaz's CGT differs from the classic grounded theory proposed by Glaser & Strauss (1978) in a number of different ways. Classic grounded theory adopts a social constructionist framework in the sense that it was inductive and concerned with exploring the social processes that people use to create their social worlds. However, it was devised as a defence against criticisms of subjectivity that are levelled at qualitative methods and advocated a process of data collection and analysis that emphasised scientific rigour minimised subjectivity. For example, Glaser & Strauss (1967) recommended that the researcher should be as removed from the research process and the subject matter as possible. This means that researchers are discouraged from conducting a literature review beforehand or building up a relationship with the participant, lest they bias the interview process. Researchers are advised to pursue any topic that the participant wishes to talk about and dispense with an interview schedule. Adhering to the suggestions would ensure that the data is rooted in the participant experience and that any theory emerges from the data collection process in a bottom up fashion, rather than being preconceived prior to the research process in a "top down" manner.

However, although Glaser & Strauss (1967) attempted to limit subjectivity they did not make allowances for any impact that the researcher may have on the research process or address reflexivity (Charmaz, 2001). Classic interpretations of grounded theory (Glaser & Strauss, 1967; Strauss & Corbin; 1990) became associated with positivism and are pointed out as

being separate from theorists advocating a social constructionist approach (Bryant, 2002; Charmaz, 2000; 2002; 2005).

Constructionist grounded theory adopts the social constructionist principles of viewing the entire research process as a social construction and recognises that the researcher will influence the research process both by interacting with the participant and by familiarising themselves with data (Charmaz, 2000; 2006; Clarke 2005; 2006). Similarly, it is recognised that although the researcher may follow the coding process advocated by the GTM[29], theory does not simply emerge from the data. Instead categories of data are assigned by the researcher who is able to make inferences about the context that they are constructed in. Overall the CGT approach strongly emphasises the role of reflexivity, proposing that by critically analysing how and why the researcher chooses to construct the research and analysis in a particular manner can yield a further insight into how the research participants construct their lives. So not only is the data scrutinised but also the entire research process, as it is all treated as a social construction.

GT has been applied extensively in the social sciences arena and the CGT variant has made a considerable impact in the area of nursing (George, 2011; Mills, Bonner & Francis, 2006; McCann & Clarke, 2003) and psychology. Within psychology, although grounded theory is well used, the application of CGT appears to be limited. One notable exception is Charmaz, who has used CGT to explore the issue of identity in relation to chronic illness (Charmaz, 2003; 2005).

Constructionist grounded theory has been selected as the most appropriate analytical framework for this thesis, because it does not suppose that findings represent 'knowledge' or truth. Instead it allows the researcher to adopt the premise that there are multiple representations of reality. This seems appropriate for research which explores the experiences of three different groups of people: ME/CFS sufferers, people in partial recovery and people claiming a full recovery, as it allows the researcher scope to cover all of the different perspectives. It also recognises that the quality of the relationship between the researcher and the participants is extremely important, not only because of 'thick description data', but also because the construction of 'knowledge' is recognised as being a

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[29] The grounded theory method (GTM) refers to a particular way of processing data which can be used regardless of the particular variant of GT the author is using.

joint endeavour. This point seems particularly appropriate as it is the researcher's personal and academic experience of ME/CFS, which encouraged people to participate and to share detailed descriptions of their experience. Employing the GTM ensures that any emergent categories are firmly grounded in the participants experience and provides a sound basis for exploring how the participants construct their social world.

3.8 Research Design

This research has a longitudinal design as it incorporates two stages of data collection with an interval of a year. This design was selected in order to present an indication of how experiences may alter over the progression of time, a concept that seems to be particularly relevant in terms of documenting the ME/CFS journey from pre-illness to post recovery. Non-longitudinal research offers a single 'snap-shot' of a single point in the life of the participant, Neale & Flowerdew (2003) argue that extending this presents a richer more detailed account of the participant's subjective experience in relation to the wider social context. This approach has become increasingly popular in the social science arena and has been adopted for research exploring issues such as identity in different contexts.[30]

The initial data set draws upon 36 semi-structured interviews and the 1 year follow up comprises 6 interviews. All of the interviews were semi-structured in nature and were fully transcribed and data analysis was performed using constructivist grounded theory.

Whilst this project was not initially conceived as involving high levels of patient-public involvement in the design, nor as participatory research is often understood, the experience of working with pwME/CFS, and the author's experience as an informal carer meant that important elements of these research approaches informed the design of the project. For example, participants played a significant role in shaping the structure of it. At the outset it was anticipated that this would be a mixed methods endeavor, consisting of questionnaires to measure features such as 'quality of life', which could then be used as a basis for follow up interviews. However, the participants almost unanimously rejected this idea because recent experiences of taking part in quantitative research had left them deeply mistrustful of

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[30] For example Walkerdine et al (2003) explores gender identity over a period of time.

it (see appendix B). As noted above, the research questions were arrived at partly as a result of consultation with members of ME/CFS support groups. Also, several of the issues attended to in analysis were addressed and framed in a way that was informed strongly by participants' own terms and concepts. For example the idea of recovery was derived from participants' formulation of the experience. The value of this level of participant involvement in the design and implementation of research has been underscored recently by a number of policies and scholarly initiatives to The need to promote user involvement in health research has been acknowledged for some time (Boote, Telford and Cooper, 2002). In research conducted within heath care organizations there is considerable institutional support for patient and public involvement in research (Howe et al 2006). In particular, patient and public involvement has been advocated strongly as valuable in under-served populations with ME/CFS (Bayliss et al.2014). As Carter et al (2014) argue, it is particularly powerful if research mobilizes the experiential knowledge of patients and carers as well as that of researchers. Moreover, as Chew-Graham et al. (2011) document, patient engagement is much enhanced if they feel they have been listened to, understood and included in the design and development of activities. Thus, the eventual shape and form of the project was aligned with a good deal of contemporary opinion on patient and public engagement and this enhanced not only the emancipatory potential of the work but also its potential to achieve fidelity to participants' experience and thus improve the rigour of the work as a whole.

3.9 Ensuring Rigour

The question of rigour in research of the kind reported here is a thorny one. As many authors, such as Bryman (2012), have documented there is at least half a century of debate and controversy surrounding the appropriate criteria for the evaluation of qualitative research. In much conventional quantitative research, questions of reliability and validity still hold sway. However, from the 1980s onwards there has been progressive divergence from the view that these criteria are meaningful within the qualitative research community (Bryman 2012, Guba & Lincoln 1994). Some have attempted to re-pose the criteria to make them more applicable (Le Compte & Goetz 1982, Kirk & Miller 1986). More radically, a well-known set of criteria focussing on constructs such as credibility, transferability, dependability and confirmability were proposed by Lincoln & Guba (1985, Guba & Lincoln 1994). The value

of using evaluative criteria specific to qualitative research and in consonance with its philosophical assumptions is increasingly seen as vital, (Leininger 1994, Lincoln & Guba 1985). Leininger (1994) extends Lincoln and Guba's criteria so as to include credibility, confirmability, meaning in context, recurrent patterning, saturation and transferability. In this case, we will use Yardley's (2000) criteria for evaluating qualitative research as they seem particularly compatible with constructivist grounded theory and aligned to the aims and research questions of the present study. Yardley's (2000) criteria include sensitivity to context, commitment and rigour, transparency and coherence and finally impact and importance. These criteria are especially suitable to qualitative research with a healthcare orientation because of the emphasis of impact and potential relevance and implications for how people with ME/CFS may be assisted through their journey from pre-illness through to recovery (Bryman 2012). Yardley's (2000) criteria inform the consideration of this study's rigour and trustworthiness.

Sensitivity to Context

Throughout the study I attempted to be sensitive to the social situation of the participants and their families. It was this sensitivity which underlay the choice to adopt a wholly qualitative approach in the light of the participants' experiences and preferences. The work they undertook to construct and formulate their accounts of their lives reflects the broader context of expectations of what it means to be a well person, a productive member of society, a good parent and so on. Moreover, these accounts are informed by the contested and contentious nature of the condition itself. The participants themselves provided significant contextual and background information about their biographies, work histories, family relationships and involvement in self help and support groups. In presenting quotations, contextual and background information has been included to highlight factors important to the data collection and interpretation. The focus on context and participants' interpretation of context also informs the follow up material and the construction of recovery as context is significant in the extent to which participants consider themselves recovered.

Commitment and Rigour

My own commitment to the topic area and firsthand experience provided an initial framework with which to see the situation, elaborated by my knowledge of earlier literature in the area. The thesis represents a substantive engagement with topic area, largely on participants' own terms as they informed the design of the study and the issues explored. This commitment extended to a thorough, defensible and evidence based reading of the interview material elicited (Yardley 2000). This has been achieved by providing an explicit account of the stages undertaken in the research process, and the use of an audit trail, especially where the elicitation of themes was concerned so that the logic of categorisation could be rendered open and could be revisited during the interpretation and writing up phases. The overall framework of constructivist grounded theory guided this process and underlies the decisions taken where data collection and interpretation were concerned.

Transparency and Coherence

Whilst identifying themes around which to structure the data presentation is a somewhat messy process, and includes influences from the participants themselves, the fine grained analysis of the interview data and ideas from the background literature, at each stage every effort has been made to provide sufficient quoted material in the body of the thesis to ensure that the themes concerned can be seen as grounded in the data and to have emerged in a bottom-up fashion from what participants said. The framework provided by Charmaz guides the analytical process, the epistemological stance and the data presentation. Analytical and presentational decisions were made so as to reflect this philosophical and methodological stance. The presentation of data has been organised with a view to coherence so that it represents a progression through the episode of ME/CFS and also represents the progress of the study itself. Consequently the thesis has a coherent structure with themes leading on from one another within chapters and a logical, linked sequence of chapters so as to form a coherent piece of work. The reflexive process of considering the interviews on a case by case basis is an important aspect of how the researcher has worked with the research participants.

Impact and Importance

The importance and possible impact of the study are summarised in chapter 8. The significance of the findings is enhanced through the links made between the experiences reported here and broader patterns of thinking in the social sciences. Rather than being entirely localised within the literature about illness experience of ME/CFS, links have been made to notions such as liminality, biographical disruption and identity with a view to showing how these experiences both exemplify and critically interrogate these ideas. In a more immediately humanitarian sense, the project is intended to help those with ME manage their illness effectively and regain their lives. The findings acknowledge that illness identity is not fixed and there may be both change and continuity over time, with consequent shifts in healthcare and social support needs. Whilst the illness may often be seen as powerful and beyond voluntary control, recovery involves a sense of being reunited with a pre-illness identity.

In these respects, then, the project addresses both the narrowly defined notion of rigour and Yardley's broader criteria relating to how the research may be meaningful, significant and worthwhile in context.

3.10 Participant recruitment

A total of 36 people took part in this research, these were divided into three groups based on the participants own self categorisations of their health status. The first group is people with ME/CFS (pwME/CFS) where people described themselves as facing daily, recurring struggles with the condition. The second group, people in recovery from ME/CFS (pirfME/CFS) was comprised of people who described their illness as having improved considerably, but did not consider themselves to be symptom free or recovered. The final group was made up of people who claimed to be completely recovered from ME/CFS (PrfME/CFS) and were symptom free. All participants had to meet the inclusion criteria of being given a medical diagnosis of ME/CFS in the UK and having English as a primary language.

The majority of the participants were recruited through local and national ME/CFS support groups. The researcher drew on existing contacts with two local self-help groups, one of

which her husband attended, and contacted other local and national ME/CFS support groups directly. In all cases ME/CFS group leaders were contacted, and provided with information that explained the research and asked for help with finding people to take part.

ME/CFS group leaders were often cautious about providing any details to their members without making further detailed enquiries about the research. Providing information about the researcher's experience and knowledge of ME/CFS was key to accessing the wider group membership. The researcher explained that her husband suffers with ME/CFS, outlined some of the difficulties they had encountered and explained that these experiences had provided the impetus to enhance wider understanding of ME/CFS through conducting research. The researcher and her husband were invited to attend some informal ME/CFS meetings and these occasions were also a way for group leaders and members to assess the credibility of the researcher. Once group leaders were satisfied that the research and the rationale for undertaking it were legitimate they included information in their newsletters, sent emails to their membership list and/or placed details of the research on their website all of which prompted a flurry of email responses from pwME/CFS.

On three occasions the researcher was asked to give an informal presentation at social events arranged by the support groups. Attending such gatherings provided a good opportunity to recruit people as the researcher was able to talk to individuals in person about the research and explain fully what was required of them. It also provided the pwME/CFS with an opportunity to ask any questions.

A high number of pwME/CFS contacted the researcher by email. Whilst some people wanted to participate others wanted to bring literature of various types (i.e. newsletter publications, articles in the press or academic articles) to the researcher's attention or simply to informally share their experiences. Local ME/CFS support groups also extended invitations to attend social events planned in the near future in order to talk about the research in person. The researcher attended three such events; two were informal 'luncheons' where there were approximately 25 people, and one formal afternoon event. The formal event was a lecture by a doctor specialising in ME/CFS with an audience of around 100 people. At each event the researcher gave a short verbal presentation describing the research, disseminated information, invited people to get in contact for more information or to participate and

stayed for the duration of the event to answer any questions. During the research process the researcher continued to attend informal social events hosted by local ME/CFS groups and maintained a constant dialogue with members of the community.

People who expressed an interest in taking part had often heard about the research in a variety of different ways as they were members of more than one self-help group or had friends who had heard about the research and informed them about it. In the end it 24 participants describing themselves of being ill with ME/CFS or being in recovery from it of the 36 participants were recruited directly or indirectly via communications with self-help groups.

People who described themselves as being fully recovered from ME/CFS were more difficult to recruit, as they had often disassociated themselves from the ME/CFS support groups and there was no way of actually contacting them directly. Two people made contact after seeing information about the research on the self-help group website and the remainder (7) were recruited via participant driven sampling. These were either procured by recovered people staying in contact with a friend who had ME/CFS who recommended they take part in the research or via a recovered person themselves who knew of other people that had recovered.

Three people sought out the researcher in the academic environment, with a view to taking part in the research, of these, two had ME/CFS and one described themselves as recovered.

This recruitment process led to the following participants being included in this research and they were divided into the following groups accordingly:

Group 1 - People with ME/CFS (pwME/CFS)

Individuals who identified themselves as being ill with ME/CFS such that it had an impact on their everyday life were placed in this group. It was made up of 10 females and 9 males ranging from 24 – 61 years of age. The duration of illness varied considerably between the participants from 8 months to over 30 years.

Group 2 – People in recovery from ME/CFS (pirfME/CFS)

This category emerged after some participants began describing themselves as being 'in recovery' rather than being 'ill'. The key difference appeared to be a considerable improvement in health and more involvement in activities of everyday life. There were 5 people in this category, 4 women and 1 man, ranging in age between 27 and 58 years. The illness duration within this group ranged from 3 years to over 30 years.

Group 3 – People recovered from ME/CFS (prfME/CFS)

People in this category identified themselves as being fully recovered from ME/CFS and claimed to be completely symptom free. There were 11 people in this category, 6 women and 5 men, ranging in age between 29 and 58 years. The duration of illness and length of time recovered varied considerably between participants.

All of the above participants were selected for the initial round of interviews. However two of these in the fully recovered group (group three) had to be removed. One fully recovered male participant requested that his data be withdrawn through fears of being identified despite being given reassurances of anonymity. The second interview, also with a fully recovered male participant, was unusable due to noise interference from a nearby air conditioning unit. Therefore there were 34 interviews and 42 hours of interview data.

3.11 participants for follow up interviews

From the initial transcripts twelve participants were invited to participate in a further interview a year later. People who appeared to be progressing through a period of transition, either trying a new 'treatment', change of employment status or role or other life events were selected. Of the people approached only six were able to participate. 3 could not be contacted through the details that they had previously provided, 2 people had become too busy with life events and 1 felt unable to participate due to ill health.

The six interviews comprised of 2 female pwME/CFS, 3 women in partial recovery from ME/CFS and 1 male participant claiming a full recovery. This second round of data collection generated 6 hours of data.

3.12 Ethical considerations

This research was fully reviewed by the Faculty of Health and Life Sciences Ethics Committee at De Montfort University and followed the ethical guidelines recommended by the British Psychological Society. In addition the research was also subject to review by three ME/CFS support group committees before information was disseminated to the group members. Participant information and personal details were also kept in conditions accordant with the Data Protection Act (1988).

It was recognized that participants were being asked to share very personal and perhaps distressing information about how ME/CFS had affected them, therefore, it was important that the interviews were conducted as sensitively as possible.The participants were fully informed about the purpose of the study through information disseminated through by the support group (See Appendix C), or via the participant information sheet (See Appendix D) which was presented to the participant prior to the interview. The participant was also asked to sign a consent form before any data collection took place and was provided with the opportunity to ask any questions that they may have about the research (See Appendix E)[31]. The consent form assured the participant that their identity would remain confidential and they would be given a pseudonym for the purposes of the research. It also specified that any 'hard copy' materials would be kept in a locked cabinet in the researcher's home and electronic material would be securely kept on a password-protected computer.

During the interviews, the health of the participant, particularly for people who were ill with ME/CFS, was of paramount importance and they were advised that they were welcome to take breaks or stop the interview at any time. The interview questions were semi-structured and the researcher used prompts in order to gain a greater understanding of some of the issues that participants raised (See Appendices F & G). A semi-structured interview schedule was also employed for the follow up interviews along with targeted questions which allowed the researcher to follow up issues that that the participant had previously raised (See Appendix H).

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[31] In the case of telephone interviews the consent form was emailed to the participants who typed their name on the signature line and returned it to the researcher via email.

Immediately after the interview the researcher asked the participant how they found the interview process and gave them a further opportunity to ask any questions that they may have. In a few cases the participant was unsettled by the interview as it had reminded them of some of the negative aspects of being ill. In these cases the researcher engaged the participant in further conversation about something they had talked positively about before finishing the conversation. The majority of participants were pleased to have the opportunity to talk about how ME/CFS had affected them and many reported finding it to beneficial. After the interview the participants were provided with a debriefing sheet (See Appendix G) which thanked the participant for their time and as the researcher is not qualified to give advice, contained the contact details of useful organisations as well as contact details for the researcher and the supervisory team.

A 'first pass' transcript of the interview was sent to the participant as soon as possible after the interviews and in accordance with the consent form they were advised that they could fully or partially remove their data within three working weeks of receipt of the transcript. As detailed above (section 3.13), one participant asked for his data to be removed within this timeframe which meant that the recording and transcript were destroyed in accordance with his wishes.

The same ethical process was applied to the follow up interviews one year later.

3.13 Data Recording and transcription

All of the interviews were fully recorded and transcribed verbatim. The interviews were digitally recorded using a small microphone which participants clipped to their clothing, the microphone was connected a generic MP3 recording device. Telephone interviews were recorded using the inbuilt recording technology on the Smartphone.

Although the quality of these recording was excellent overall there were instances where participants movements interfered with what the participant was saying and caused fluctuations in sound levels. Causes included participants moving about in face-to-face interviews, which created additional noise or temporarily covered the microphone, or participants moving the phone away from their ear or using hands free kits during telephone

interviews. The variability of voice levels is not treated as a function of speech for the purposes of this thesis but as an unavoidable feature of recording the interviews.

All of the interviews were transcribed verbatim to the standard of a 'first pass' and were returned to the participants in order to check for accuracy and allow the participant the opportunity to clarify points that they had made. Extracts selected for data analysis were refined several times before being considered to be of suitable quality, which involved continuous listening to the recording whilst reading the extract.

3.14 Data Processing using the Grounded Theory Method

The grounded theory method advocates a simultaneous process of data analysis and data collection which means that the first stage of open coding begins once the initial interview has taken place. All of the transcripts were transcribed to the standard of a 'first pass' for open coding which was followed by selective and finally theoretical coding. A full account of this process is outlined below:

3.15 The coding process

The first stage of data processing involves the researcher thoroughly reading the transcript several times and noting things of interest that emerge from the data. In this case the researcher was occupied with identifying key points, labelling items or categories and identifying features of speech which stood out as being important to the interviewee. The alternative was to engage in the process of "micro-coding" that Strauss & Corbin (1998) recommend which involves scrutinising the transcript line by line and coding the meaning derived from each line. Glaser warns that following this process can be detrimental to the research process by causing "over-conceptualisation" (Glaser, 1992; p40) as well as being time consuming and making it difficult to clearly identify key concepts from the furore. Due to the volume of the interviews it was determined that identifying key concepts would make the system of constant comparative analysis more efficient.

The process of simultaneous data collection and analysis was followed as closely as practically possible. At times it was necessary to conduct interviews in succession meaning that it was not possible to code a transcript before moving onto the next. In these cases the

transcripts were reviewed in the order of the interview at a later date in order to minimise any effects upon the data collection process.

An example of the open coding process adopted for each transcript can be found below:

Transcript data (Laura Group 1- pwME/CFS)	Coding
I've also found going into groups of people coz y'know coz if I just sort of give you an idea of what I could do socially I mean I have been off work for a whole year so that's been that's been obviously I'm not fit to work coz but if a friend called round in sort of October November December I could manage about twenty minutes and that's about it that's enough but now that's built up to an hour I mean I can manage an hour quite comfortably now	Socialising Past tense Old me Isolation Limitations (Working on limitations) Pushing Boundaries

The initial process of open coding generated a large number of codes (243) which were further refined later in the process. The huge number of codes arose because open coding is quite emic as it places the researcher at the heart of the process and Charmaz (2000) argues researchers should maximise this stage by also using memos that they collect throughout the research process.[32] Therefore information from notes taken at each interview were also used for open coding at this point. As Charmaz states they considered to be a valuable resource for ensuring that the coding stays true to the participants experience and provides a stable basis for the selective coding process that follows.

The coding procedure forms part of the constant comparative analysis which saw each transcript coded in the same way before the previous transcripts were re-read. The re-reading of the transcripts led to coding categories being increased redefined or considered defunct depending on how they appeared in other transcripts. This is because the way that codes were presented led to the situation of constant, continual analysis of the data.

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[32] Memos relate to notes that a researcher makes throughout the research process when any idea, concept, thought or feeling strikes as being relevant. They are particularly useful for making notes immediately after the interview of things that are striking. Goudling (1999) argues that making these initial notes helps the researcher stay 'true' to the data as items that appear to the most poignant at the time of the interview are noted.

As the analysis process progressed transcripts were placed in groups according to the interviewees self-categorisation of their illness; pwME/CFS, people in partial recovery and people who claim to be fully recovered. The transcripts were reread and re-coded in the context of these separate groups, which allowed the researcher to capture any features that appeared to be a unique feature of the illness or recovery experience.

The second activity of selective coding involves drawing related codes together from individual transcripts into broader 'umbrella' categories. This process involved listing all codes for each group of transcripts and reading across the transcripts to see where codes could be grouped into larger categories. One of the striking things at this point was the similarities in codes between the three groups of transcripts which prompted a re-read of the material to check for error. As a practical illustration the code of 'past' tense was incorporated into a larger category of 'timeline', the code of 'old me' was incorporated into the broader category of 'past self' and the code of 'limitations' was incorporated into 'boundaries'.

The final step of the process was to interpret the codes and categories that had emerged in to a theoretical framework. At this stage, with confidence that categories had arisen from the data in a 'bottom –up fashion' it was possible to relate them to themes within the existing body of literature. Whilst engaging in this process it was recognised that it would be beneficial to merge the transcripts of pwME/CFS people claiming a full or partial 'recovery' together for two reasons; Firstly because the codes generated from their experiences were remarkably similar, and; secondly because some of the categories did not meet saturation point within the separate groupings of pwME/CFS, partially recovered people and recovered people.

It should be mentioned that as the categories did not reach saturation point as other researchers have deemed to be good practice (Charmaz, 2000; 2006; Strauss & Corbin, 1990) the technique employed deviated from the grounded theory method. This was a regrettable circumstance that stemmed from the difficulty in sourcing participants who were claiming to be either partially or fully recovered. However, within these groups it was notable that themes were being repeated and the researcher ensured that they were representative of the data set within each group before progressing.

Once the three participant groups were merged together it was possible to generate the theoretical codes which inform the four analytical chapters. These theoretical codes were deliberately 'broad' in order to accommodate the expression of the three different groups of participants. As, for example, the crux of participants' experience was similar enough to generate similar coding yet they were at different and distinct stages of the pre-illness to post-recovery journey. Therefore the theoretical codes were developed as an 'umbrella' category which could accommodate differences in experience and perspective which occur within the three groups. So in order to accommodate these diverse experiences the theme titles of Liminality, Biographical Disruption, Identity, and Recovery are deliberately broad.

Although the coding process revealed many interesting features from the data set which could have been incorporated into themes, including difficulties in communication amongst pwME/CFS themselves as well as with medical professionals and significant others. Also there were obvious tensions and difficulties associated with being part of an ME/CFS support group. Some members, mostly covertly, questioned other sufferers' claims to have ME/CFS. Other issues included the impact that being had upon friends and family and the difficulties that it caused to inter-personal as well as working relationships. These issues and many more were worthy of investigation, however after reviewing the categories within the context of the academic literature and drawing on anecdotal information gathered within ME/CFS support groups the researcher selected themes that highlight issues which are of importance to the participants but are sorely lacking from the literature to date.

The first of these, Liminality suggests that the participants' experience of ME/CFS can be understood in the context of being stranded *'betwixt and between'* (Turner, 1960) the social categories of being 'ill' and being 'well'. It introduces the notion that having a liminal status causes additional problems and issues for the participants to manage, particularly in the 'recovery' stages whereby the participants are transcending these social categories. The second chapter adds a different perspective to Bury's (1986) concept of biographical disruption and suggests that pwME/CFS experience additional and enhanced forms of life disruption because of the controversial nature of their illness. It raises awareness that issues such as trying to improve their health can be perceived as being disruptive to their already limited ability to take part in 'normal' life. Once again these issues are particularly poignant for people who are in a partial or full recovery.

The third analytical chapter explores how the participants' talk about their identity and sense of self from pre-illness through to post-recovery. Thus it offers a new and different perspective to literature to date by including stages of illness and people who have previously been omitted. It proposes that pwME/CFS experience different and additional challenges to their identity whilst they are ill, due to the controversial nature of ME/CFS. However, it also suggests that people who have recovered are able to return to a pre-illness identity.

The Longitudinal Chapter follows up with 6 of the participants after an interval of a year and offers a unique insight into how they view their health over this period in relation to their description of being 'ill', 'partially recovered' or 'recovered'. The chapter revisits some of the findings of the previous chapters as well as providing an additional insight into how the participants' lives have changed over this period.

The themes are presented in the order of: Liminality, Biographical Disruption; Identity and Longitudinal in order to reflect how these issues seem to be interwoven in the subjective experience of the participants. By keeping the theme titles as broad as they are it is possible to compare and contrast experiences across the data set regardless of the stage of illness or recovery. Within each Chapter, four themes are presented which represent four stages of the pre-illness to post recovery journey; pre-illness; illness, partial recovery and full recovery, which is a unique and unusual way to examine the subjective experience of ME/CFS.

The purpose of the analysis is not to generate a theory in its entirety from the data, but to seek points of confluence and difference with previous research into ME/CFS and chronic illness. Throughout it provides an illustration of how the participants use language to construct their social world using a framework of CGT. The extracts selected and included in this thesis are representative of the larger data set and reflect phenomena from across the body of transcripts.

Chapter 4

Liminality: ME/CFS - The before and after story.

Introduction

The principal analytical focus of this thesis is *how* and *what* people talk about when they are asked to relate their experiences of being ill with, or of being in recovery from, ME/CFS. As discussed in Chapter 2, the literature surrounding ME/CFS is diverse and encompasses a wide variety of opinions and perspectives about what the illness actually is and the best way of managing it. However, the views of people suffering with ME/CFS have largely been overlooked within this body of research, particularly in relation to the pre-illness and post-illness experiences. Therefore, the analytical purpose of this thesis is to identify what the participants themselves choose to make relevant when they talk about things that have happened to them.

Chapter 2 presented some of the issues that have been constructed in the wider chronic illness literature, as well as within ME/CFS literature, with specific emphasis upon how chronic illness is socially constructed and the assumptions and *expectations* that the construction entails. For instance, the term 'chronic' may lead to the assumption, on behalf of the medical profession and others that the illness is for life; a diagnosis may also lead to assumptions that medical professionals and sufferers will accordingly behave in a certain way.

The literature reviewed in Chapter 2 also highlighted the 'culture of discontent' that surrounds ME/CFS. In their accounts participants construct descriptions of things that have happened to them retrospectively and in some cases many years after they have happened. Consequently they are likely to be drawing on the culture and language of ME/CFS, the 'culture of discontent' that they have become immersed in during their illness to recovery journey. The issue of ME/CFS being a contested illness has become a dominant influence in culture and society and it appears that when participants are accounting for events they are constantly making a case for the credibility of the illness and defending their identity as being a credible person.

Chapter 2 also introduced literature which looked at how the concept of recovery is constructed for a variety of conditions, including some where a recovery could be medically verified (i.e. cancer), to other illnesses where this was not the case (mental health, alcoholism). Recovery in terms of chronic illness represents something of a dilemma because it is something that is not regarded as being *possible,* talking about it, describing it and quantifying it therefore becomes problematic. How the participants construct this difficult category is a further on-going focus of these data chapters.

One of the first noticeable topics that emerged from the interview process was the way in which the participants' experiences of events such as diagnosis, illness management, recovery and nature of interactions with other people seemed to be different to what they may have been expecting. Their pre-conceived expectations had arisen either through personal experience of other illnesses or from an amassed general knowledge of how illnesses are diagnosed, managed and treated. Becoming ill with ME/CFS which is difficult to diagnose, manage and treat is problematic because the contested nature of the illness means that these preconceived expectations are often not met. Instead people seem to be excluded from the social categories of being 'ill' or 'well' throughout the pre-illness to post recovery journey. The participants' accounts of events which could be construed as liminal are the analytical focus of this chapter. Alongside it is also interesting to note how the participants describe and construct the social categories of being 'ill' or being 'in recovery'. Therefore, particular attention is paid to the language that the participants use to accomplish this.

Before presenting the data analysis, I will provide a brief account of where and how the concept of liminality has been applied to health and illness literature to date and provide some indication of its relevance to ME/CFS.

4.1 Being 'betwixt and between'

ME/CFS is recognised as an illness that is difficult to manage because many things about it are difficult to define accurately and almost all aspects of the illness are debated, which is

unusual[33]. As the literature in Chapter 2 suggests, ME/CFS falls between socially established categories of 'health' and 'illness' which affords it a liminal status. Participants talk about their experiences in a way that seems to suggest that they experience 'grey areas,' whereby their experience falls outside of what may be expected. Therefore, this chapter explores these experiences drawing on the concept of liminality. The following analysis explores these 'grey area' experiences and draws on the concept of liminality.

Liminality is a term borrowed from early 20th century anthropology which was initially developed by an anthropologist, Arnold van Gennep, in order to explain events or phenomena that fail to fit into socially constructed categories. As a result such phenomena and events are then classed as not being 'normal' (Jackson, 2005; Turner 1965; Van Gennep, 1909/1960). They are regarded as being '*betwixt and between'* (Turner, 1967) or occupying a grey area between recognised socially constructed categories. In anthropological studies the liminal state is a temporary, transitional period which occurs when a person is making the journey of moving from one social category to another[34]. Examples of this may include moving from childhood into adulthood, whereby, the period of adolescence, when the person is neither an adult nor a child, represents a liminal period. In some cases, such as moving from being single to being married, the end of a liminal period is marked by a ritual or religious ceremony (Turner, 1969). Although these descriptions of liminality stem from anthropological research, the notion of being *'betwixt and between'* social categories is also fitting for health and illness research.

As highlighted in Chapter 2, 'health' and 'illness' are socially constructed categories (Bury, 1986; Herzlich, 1973) so it stands to reason that the concept of liminality can also be applied to these areas. A small number of health researchers have adopted the concept of liminality to explore the lack of congruence between the subjective illness experience reported by patients and the dominant medical discourse (e.g. Jackson, 2005; Thompson, 2007). Although this research is described in more detail below, it should be noted that the analysis

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[33] Unusual because even the medical profession are divided over whether it is a physical or mental illness, this is different to contested illnesses such as Morgellons where the medical profession are resolute that it is a psychological condition but sufferers claim to the contrary.

[34] Turner (1967) described liminality as a journey from a known social role into the unknown, where pre-established perceptions of status and identity become defunct. It was considered to present an opportunity for an individual to 'grow' in a spiritual sense and re-join society in a different, often elevated, social position at a later date.

in this chapter and throughout the thesis differs, because it focuses on illustrations of liminality *within* the participants' accounts of their experiences.

The literature to date suggests that people enter a liminal state once they suspect that something may be wrong with them. Once a person becomes aware that they are not 'healthy', but are not yet considered to be 'ill' they occupy a space *'betwixt and between'* these social categories (Sibbett, 2006)[35]. In this sense, the liminal state could be perceived as arising from concerns about one's health, which are constructed from the person's *knowledge* of what constitutes health or illness. However, in the case of cancer it is also proposed that the liminal state persists after a diagnosis and in fact becomes more acute, as many people are forced to relinquish their employment, familial and other obligations in order to undergo urgent and immediate treatment (Little, Jordens, Paul, Montgomery & Philipson, 1998). They argue that this loss of autonomy and agency signifies a period of acute liminality, but once the immediate danger has passed, the patient enters a sustained liminality, which is marked by a chronic period of illness. This sustained liminality persists for the remainder of the person's life, even if they do recover. Potentially constant reminders of illness, such as bodily changes resulting from their illness or treatment and the need for medical check-ups, (Little, Jordens, Paul, Montgomery & Philipson, 1998) as well as an awareness of the recurrent nature of their condition (Thompson, 2007), make it impossible for people to fully resume a 'normal' life. So in this sense liminality can also be understood as a response to the physical reality of having a medically verifiable illness such as cancer.

For contested illnesses such as ME/CFS, where the presence of illness cannot be medically verified[36], it is argued that the status of being liminal is compounded by the disbelief and stigma these illnesses incur (Honkasalo, 2001; Jackson, 2005). Chronic pain is similar to ME/CFS as it has no definitive physiological basis, which means that the sufferers occupy a liminal position, whereby, they are not well because of the pain, yet they are not ill because the medical profession cannot find a cause. It is argued that because an illness does not fit into the medically defined categories of being either physical or psychological in origin and

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[35] Sibbett (2006) proposes that people are suspended in liminality between life and death once they suspect that they may be at risk of having or developing cancer.

[36] There is no definitive medical test for ME/CFS. Instead diagnosis of ME/CFS is reached when tests for other conditions which could explain the symptoms are inconclusive. Therefore it is known as a diagnosis of exclusion.

appears to transgress both, it incurs a liminal status (Honkasalo, 2001). Due to the complex nature of the illness pwME/CFS fall between the social categories of being either a 'normal' well person or an 'ill' person and the fluctuations in health mean that they have good days and bad days and often transcend these categories.

The ability to transcend or switch between social categories or occupy more than one at the same time as pwME/CFS can often do, incurs additional negative connotations. Douglas (1976), for example, claims that phenomena are often regarded as offensive or distasteful if it appears outside of its expected categories. Although Douglas originally applied this concept to physical matter, such as blood or hair which becomes distasteful when detached from the body, Jackson (2007) has extended this definition to include things that are considered to be morally reprehensible. It is argued, for instance, that people with contested illnesses, especially those who are in receipt of perceived secondary gains (i.e. welfare benefits), can be regarded as being liminal and distasteful as their 'right' to such benefits is not clear. Douglas (1976) also argues that this ability to transcend boundaries, as people with contested illnesses do, as they can be relatively well one day and quite ill the next, makes other people suspicious and wary of them[37]. The point here is that there is an expectation for all phenomena to fit into a specific social category, therefore the ability to transcend boundaries inevitably arouses suspicion and intrigue.

Returning to ME/CFS, it is possible to understand how the stigmatisation of a fluctuating condition, where there are 'good days' and 'bad days', can lead to having a liminal status. Some of the consequences that becoming ill may cause, such as an inability to work and a need to be dependent on receiving benefits can also lead to liminal status as described above. So ME/CFS can be perceived as liminal, based on how other authors have defined it. The point of analytical interest here though, is how the concept of liminality is managed within the participant's accounts of their experiences. To date, the liminality literature has focused on the experience of being 'ill', only a small proportion has looked at contested illnesses and the concept has not been applied to 'recovery' at all. This chapter addresses

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[37] Douglas provides the example of amphibious creatures as they are often the subject of suspicion and fascination due to their ability to live successfully both on land and in water, as they defy expectations that creatures will fall into a category of being either a land or water dweller.

these shortfalls and provides an analysis of how participants at different stages of the pre-illness to post recovery journey account for being *'betwixt and between'* social categories.

This analytical chapter explores four themes. The first, *'In sickness? or in health?'* explores the difficulties that people encounter prior to diagnosis when they instinctively know that they are not 'well' but struggle to obtain a medical diagnosis leaving them in limbo between being ill and being well.

Secondly, *'A healthy resolve'* explores the participants' attempts to manage their condition using a variety of knowledge at their disposal but with limited support from the medical profession and varying degrees of support from elsewhere. Essentially this theme covers how people manage the space between being ill and being well.

The third theme, *'Routinely normal'* explores the accounts of people who claim to be recovered, yet whom, from the description of their day-to-day activities also seem to be suspended in a sustained liminality.

Finally fourth theme *'A deception of perception'* examines an intriguing feature of the illness experience, highlighting the move towards what is seen as a more permanent recovery which seemingly involves disassociating oneself from the ME/CFS community.

4. 2 In sickness? Or in health?

This theme explores the pre-illness experience that pwME/CFS have often reported feeling unwell prior to any formal diagnosis. It is a time when they are subjectively aware that they are not well but medical investigations fail to find anything definitively wrong.

The first extract below demonstrates how the illness experience can be perceived as liminal as Eve talks about her initial experiences and about receiving her diagnosis. During the interview she has talked about returning repeatedly to the doctors with her symptoms and although they were difficult to quantify they were nonetheless disruptive to her life both as a mature student and single mother.

Extract 4.2:1 Eve (Group 3 – fully recovered)

1   I just felt awful the whole time and I was permanently sneezing

2	and blowing my nose and I always had a headache
3	and I couldn't seem to recover from it
4	you know normally before if I'd pushed things harder
5	as I was just saying you know you would be able to
6	take things easy for a week and then you are ok erm so finally
7	I went to speak to my GP who was a student GP at the time and he said
8	oh well it sounds like you have some kind of a fatigue syndrome
9	erm he said you have TATT that's what he said Tired All the Time
10	erm which I had never heard of
11	erm Yeah, yeah that's what he called it
12	and he just said we'd just kinda keep an eye on it erm
13	and then I went back it's hard to remember all the details
14	but I went back to him after a while and was feeling worse still and
15	he said yeah it sounds like you have a chronic fatigue syndrome
16	quite possibly

(Eve, Data set 1: lines 50-64)

Eve talks of experiencing seemingly innocuous symptoms which are synonymous with the common cold, but she recognises them as being out of the ordinary because she "couldn't seem to recover from it" (line 3) in a manner that one may normally expect. She also emphasises the severity of her symptoms as being greater than what may be considered to be 'normal' as she talks of "permanently sneezing" (line 1), that she "always had a headache" (line 2) and "I just felt awful the whole time" (line 1). She uses Extreme Case Formulations[38] (ECFs) (Pomerantz, 1986) of 'permanently', 'always' and 'whole time' to describe her ailments which serves to stress how troublesome they were and that they were different from the, more trivial, common cold. So, using ECFs helps Eve to present her suffering as extreme and at the same time it also acts to legitimise her experiences by making her account seem more persuasive.

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[38] Pomerantz (1986) argued that extreme case formulations provide people with a way of legitimizing their claims. People use them when they expect that other people may challenge or question the legitimacy of what they are saying.

She depicts a sharp contrast between her subjective experience of feeling ill and the low level response of her GP as she recalls being advised on two occasions "it sounds like you have some kind of a fatigue syndrome" (lines 8 & 15). The doctor apparently begins his comments with "oh well" (line 8) and "yeah" (line 15) which seems to imply that Eve's ailments do not present much cause for medical concern. It is also notable that Eve recollects her GP telling her "you have TATT...Tired All the Time" (line 9) which not only reinforces the idea that she has nothing medically serious but presents a rather ironic acronym to illustrate the point.[39]

Eves account also suggests that even when she returns to the doctors "feeling worse still" (line 14) there is a lack of certainty concerning her diagnosis, as her experience with the symptoms could be attributed to one of many "a chronic fatigue syndrome" (lines 8 & 15). Instead of suggesting any treatment, the doctor seems to further play down any need for medical attention saying "we just kinda keep an eye on it" (line 12), which has again been constructed to appear to be casual.

This extract brings the issue of liminality to the fore. Eve's ailments are not subsiding in a manner that she may expect with an 'ordinary ill' such as a common cold. Furthermore her symptoms do not clearly correspond with a medical condition that the doctor can easily recognise and diagnose. The sharp contrast between the on-going, troublesome ailments that Eve experiences and her doctor's seemingly unconcerned and casual response corresponds to being stranded between the social categories of being ill and being well. Not least because she does not receive the response that she may be anticipating from the doctor.

In the following extract Dina also talks about her experiences of being in a cycle of making repeated trips to the doctor's surgery in order to try and establish why she felt so unwell.

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[39] In colloquial terms 'tat' is a derogatory term that can be applied to superfluous, low quality material items which are considered to be of low significance.

Extract 4.2:2 Dina (Group 2 – partially recovered)

1	I went back to the doctors and he said well y' know try
2	this that and the other tablets to help you sleep
3	and come back in a fortnight and so I went back in a fortnight
4	and I still wasn't any better so he signed me off work for another few more
5	weeks and it took about four months
6	I had fortunately I had a very supportive doctor who kept seeing me
7	regularly erm but it was never actually mentioned by him
8	that it could possibly be ME y'know
9	and I think I did pick up {enough] to work on a part time basis in the summer
10	but I knew I wasn't right because I still had to sleep every afternoon from 2
11	til 4 erm and therefore couldn't work or anything like that at that time
12	and it was about six months later I think
13	erm when I had to see another doctor about something else
14	and I said to him coz it had still gone on and I was suffering these relapses
15	and tiredness exhaustion and various other symptoms
16	erm and I actually said to him... y'know because a friend of mine and I
17	had been chatting about the possibility of it being ME
18	because it it was long term because it had gone on so long...
19	and I said to him could this is ME?
20	and he just sat there and said yes
21	and I was quite taken aback by that
22	because although the other doctor had been supportive
23	he never actually put forward that it could be ME
24	erm so erm so erm and and that was it really
25	it's very much sort of er not much to be done - go away
26	and a lot of in fact he advised me to contact a self help group

(Dina, Data set 1: lines 20-50)

The way that Dina talks about the pre-diagnosis period here reflects a liminal status because she had consulted her GP about her symptoms but did not appear to be getting any better. She also depicts the period as being monotonous and laborious in two different ways. Firstly because she says the doctor advised "try this that and the other tablets" (line 2) implying both that the doctor frequently gave out tablets with little conviction that they would work, and that this may have happened too frequently for Dina to be any more specific. The use of this phrase also sets taps into humorous colloquial expectations of the dismissive doctor saying, 'take the pills and come back in a fortnight', which contradicts Dina's later claim that her GP is "very supportive" (line 6).

Secondly, Dina emphasises how drawn out the process of being diagnosed was by emphasising the increasing increments of time between events and trips to the GP when she talks of "a fortnight" (line 3), "four months" (line 5) and "six months" (line 12). Later she stresses "it had still gone on" (line 14) and she illustrates her point with a three part list saying "I was suffering these relapses and tiredness exhaustion and various other symptoms" (lines 14 & 15). A three-part list is recognised as being a persuasive rhetorical device and it seems that Dina employs it here to illustrate that she was *suffering* during this period. She presents a second three part list which serves to justify her action of approaching her GP where she explains "because a friend and I..... because it was long term because it had gone on so long" (lines 16, & 18). It seems that emphasising both the elongation of time and the relentlessness of the symptoms reinforces the notion that Dina was suffering throughout this period and that there were ample opportunities for the problem to be recognised and diagnosed. She comments that the doctor had "never actually mentioned" (line 7) and "never actually put forward that it could be ME" (line 23) which fits with her earlier portrayal of the doctor being uncertain of how to treat her illness. In fact she appears to suggest that she herself was able to decipher that she may be suffering with the symptoms of ME by casually "chatting" about her experiences with a friend.

It seems that Dina also experiences the liminal status of subjectively knowing that something is wrong for sometime before receiving a diagnosis in a similar way to how Eve (see extract 4:1.1.). It seems that being in this liminal status, outside of the socially constructed categories of being either ill or well spurs Dina into researching possible causes of her symptoms for herself and proposes her diagnosis to the doctor. However being diagnosed with ME/CFS appears to increase rather than resolve Dina's liminal status as the lack of a treatment plan or any medical help denotes that the illness is not recognised as legitimate and therefore she remains in a liminal state between the socially constructed categories of being well and being ill.

In extract 4:1.3 below, Izzie talks about her experiences of trying to secure medical help and becoming aware of a need to conduct her own illness research after consulting a series of private medical specialists about her diverse range of symptoms.

Extract 4.2:3 Izzie (Group 2- partially recovered)

1	my GP wasn't the best to go to she wasn't
2	she wasn't really good erm I would have erm
3	coz my dad was part of BUPA erm through his work
4	so we went to BUPA for a lot of stuff erm and numerous times
5	and the only erm, I went for a gastroenterologist and he was quite good and
6	erm helping me and it gave us the initial diagnosis of ME
7	you know there's nothing else we've tested you for everything
8	erm I went to a radiologist that wasn't the nicest experience
9	he he basically insinuated that I basically had some eating disorders
10	and things like that, which wasn't the nicest thing
11	coz if I could have eaten I would of and if I didn't feel sick all of the time
12	I would have you know happily eaten a bag or whatever
13	yeah anything yeah anything erm you know it wasn't you know erm
14	I felt at the time that I was completely on my own
15	and so I I sort of did a lot of research myself of treatments

16   and and things like that

(Izzie, Data set 1: lines 159-175)

Izzie talks of experiencing an elongated pre-illness period whereby in addition to visiting the GP she "went to BUPA[40] for a lot of stuff erm and numerous times" (line 4). However, her experiences seem to be tempered by how helpful she imagined the healthcare professionals to be as she says "she wasn't really good" (line 2) and "that wasn't the nicest experience" (line 8). It seems that her eventual diagnosis arose following a process of elimination as she recalls being advised "there's nothing else we've tested you for everything" (line 7). The use of the ECFs of 'nothing else' and 'everything' here implies that testing has been extremely thorough that a diagnosis of ME/CFS is a last resort. However what is telling here is that despite being given a diagnosis Izzie too seems to describe a feeling of liminality as she says "I felt at the time that I was completely on my own" (line 14) and feeling separated from or set apart from others is considered to be part of the traditional liminal experience. Her impression of being alone seems to spur her into taking action to resolve the situation as in the absence of any definitive help she "did a lot of research myself of treatments" (line 15).

The above analysis captures the pre-diagnosis and diagnosis phase of having ME/CFS, a stage at which it appears pwME/CFS are uncertain whether they are 'in sickness' or' in health'. Their situation can be described as liminal because prior to diagnosis the participants appear to be trapped in a situation whereby they feel unwell but the medical profession are unable to confirm that anything is physiologically wrong. Although the early period of any illness, when people suspect something is wrong but are awaiting a diagnosis, can be described as liminal (e.g. Jackson, 2005; Little, Jordens, Paul, Montgomery & Philipson, 1998) the elongated diagnosis period for ME/CFS means that the liminal period is also exacerbated for pwME/CFS. It also proposes that receiving a diagnosis does not end the liminal period.

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[40] British United Provident Association (BUPA) is a private hospital in the UK.

For people with medically recognised illnesses this particular phase of liminality ends after diagnosis as the illness is sanctioned as a medical reality whereas pwME/CFS appear to enter a different type of liminality as although they have a diagnosis, the illness is contested. This suggests that people with medically sanctioned illnesses are able to occupy a social category of being legitimately ill, although they may go on to experience a different type of liminality through experiencing a loss of autonomy (e.g. Thompson, 2007). After diagnosis PwME/CFS move towards a liminality which is defined by the medical status of their illness; they are not well but not *legitimately* ill.

What is particularly thought -provoking about the accounts above is the way that being trapped in a liminal status either before or after diagnosis appears to inspire the participants into taking action to try and resolve their situation. Prior to diagnosis this may involve researching illnesses that appear to fit their symptoms and arming oneself with information to present to a GP. Afterwards it may involve trying to find treatment options which make the illness more manageable. The participants talk about how to adapt to managing and improving their lives with ME/CFS in the second theme below.

4.3 A Healthy Resolve

The analysis above introduced the notion that falling ill with ME/CFS can be classed as a liminal experience even after a medical diagnosis has been provided. Whereas with other illnesses the 'patient' may be expected to refer and defer to the 'expertise' of the doctor this is perceived as different for most people with ME/CFS. This theme explores how pwME/CFS manage this difference and become motivated to find ways to improve their health themselves, in fact they adopt a *'healthy resolve'* towards achieving this aim.

In extract 4:3.1 below Jack talks about his attempts to find things that might help with his ME/CFS symptoms and/or eradicate the illness.

Extract 4.3:1 Jack (Group 3 – fully recovered)

| 1 | I was prepared to try anything I was just trying to find a solution |
| 2 | always trying to find a solution and so I tried a number of things |

3	the minute someone told me about about caffeine
4	I gave up caffeine immediately
5	y'know I was just trying to do everything
6	to get better the whole time and so I tried the one anti depressant
7	I then tried the old school the tricyclic depressant
8	which the psychologist he said that from his research
9	that worked better for people with chronic fatigue ME
10	so I tried a course of that that did not help either
11	so I was confident trying everything I had been told
12	and I was still always through the whole process

(Jack, Data set 1: lines 788-799)

Jack's experience can immediately be perceived as 'out of the ordinary' as he says that he was "always trying to find a solution" (line 2). This suggests that he perceived his ME/CFS as a problem that he was constantly motivated to try and resolve. He seems to present this task as difficult because it involves trying "a number of things" (line 2) and refers to it as being a "whole process" (line 12) which may indicate that this is something complex and laborious to undertake. He also seems to suggest that he gives equal credence to things that "someone" (line 3) has said as well as advice from medical professionals and becomes equally as committed to trying both.

He outlines his approach to the problem of trying to "get better" (line 6) by emphasising what appears to be a positive attitude. For instance he states how proactive he was by claiming to have "tried a number of things" (line 2) and being willing " to try anything" (line 1) and "do everything" whilst at the same time hinting that he was very diligent and thorough about his commitment to improve his health. The way that he talks about the timing of his efforts, claiming to have acted "the minute" (line 3) he learned that something may be helpful or even "immediately" (line 4) depicts a constant momentum of moving forwards and reaffirms his commitment to "get better" (line 6).

So for Jack it seems that adopting a *'healthy resolve'* helped him overcome some of the problem of his ME/CFS. The liminal status of his illness means that Jack is stranded between being well and being ill. Being stranded appears to have an effect upon his attempts to find a solution and be thorough as he takes advice and information from both the lay and medical domains. What is interesting here is that Jack maintains that his positive approach to resolving his illness was a contributory factor to his own recovery.

In the following extract Dina talks about her approach to managing her illness following her GP's advice to join a self help group which she had interpreted as an indication that he was unable to assist her (see extract 4.3:2).

Extract 4.3:2 Dina (Group 2 partially recovered)

1	as I say the advice was to join a self-help group
2	and see what they suggest so I did erm
3	and that was that was useful but erm as you know
4	different people respond to different treatments and things
5	they prefer tactics strategies and erm and erm
6	I did have and one of the doctors suggested Echinacea
7	on a short term basis and erm and again I found that helpful
8	because erm I think well y' know my glands were up
9	or I felt under attack my immune system felt under attack
10	y'know like with a cold or flu virus or something like that
11	y'know sore throat if I take Echinacea for three or four days
12	then that's it I'm sorted it really works for me and so again
13	y'know I suppose you learn to use what suits you
14	and to reject what doesn't

(Dina, Data set 1: lines 192-204)

Although she has been directed towards a self-help group for assistance with her ME/CFS, Dina also seems to take equal heed of lay advice and that "one of the doctors suggested Echinacea" (line 6) which in effect places her in a liminal position. She hints at difficulties with gathering helpful information from the self-help group as she says "different people respond to different treatments and things" (line 4) they use "tactics strategies" (line 5) to find something to help them. This implies that Dina, like Jack also, perceives trying to improve ME/CFS as a complex process which requires individuals to formulate a logical and organised approach towards navigating the potential treatment options rather than adopting an ad hoc random system. Her use of the words 'tactics' or 'strategies' is particularly compelling here in terms of her talking about times when she "felt under attack my immune system felt under attack" (line 9) as formulating a response to being under attack invariably has military overtones to it. However, Dina also seems to present the notion that improving her illness is a drawn out, individual process as she says "you learn to use what suits you and reject what doesn't" (lines 13-14).

So Dina presents the notion here that finding things to help with her ME/CFS is a lengthy, complicated process which requires a commitment or a *'healthy resolve'* on her part. She also introduces a further liminal feature here when she talks about people with ME/CFS experiencing the illness differently by suffering with different symptoms and/or finding certain 'treatments' beneficial and not others. This implies that the process of finding things that may be helpful is individual, and therefore potentially isolating, which is consistent with having a liminal status. This process presents something else that the participants have to manage.

Like Dina, Sally (extract 4.3:3) also talks about the methods that she adopts in order to try and find ways to improve her health.

Extract 4.3:3 Sally (Group 2 Partially recovered)

1	Working backwards is probably the most useful
2	my current regime because I'm always managing my health
3	actively my current regime consists of a fairly erm major
4	supplement regime I've been on quite significant quantities of
5	supplement since ninety-six and I would say that just keeps me
6	functioning and I see a kinesiologist once every couple of months
7	to check my supplement regime

(Sally, Data set 1: lines 170-176)

It is noticeable here that Sally repeatedly refers to her system of trying to improve her health as a "regime" (lines 2,3 &7) as it implies that she feels a need to adopt a disciplined, organised approach to resolving her health issues. It also has military overtones to it and bears similarities to Dina (Extract 4.3:2) who talks about adopting 'tactics' and 'strategies' as a way of dealing with the problem caused by the illness. It is notable that Sally points to a broader "current regime" (lines 2 & 3) which may refer to a broad spectrum of things that she does to try and improve her health and then, within this, she talks specifically about "my supplement regime" (line 7) which denotes a very detailed and specific approach to one single aspect of her health management. Overall this implies that for Sally managing her health is complex and requires considerable input of her time and attention. Yet she also says that her efforts "just keeps me functioning" (line 5) suggesting that she is still not fully operational or able to do things as 'normal' despite her best efforts to improve her health. Her use of the term 'functioning' is worth noting here as it introduces the idea that she has a method of measuring how beneficial a 'treatment' has been for her by gauging how much she can participate in 'normal' life.

It appears that during this mid-illness period participants incur an additional liminal situation that stems from being stranded between the social categories of sickness and health and they purposefully seem to have to adopt a *'healthy resolve'* in order to find ways to improve their health. The additional liminal situation is caused by having to give equal credence to both lay and medical advice in an effort to thoroughly explore

every possible avenue of improving one's health. Although they appear to imply this is a difficult and laborious process, the participants also seem to emphasise that an organised and proactive approach is necessary to combat it.

There does however appear to be a further liminal feature of the illness experience as participants indicate that any 'regimes' or approaches to health improvement are an individual process and there is no universal approach to improving the illness that can be used by all ME/CFS sufferers. Therefore it seems that even within a self-help group setting the search for help or assistance is an individual, personal experience, being isolated and facing a 'journey' alone corresponds with the stages of having a liminal experience.

Adopting a *'healthy resolve'* has also touched on another problem pwME/CFS face, which is how to establish, measure and articulate a recovery in the absence of any definitive medical 'proof'. The next analytical theme *'Routinely normal'* looks at how pwME/CFS manage the problems of deciding that they are 'recovered' or 'in recovery' and then how to go on to manage a 'normal life'

4.4 Routinely Normal

The first two themes have described the participants' experiences as being liminal before and after diagnosis as well as in the early stages of the illness. The following analysis explores how pwME/CFS manage their illness to the extent that they become able to participate in aspects of everyday life and become *'routinely normal'*.

At the time of the interview Sally described herself as being 95% recovered from ME/CFS. In the extract below she talks about how she has organised herself in order to keep a 'normal' job.

Extract 4.4:1 Sally (Group 2 partially recovered)

1	I work full time in four days yes
2	so I manage my basically I sort of do boom and bust

3	so I don't do pacing I do overdraft and then rest
4	which works really well for me
5	I know it's not what they say in the guidance
6	I don't know how the hell I'd hold down a job if I
7	you know a nine to five type job if I had to do strict pacing?
8	so, I don't do strict pacing I do everything wrong for four days a week and
9	everything right for three days a week
10	and I live on caffeine and all sorts of rubbish
11	but, you know, I have an income which I'm very happy with
12	so I'm not saying I'd recommend it to anybody else, [laughs]
13	it works for me

(Sally, Data set 1: lines 132-142)

It seems that Sally is talking about extremes of living here as she explains that she has a cycle of "boom and bust" (line 2) and "I do overdraft and then rest" (line 3). What is immediately striking here is that she uses financial terminology to explain her approach to managing a normal life and the effect that this has on her illness. She says "I...do boom and bust" (line 2), drawing upon a colloquial phrase which is used to denote a cycle where the economy moves from a healthy financial state to one of fragility such as being a recession. So she indicates that actively 'does' two extremes a 'boom' whereby life is 'normal' because she is able to work and 'bust' when she is ill. She also talks about this as "I do overdraft and then rest" (line 3), which compels the image of borrowing. It seems that in this instance she is referring to 'borrowing' energy which she then repays by resting until she has a balance of energy again and can once again return to work. Sally's use of financial terms is particularly innovative as it represents a new and different way of talking about ME/CFS and this way of talking reoccurs in many of the following extracts as it was a common feature in the data set. It presents a way of describing the experience of being ill in a way that is unique to ME/CFS, as people other conditions adopt different ways of doing this. Lupus sufferers,

for example, use the 'The Spoon Theory'[41] to illustrate that they have a limited amount of energy available to them at any given time and that because of this they have to carefully choose which tasks or events to manage. It is so-called because the sufferer physically hands the listener a number of spoons, say 12, each of which represents a unit of energy. Then the sufferer asks the listener to describe the type of mundane activities they would expect do on a typical day (i.e. have a shower, get dressed, have breakfast) and removes a spoon to show that the 'energy' has been used up by doing each of these mundane things and is no longer available. This process continues until all of the spoons are gone. This method conveys that a person with Lupus has to think about the effects of mundane, routine tasks in a way that a 'well' person would not have to consider. It is way to visibly demonstrate that once certain things have been completed there is no more energy available, regardless of what further activities may need to be done. Sally and other pwME/CFS appear to be doing something similar by suggesting that there is only a finite amount of capital (energy) to use and although it is possible to beg and borrow there are penalties for doing so. It seems to be a way of talking about one's illness that is unique to ME/CFS.

Sally also says "I know it's not what they say in the guidance" (line 5) which demonstrates an awareness that her system of managing her health defies advice from both ME/CFS support groups and medical professionals who advocate that pacing activities and maintaining a constant routine are the best ways to manage ME/CFS. She goes on to say "I do everything wrong for four days a week and everything right for three days a week" (lines 8 & 9), which is a very telling statement as it again, suggests that she creates and manages extremes. It seems that 'everything wrong' refers to the four days when she is working as a 'normal' person would and 'everything right' refers to the other three days when she engages in behaviours that are synonymous with illness such as resting. Sally's week it seems is divided between acting as a "well person" by working and then acting as an "ill person" by resting. This denotes that she does not consistently remain in one category or the other but moves repeatedly

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[41] Christine Misbranding (2003) is credited with devising 'The Spoon Theory' and a full explanation can be found at www.butyoudontlooksick.com.

between the two. A situation which seems to place her in what Douglas (1976) calls a 'neither nor' category, transcending the boundaries of two social categories in this manner leads to a liminal status.

Interestingly though, despite managing her health in a way that goes against any advice, Sally stresses twice that "it works" (lines 4 & 18) for her. It seems that she actively manages her week to accommodate necessary illness behaviours by condensing her working week and then spending the remaining three days resting and by adopting this routine she manages aspects of 'normal life'. It could therefore be understood that Sally is actively deciding to be in one social category at a time as it presents the best way for her to manage a 'normal' life and her ME/CFS.

Dina (extract 4.4:2) describes herself as being 90% recovered from ME/CFS and talks about how she employs a routine to help her manage having a normal life.

Extract 4.4:2 Dina (partially recovered)

1	it's great because I feel quite normal really
2	apart from tired time of 5 til 7 erm and I do I am aware of it
3	because sometimes like yesterday it creeps in earlier
4	and yesterday it was 4 o clock I had some friends round yesterday
5	to do this arts and crafts session and it was a lesson
6	I did need to concentrate and we didn't have lunch until later
7	than we thought and by that time I'd got a headache
8	and and so by 4 o'clock I had this pounding headache
9	and I was feeling hot hands is my sign hot tingly hands
10	erm and a fuzzy brain y' know ha ha
11	and even I I went to the travel agents yesterday I said to Neil
12	I said I just can't think straight and I need to lie down
13	so (coughs) can we come back tomorrow
14	and they said yeah go away and think about it y' know

15   and I went straight to bed at half past four or thereabouts

(Dina, Data set 1: lines 652-644)

Dina illustrates that she also experiences extremes on a regular basis, saying "I feel quite normal really apart from tired time of 5 til 7" (lines 1 & 2) which implies that she perceives that her ability to be normal is compromised by the need to engage in daily illness behaviours. What is worthy of note here is her observations of "I am aware of it" (line 2) and sometimes "it creeps in earlier" (line 3) which suggest that the need for rest time is something that she has little control over and even that she has to watch out for it whilst she tries to go about normal activities. She seems to suggest that without the rest period she cannot keep her ME/CFS symptoms at bay as she says "I was feeling hot hands is my sign hot tingly hands" (line 9). The notion of there being a 'sign' that ME/CFS is about to get worse is something that sufferers often speak of and they interpret it as a warning to rest and prevent the illness from becoming worse. The way Dina describes this is reminiscent of 'relapse signatures' that people with mental health conditions talk about. These are described as specific symptoms which an individual sufferer recognises as being an 'early warning sign' of an impending psychotic relapse (see Birchwood, Spencer & McGovern, 2000). In the event that this does not happen Dina describes becoming both mentally and physically incapacitated by the illness saying "I just can't think straight and I need to lie down" (line 12).

For Dina it seems that adopting a daily routine that incorporates a rest period is essential to her ability to function 'normally' even in a leisurely capacity. Therefore it seems that she too, like Sally (extract 4.4:1)moves between the categories of being ill and being well as she has to make allow for her need to engage in illness behaviours.

So Sally and Dina who both claim they are almost recovered appear to have to work at being *'routinely normal'*, that is to adopt a routine that allows for necessary illness behaviour which then enables them to participate in the events of 'normal' everyday life.

Pip (extract 4.4:3) says he recovered from ME/CFS 19 years ago and talks about how he now goes about his everyday life.

Extract 4.4:3 Pip (Group 3 Fully recovered)

1	I don't want to push myself too far
2	because tennis tennis is fairly aerobic but it's not too too bad really erm erm
3	I pretty sure I would know as soon as I had
4	I have to walk to and from the bus every day as well
5	so I'm probably walking about three miles every day just commuting
6	y'know erm y'know
7	a mile and half there and a mile and as half back y'know
8	getting the bus but I'm tracking myself
9	and I'm trying to monitor my muscles really to see if I feel fatigued
10	so so the thought is always there I have to say
11	I'm always sort of thinking y'know am I am I gonna get this

(Pip, Data set 1: lines 520-532)

Pip is talking about seemingly mundane activities of commuting to work and exercising and it appears that they present him with a dilemma as he says "I don't want to push myself too far" (line 1). It may be that he is drawing on a that very active people are prone to getting ME/CFS which makes him wary of 'overdoing it' yet at the same time he manages to engage in sport that is "fairly aerobic" (line 2).

He seems to approach this problem by adopting two methods which allow him to maintain his activities and also monitor his health. Firstly he seems to keep a watchful eye for any signs that his illness may be returning as he says "I'm tracking myself" (line 8) and "trying to monitor my muscles" (line 9), the terms he uses here, 'tracking' and 'monitoring' hint at this being an on-going, constant process which requires considerable attention. Secondly he seems to involve keeping very detailed records of the amount of activity that is undertaken such as "three miles every day" (line 5) and "a mile and a half there and a mile and a half back" (line 7). This implies that for Pip the activity of merely walking to work is not as straight forward as it may be for other people without ME/CFS, as he is also using it as a way to gauge his level of health. It seems that despite claiming to have been free from ME/CFS for 19 years Pip's fear of it

returning and the activities he engages in to try and prevent this happening places him between being ill and being well which again is a liminal status.

The analysis of the above extracts suggests that implementing a routine is important for Sally, Dina and Pip as allows them to maintain a balance between engaging in illness behaviours and managing a 'normal' life. What is important here is the regimented nature of these routines and the way that the participants describe them as they meticulously quantify the type, timing and range of their activities suggesting that maintaining a 'normal' life with the illness is an involved and complex process. It has also been noted that the participants use financial language to describe how they *balance* their activities using a process of debits (overdraft) and credits (see extract 4.3:1) which is way of talking which may be unique to ME/CFS. It also seems that people still fall between the categories of being ill and being well because their concerns over managing or looking out for ME/CFS make it difficult for them to participate fully in normal activities. However their ability to participate in normal life, albeit to a reduced degree, challenges their position with the category of being 'ill'. Therefore it seems that the participants can manage to be *'routinely normal'* by working within the constraints imposed by the illness but that they incur a liminal status as a result of this.

This raises a significant question over the nature of the liminal state and if it qualifies as being different from the type of liminality that participants find themselves in prior to and after diagnosis and during the middle stages. The next theme "A deception of perception" investigates this and explores the participants' experiences after 'recovery', an area which has mostly been overlooked in the illness literature to date.

4.5 A deception of perception

The participants focus upon a specific aspect of their recovery experience in this analytical theme which is how others reacted to the 'news' of their 'recovery'. As already mentioned the expectation of 'chronic illnesses' is that they are life-long

conditions from which a recovery is not possible. This means that the legitimacy of any claims of recovery from ME/CFS are likely to be questioned anyway because of its status of being a chronic illness and the perception of what this means in terms of the likelihood of recovery. However, the experience of sharing recovery stories seems to incur a *'deception of perception'* as things that participants took for granted are challenged by others.

In the extract below Janet, who had ME/CFS for 18 years talks about sharing her experience of recovery with her friends.

Extract 4.5:1 Janet (group 3 fully recovered)

1	When I got better and explained [what] Professor (removed)
2	did for me again sort of look in disbelief
3	'Ah well y'know how can that work when modern medicine can't work?'
4	And and that that was a bit hurtful too really as well
5	because I know I know it worked and
6	I just felt hang on why on earth would I make all of this up?
7	Y' know that that was a bit sort of erm very insulting really
8	Y'know you think you've got some good friends
9	and then when they kind of like look at you y' know in disbelief
10	you think well are they good friends after all? [laughs]

(Janet, Data set 1: lines 810-829)

Janet stresses that she found other peoples' reactions to her recovery story were "a bit hurtful" (line 4) and "very insulting" (line 7). She depicts her audience as being openly sceptical of her story as they responded by asking her "how can that work when modern medicine can't work" (line 3). This implies that her recovery defies expectations of *how* people are expected to recover such as with appropriate help from the medical profession. Janet appears to interpret such responses as an attack on her own morality as she says "I just felt, hang on, why on earth would I make all of this up?" (line 6). This, along with her claims to have been met with "disbelief" (lines 2 & 9)

presents the possibility she considered that others' perceived her as being deceptive or dishonest. She also says "I know it worked" (line 5) which may suggest that the negative reaction she encounters contrasts with her own strength of conviction that she has indeed recovered from ME/CFS.

It could be inferred that her depth of emotive feeling implies that she was not expecting to encounter this reaction from others and that she expected people to treat her recovery story with credibility. Instead she suggests that people believed that she was deliberately deceiving them and openly discredited her claim to have recovered. Thus it seems that there is a *'deception of perception'* at play here as Janet expects a positive reaction to her news but instead she is perceived as being deliberately deceptive.

In terms of liminality Janet is describing a situation of being doubted and disbelieved which is similar to stories of pwME/CFS trying to convince others that their illness is genuine once they become ill, which, as already highlighted, has features associated with a liminal status. However, it appears that Janet's experience of recovery, which is met with disbelief because it does not conform to expectations of what 'recovery' entails, also incurs a liminal status. Janet, herself seems to question assumptions about her fit with people in a social category as she says "you think, well are they good friends after all?" (line 10). This may further indicate the presence of a liminal status as in accordance with Turner's (1967) argument people become liminal once they fail to fit into a current social category.

Mary, (extract 4.5:2) claims to have been recovered from ME/CFS for 4 years and below she talks about her experiences of sharing the news of her recovery on a self-help group forum board.

Extract 4.5:2 Mary (Group 3 –fully recovered)

1	Interestingly there was a message board

2	which I haven't been on for many years now called (removed)
3	a couple of us put our [recovery] experiences down
4	and we said y'know please please consider it and think about it
5	and we got very very abusive replies from people
6	it really got quite horrible in the end y'know
7	my husband said y'know 'that's it you're not going on again'
8	because it was really upsetting that people really thought
9	you were pulling the wool over their eyes, y'know?
10	'you didn't have ME in the first place'
11	'if you had ME like I've got ME it wouldn't have worked for you'
12	etc, etc and just, just I got really upset about it.'

(Mary, Data set 1: lines 348-362)

Mary implies that she was enthused and motivated by sharing her experience of recovery in order that other people could benefit from it. As she says, "we said please please consider it" (line 4) which is almost imploring in its delivery. The strength of feeling is matched by the response that she recounts receiving which presents a stark contrast to her enthusiasm as she says, "we got very very abusive replies" (line 5). She also talks emotively about her sharing experience as something that "got quite horrible" (line 6) and was "was really upsetting" (line 8) which again contrasts with her apparent initial enthusiasm for helping others and suggests that the response that she received was not the one that she was expecting.

She says "people really thought you were pulling the wool over their eyes" (lines 8-9) which insinuates that she perceived that pwME/CFS perceived her as deliberately trying to deceive them, which is also similar to Janet's experiences (extract 4.5:1 above). However, for Mary the response she receives suggests more than her recovery story being discredited by the ME/CFS community. She talks of people challenging her claim to be ill in the first place by saying 'you didn't have ME in the first place' (line 10) and "if you had ME like I've got ME it wouldn't have worked for you" (line 11). Questioning the credibility to her claim of being ill with ME/CFS in the first place also challenges Mary's place in the category of being an ME/CFS sufferer and her right to be

a member of the support group. Therefore Mary appears to be in a liminal state; she appears to be ostracised by the ME/CFS community because her claim to recovery does not tally with other ME/CFS sufferers' perceptions and experiences. There is also an issue that her original claim to illness is retrospectively delegitimised, suggesting that there was nothing to recover from.

In the last extract below, Jack also recounts his experiences of talking about his recovery on an online ME/CFS support group forum.

Extract 4.5:3 Jack (Group 3 fully recovered)

1	I also erm coz on the forum then people who were complaining
2	I spoke to them individually or wrote to them individually
3	and told them that look I have got better
4	and it was basically full of scepticism and
5	'Oh your situation was different to my situation'
6	and 'no no no I'm much worse that you are' or blah blah blah blah blah
7	so they just weren't in a position or ready to hear or to get better
8	and so they weren't weren't in that space
9	and it just frustrated me and I thought well I now completely understand
10	why people remove themselves which I was told to remove myself
11	but I thought that if I could just help one or two people
12	then I have done my part coz I have felt better
13	and I would feel guilty if I didn't share that knowledge
14	or help at least one other person get better
15	so I stayed there to try and then I just said OK
16	and I I I relinquished I unsubscribed from everything

(Jack, Data set 1: lines 663-678)

Jack suggests that he felt obligated to try and help others improve their health after his own successful recovery saying "if I could just help one or two people then I have done my part" (lines 11 &12) and he implies that he made a considerable effort in this regard (see lines 1 &2). However it appears that the response he received "was basically full of scepticism" (line

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4) indicating that people inferred that he was trying to deceive them. He also implies that people questioned the legitimacy of his status as an ME/CFS sufferer and that his experience was somewhat different to their own (lines 5 &6) and therefore did not concur with what they subjectively know about ME/CFS. So he, like Mary (extract 4.5:2), has both his claim to be ill in the first place and his claim to be recovered undermined by others.

Tellingly however Jack also suggests that he and ME/CFS sufferers are at different stages of their ME/CFS journey when he says "they weren't in that space" (line 8). This hints there is an optimum point for recovery to take place. The realisation that he is at a different stage and perceiving his efforts to help others as being in vain appears to prompt Jack to realise that he no longer 'fits' within this social category as he says "I relinquished I unsubscribed from everything" (line 16), as though it was a conscious decision to cut ties with the ME/CFS community. He almost presents this action as being an inevitable expectation of a complete recovery from ME/CFS as he says he can "now completely understand why people remove themselves" (lines 9 &10) suggesting that he is not the only one to take this particular step.

Severing ties with a social group is a feature of liminality as Turner (1957) suggests and usually signifies a periods of liminality before moving into a new social category. It seems that Jack's experiences concur with this concept of liminality.

This theme of *'Deception of perception'* highlights that even recovery from ME/CFS leads to a period of liminality as the recovery experience is treated with 'scepticism' and 'disbelief'. It is worthy of note that the way the participants talk about this experience is similar to the way that they describe telling people about becoming ill in the first place. As described in Chapter 2, as their claim to be ill cannot be medically verified the morality of the person themselves is classed as dubious and it seems that this also happens in recovery because this cannot be verified either.

However, it seems that within the ME/CFS community at least claiming to recover from ME/CFS casts doubt on the legitimacy of the person's original illness and the likelihood that they had ME/CFS in the first place becomes debateable. Usually, the ME/CFS community is the place where ME/CFS, with all of its tenets and quirks, is accepted in a public setting and possibly the only place that people expect to receive acceptance and support. It seems that

having an ability to recover defies what is *known* about ME/CFS and can differ from the experiences of others within a self-help group setting, therefore claims to have recovered are sometimes treated as dubious.

Participants talk about receiving a response from other pwME/CFS which is not what they would have expected and they claim to suffer a range of negative emotions when they try to impart their own experience. They appear to perceive this as a sign that they have become different and they no longer fit within the same social category as other pwME/CFS, which is an important feature of the liminal experience. Turner (1967) argued that the transition from one social category to another often involved severing ties with a previous group and it may be that this is an important part of a transition between becoming ill and becoming well.

4.6 Summary

This chapter presents four themes which explore the participants' experiences of ME/CFS and either full or partial 'recovery' in terms of being betwixt or between or 'liminal' and so presents a different way of understanding these experiences.

The first theme 'In sickness? Or In Health?' draws upon the body of research which identifies how pwME/CFS typically talk about having an energetic and busy pre-illness lifestyle[42]and considers how the pre-diagnosis and post-diagnosis illness periods can also be interpreted as liminal. The analysis suggests that being 'betwixt and between' (Turner, 1957) is an appropriate framework for understanding how the participants' subjectively experience the pre-illness to post-recovery journey. It also provides a way of drawing together and expanding the previous ME/CFS literature. At a basic level the way the participants talk about their pre-diagnosis experience reflects an incongruity between them feeling very ill and yet the medical profession are unable to find any reason for it. Thus the person is in a liminal position between the social categories of being 'ill' and being 'well'. Previous research has noted that pwME/CFS tend to describe their ME/CFS starting after they have a 'virus' (see Clarke and James, 2003; Clements, Sharpe, Simkin, Borrill & Hawton, 1997) and

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[42] See chapter 2 section 2.12 for review of literature

this chapter has suggested that these early experiences set the context for the ME/CFS experience being out of the ordinary and liminal.

The post-diagnosis experience can be understood as liminal because once a diagnosis of ME/CFS has been confirmed participants are informed that the medical profession can do very little to help. In both instances the participants are stranded between being 'In Sickness' and 'In Health' because they firstly do not have a medically sanctioned reason for being unwell and secondly because being given a diagnosis does not provide any medical treatment as may be expected with other illnesses. Interestingly Dickson, Knusson & Flowers (2007), when discussing the deligitimisation and stigma that pwME/CFS encounter, talk about finding that sufferer's often feel pressurised to present themselves as being ill or being well. They suggest that this is because being ambiguous over their state of health is seen as inviting scepticism and disbelief. Although Dickson et al do not specifically refer to liminality it seems that their findings can be interpreted within this framework, particularly as scepticism and disbelief are noted to be a feature of having a liminal status (Douglas, 1976).

It seems that being stranded between these categories motivates the participants to mobilise their own resources in an attempt to find out what they are suffering with and to find a way of improving their health. Previous research has suggested that obtaining a diagnosis is difficult (for example Clarke & James, 2003) and that sufferers may embark on trying (CAMTS)[43] (Arroll and Senior, 2008). This chapter explores these processes in more detail, exploring them in the context of being liminal. Prior to diagnosis for instance participants talk about researching different illnesses, trying to discover an explanation for the symptoms that they are suffering themselves and proposing the idea of suffering with ME/CFS to the doctor. In other words they take a proactive approach to resolving their health problems. Following diagnosis, with no forthcoming treatment recommendations, participants are again motivated to explore potential treatments and remedies to help their condition themselves.

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[43]Complementary or Alternative Medicines and Therapies (CAMTs)

The way that the participants describe responding to the practical problem of being ill with ME/CFS bears some similarities to how anthropological studies propose people behave when they are in a liminal state. Turner (1957) and Van Gennep (1909/1960) claim that liminal people become anxious tore-join a social category and often seek to fulfil any necessary criteria which will help with this quest. Something very similar appears to be happening amongst pwME/CFS during this period as they seem to be doing two things. They are trying to find a way to join the category of being legitimately ill by trying to find a *reason* for feeling unwell and to demonstrate that there is something tangibly wrong. Secondly, they are also involved with trying to improve their health and manage their symptoms themselves, in other words they are motivated to try and get better and be seen as 'well'.

The second theme *'A healthy resolve'* has shown how participants are more motivated to resolve the problem of their ill health themselves and it also highlights how their efforts are hampered by being betwixt and between 'sickness' and 'health'. De Carvalho Leite, Drachler, Killett, Kale, Nacul, McAurthur et al (2011) argue the pwME/CFS describe encountering 'complex barriers'[44] when they try to manage their health, this theme explores how pwME/CFS manage in these circumstances. It is evident from the findings that attempting to improve one's health requires a great deal of commitment and the participant's talk of adopting a structured, regimented approach towards it. This experience again resonates with being in a liminal state in the sense that participants are taking the unusual step of trying to manage the illness themselves. The medical profession are described as being unable to help and as a result pwME/CFS talk about adopting methods of managing their own health that are unique and personal to them as there does not appear to be any consistent way of managing or improving the condition. Adopting a *'healthy resolve'* emphasises the notion that having ME/CFS, managing it and recovering from it are individual processes involving a trial and error system and often complex strategies for maintaining better health.

This process however is hampered by the liminal status associated with being between sickness and health because in the interests of being thorough, instead of taking heed of

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[44] De Carvalho Leite et al refer to the difficulties participants report experiencing when they try to access medical care or financial support from the welfare system

only advice in the medical domain, it appears that participants need to investigate lay ideas and advice too. Overall this process is presented as being laborious and time consuming to undertake yet participants emphasise their enthusiasm to actively take this on and they appear to adopt a *'healthy resolve'* in this regard too.

The third theme, *'Routinely normal'* looks at how the participants talk about being able to manage their ME/CFS effectively enough to allow them to participate in a 'normal' life. Research to date has noted that people are addressing issues relating to their identity when they embark on these processes and perhaps find new ways of engaging in usual activities and hobbies (see Asbring, 2000 for example). Again this concept fits well within a liminal framework because as participants describe being able to partake in 'normal' activities to an extent providing they make accommodations for their illness. These accommodations include a need to engage in regular illness behaviours such as resting and a need to be vigilant for the ME/CFS symptoms. Therefore they adopt a routine which allows for their own needs, hence being *'routinely normal'*.

Clearly the need to include 'illness behaviours' into any 'normal' routine means that the participants are still stranded between sickness and health because they are not constantly occupying one category or the other, a feature which in liminal terms, is crossing boundaries. It seems though that the ability to do this and participate in aspects of 'normal' life provides them with a sense of satisfaction and rather paradoxically being able to do 'normal' things, such as work, seems to be a way of effectively managing their liminal status. Thus, for these participants, the ability to transcend boundaries or simultaneously occupy two social categories is positive because it affords them an opportunity to do 'normal' things. This finding presents a different way of viewing the liminality literature as Jackson (2005) argues that the ability to transcend boundaries or simultaneously occupy two social categories, which is effectively what the participants are doing, incurs negative connotations such as distrust, stigma and suspicion. Yet here the participants are able to turn the ability to do this to their advantage.

What is also captivating is the way that the participants talk about how they manage their ME/CFS, particularly the use of financial language that Sally introduces in extract 4.4:1). She uses terms such as 'boom and bust' and 'overdraft' to illustrate how managing normal life

and her ME/CFS is a fine balancing act which she must constantly attend to. This use of financial language provides Sally, and other participants throughout the data set, with a way of explaining the subjective effect of the illness in a way that others can understand. Sufferers of other illnesses have adopted their own ways of describing how they manage their illness. As previously discussed Lupus sufferers use spoons to demonstrate that energy is used up and taken away when they do ordinary things. The use of financial terminology, however, is very specific to ME/CFS and it seems to portray an intricate system of 'checks and balances' which allows the sufferers to borrow, trade and cash energy. At the same time it reminds them that they only have a finite amount of energy (capital) available to them. This way of talking about how sufferers manage their illness is unique to ME/CFS.

The way participants talk about needing to be vigilant for any sign that their ME/CFS is getting worse is also intriguing. Dina (extract 4.3:2) and Pip (extract 4.4:3) both suggest that ME/CFS is something that is difficult to pre-empt, Dina says "it creeps up" and Pip has an on-going concern of "am I gonna get this?" So there is a hint here that ME/CFS, somehow has a life of its own and yet the participants seem to be compelled to be continually vigilant of their health. They talk about looking out for signs and signals that they need to be aware of and pay heed to as they may indicate a worsening of their ME/CFS symptoms. They describe being meticulous about measuring their activities as well as monitoring themselves for any of the aforementioned signs. This suggests that participants are unable to have unhindered episodes of normal life because there is always a need to be vigilant for signs that they need to engage in illness behaviours.

Therefore it seems that the participants encounter a number of liminalities when they are *'routinely normal'* which provides a significantly different way of looking at the experience of being partially recovered.

Finally, '*A deception of perception*' highlighted the experiences of those participants who claim to be partially and completely recovered from ME/CFS, an area that appears not to have been examined in the illness literature before. These experiences are also liminal because recovering from a chronic illness is not deemed to be medically possible (the definition 'chronic' itself suggests that the condition is life-long and incurable) therefore by declaring a recovery participants are defying these expectations. However what became

clear in the analysis was that participants' liminal status was enhanced because they were also contravening lay knowledge of ME/CFS by claiming to 'recover'.

Participants described experiencing as being met with scepticism and disbelief when sharing their experiences of recovery with others, particularly in a self-help or support group setting. It seems that rather than reports of their recovery being welcomed by peers, as the participants expected, they were instead perceived by other pwME/CFS, at times, as being deceptive and dishonest. Participants subsequently felt that their experience and story of recovery was discredited by the wider community. Somewhat ironically this places some participants back into a liminal status as some pwME/CFS also consider their claim to ever have been ill with ME/CFS in the first place as dubious and so this is discredited in a similar manner to their 'recovery'.

What is particularly striking here are the similarities between the experience of becoming ill with ME/CFS and recovering from it which both lead to a liminal status whereby the person is considered to be neither in sickness or health. This may be because the participants are contravening what is *known* about chronic illness both medically (i.e. recovery is not possible) and in lay circles whereby recovery without medical treatment is not possible or common.

The participants' stories of recovery arouse suspicion and intrigue amongst people who are still ill with ME/CFS because they are seen to be doing something that is unusual. As a result it seems that pwME/CFS become keen to distance themselves from people claiming a recovery and as Mary (extract 4.5:2) suggests, they emphasise that their illness is very different to any illness that the recovered person must have had. Being socially ostracised in this manner, again, fits with having a liminal status. Strangely though, it appears that being rejected from a support group can signify a turning point for people claiming to recover as they then chose to sever ties with the group as they have come to realise that they no longer belong or 'fit' into it. Instead some realise that they have more in common with 'well' people. The latter point is a further feature of the liminal experience and part of the process that marks a successful transition from one group to another.

This chapter has drawn on the concept of liminality in order to explore the participants' subjective experiences of the pre-illness to post-recovery journey. The analysis presents a

unique way of interpreting the problems and dilemmas that the participants encounter at different stages of their journey by suggesting that they can be understood within the framework of liminality. The following chapter continues to develop liminality by focusing on the type of difficulties participants encounter and how they manage them using the concept of Biographical Disruption.

Chapter 5

Biographical Disruption: Pre-illness to post-recovery.

Introduction

It was noted in Chapter 2 that a number of studies have highlighted that biographical disruption is one of the consequences of becoming chronically ill (Asbring, 2001; Bury, 1986; Charmaz, 1983;Wilson, 2007). The focus of this previous research however has typically only related to the *illness* period. How participants talk about the pre-illness and the recovery stages of their illness experiences have to date been overlooked. This chapter addresses this oversight and explores how people talk about life events during their pre-illness to post recovery journey.

The findings of Chapter 4 introduced the notion that being 'in limbo', stranded between the social categories of being 'ill' and being 'well' is part of the participants' subjective experience of ME/CFS. It was also suggested that participants employ a complex range of 'tactics' and 'strategies' in order to manage their ME/CFS effectively and enable them to engage in aspects of normal life such as working. As becoming ill is associated with biographical disruption anyway, it may be reasonable to expect that having to manage a liminal status in the way that the participants' describe in Chapter 4 would exacerbate the level of disruption that they experience. This chapter analyses how the participants talk about their life experiences and looks at how living their lives in this way can be perceived as being biographically disruptive.

In Chapter 2 it was highlighted that biographical disruption is a complex concept and that the definition proposed by Michael Bury (1982) has been adapted and expanded considerably[45] by different researchers. Bury (1982) used the term to describe the disruptive effect that becoming ill with a chronic illness has upon the biography of an individual's life. People assume that their biography or life plan will follow a trajectory based upon socially

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[45] For instance researchers have noted biographical flow (Faircloth, Boylstein, Rittman, Young & Gubrium, 2004), biographical reinforcement, biographical continuity (Williams, 2000) and biographical abruption (Locock, Ziebland & Dumelow, 2009), which is discussed in Chapter 2.

constructed expectations of what it may entail. These expectations might include things such as leaving school, going to university, getting a job, getting married, becoming a parent and grand-parent and retiring from work. Bury recognised that a chronic illness often presented a considerable disruption to peoples' biography, as they were obliged to cease studying or working. This not only presented an immediate disruption for the ill person, such as financial difficulties, but also disrupted their longer-term life plan, by for instance affecting their retirement pension.

It has been noted in the literature that peoples' experiences of biographical disruption varies enormously. This variation is dependent upon a number of individual factors including age (Bury, 1982; Sanders, Donovan & Dieppe, 2002), co-morbid conditions (Faircloth et al, 2004; Lindsay, 2009), life experience (Ciambrone, 2001) and the number of 'normal crises' that they have encountered (Pound, Gompertz, & Ebrahim, 1998; Williams, 2000). Therefore, biographical disruption is recognised as being an individual experience.

To date ME/CFS literature notes that sufferers experience disruption to their lives when they become ill particularly in the spheres of education, employment, sporting or leisure activities and relationships (e.g. Asbring, 2001; De Carvello-Leite, Drachler, Killett, Kale, Nacul, McAurthur et al, 2011; Whitehead, 2005). This previous research has focused upon disruptions occurring after diagnosis and focusing upon a sufferer's identity rather than 'life' in general (See Chapter 2 and Chapter 6).The research and analysis presented in this chapter is different because it looks at how the participants' experiences of ME/CFS can be construed as disruptive throughout the pre-illness to post recovery journey. As discussed in Chapter 2, ME/CFS is surrounded by a 'culture of discontent', which may have an impact on how sufferers and people in recovery talk about and understand the disruptive impact that ME/CFS has upon their lives.

The following analysis complements the findings presented in Chapter 4 by adding an alternative perspective to our understanding of different stages of the pre-illness to post-recovery journey. It adopts the same format of the previous chapter, presenting four themes. The first, *'Disruptive lives and troublesome ills',* focuses on the early stages of ME/CFS and investigates the participants' accounts of when and how they came to realise that they were ill.

Secondly, '*Treatment without a cause'*, explores the mid stage of ME/CFS, where the participants face the problem of trying to manage their illness effectively and at the same time try to maintain some continuity with the way they 'normally' live their lives.

The third theme, '*Better the disruption you know'*, concentrates on the experiences of partially recovered participants who manage the disruption that the ME/CFS causes in their life so effectively that they appear to be able to maintain a 'normal' life.

The final theme, '*Out with the old and in with the new'*, explores the experiences of people that claim to be fully recovered from ME/CFS, yet whom also seem to experience on-going life disruptions because of it.

5.1 Disruptive lives and troublesome ills

Within this theme the participants describe how and when they became aware that the ill health that they were experiencing (see Section 4.4:1) was not just a 'normal' illness but was indicative of something more troublesome.

In the first extract below, Riley is talking about his experience of becoming ill. He has previously talked about being ill for 18 months before receiving his ME/CFS diagnosis.

Extract 5.1:1 Riley (Group 1 – pwME/CFS)

1	Well it kicked off with the kind of the standard flu like virus
2	Actually arm and I kind of felt like I never recovered from that
3	And then it morphed into something a bit more serious

 (Riley, Data set 1: lines 17- 20)

Riley says here that he initially became ill with what he recognised to be "the standard flu like virus" (line 1). The way he describes it, as "the standard", suggests that it was something he regarded as very normal, whinchat the time did not appear to strike him as being out of the ordinary or raise any particular cause for concern. It also suggests

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that he has preconceived expectations of what to expect from suffering with this common ailment, such as how it may make him feel and how long he is likely to suffer with it for. Yet he goes on to present his experience of it as different on this occasion saying he "never recovered from that" (line 2). What is particularly remarkable about this extract is Riley's claim that his ordinary illness "morphed into something a bit more serious" (line 3) suggesting that its origins lie in a recognisable 'ordinary ill' but that it changed its shape and form and became ME/CFS. There is also a suggestion here that the transformation from 'standard flu' to "something a bit more" serious was stealthy and gradual and therefore, outside of Riley's control. The language that he uses here echoes Dina's description of the illness as something that 'creeps in' (see extract 4.3:2).

This extract suggests that any biographical disruption caused to Riley's life by becoming ill was in the first instance caused by a deviant flu virus and it was in the midst of this disruption that his illness somehow changed into ME/CFS. Thus, the key point here is that his experience makes biographical disruption relevant to how and when participants may realise that there is something wrong. In the following extract Amy talks about becoming ill in the context of experiencing other difficult and disruptive life events in the year prior to her being diagnosed with ME/CFS.

Extract 5.1:2 Amy (Group 1 – pwME/CFS)

1	So I had two things going on
2	one I was just working like a slave I mean I was working really long
3	hours I was taking work home at the weekend I was working over
4	bank holiday y'know all that plus y' know my relationship with my
5	boyfriend then was y' know going down the tube so y'know and then
6	at the end of that of that year then I got really ill so I think y' know I
7	probably got ill because of all the stress and all the work then I had
8	that really bad illness and then and then over the following year
9	I seemed to just not really recover and just get worse and worse

(Amy, Data set 1: lines 922-932)

Amy suggests that she had a hectic lifestyle before she became ill. She emphasises how busy and stressful her working life was, saying she was "working like a slave" (line 1). The phrase is emotive as it conjures up images of her undertaking tedious and laborious work for little or no reward and she goes on to say "I was working really long hours" (line 2), "I was taking work home at the weekend" (line 3) and "I was working over bank holiday" (line 4). This further implies that her work was disruptive to 'normal life' as she claims to have been working during periods that are typically associated with leisure time or holidays. It could be construed here that Amy is making the point that her working conditions were unfair and by referring to herself as a 'slave' this implies that she felt powerless to do anything about this situation. However, her account of how busy she was at work could also be regarded as part of an attempt to present herself as a diligent, hardworking person and as a way of heading off any possible implications to the contrary.

She goes on to describe how at the same time, her "relationship with my boyfriend then was y'know going down the tube" (line 5), so she was faced with yet another stressful and disruptive life event that she also had to manage. Amy has presented two major life disruptions which are sometimes known to make people more susceptible to illness (Williams, 2000). Amy seems to recognise this and makes the common sense deduction that she became ill "because of all of the stress and all of the work" (line 7) and hints that she may have expected *some* repercussions to working harder than may 'normally' expected. Like Riley (see extract 5.1:1), she does not present this initial illness as being unmanageable until a second illness occurs later, which she describes as being "really bad" (line 8). This second illness seems to be more problematic for her, because it does not abate in a manner that may be expected and instead she became "worse and worse" (line 9), until eventually being diagnosed with ME/CFS a year later.

So it seems that for Riley (extract 5.1:1) and Amy (extract 5.1:2) their perception of becoming ill initially confers with a lay common sense deduction, namely that it is a, possibly anticipated, consequence of having a busy and hectic lifestyle. Such a view corresponds with previous research (e.g. Gray and Fossey, 2003).Yet explanations of

this type are seemingly abandoned by participants once the illness persists beyond a reasonably expected point. In extract 5.1:3 below Tara talks about how busy her life was before she became ill and became diagnosed with ME/CFS three months later.

Extract 5.1:3 Tara (Group 1 – pwME/CFS)

1	I did used to burn the candle at all of its ends
2	I was very busy at work I pushed myself at work to get various
3	promotions take on more responsibility
4	I pushed myself physically to do various cycling or running challenges
5	erm and then socially we were very busy
6	so I know that I was living life to the full or living it to the limit
7	erm but equally I still know lots of people that do that
8	I also know that I did have this it was flu was the virus that I had
9	and I know that it did take some time to get over it
10	and again I went back to work too early
11	I, I felt guilty having the time off (sigh/pftt noise)
12	so they could be valid reasons

(Tara, Data set 1: lines 896-911)

Tara talks about having a busy, zealous lifestyle prior to becoming ill as she says "I did used to burn the candle at all of its ends" (line 1) which is an exaggeration on the traditional[46] saying as it sets the scene for Tara's activities being extraordinary. She seems to describe herself as the proactive instigator of her hectic life as she talks of being "very busy" (lines 1 & 5) and about times "I pushed myself" (lines 2 & 3) in a professional and personal context. It appears that Tara, like Amy (extract 5.1:2) is presenting herself as a hardworking person in order to negate any possibility of being perceived as a malingerer. By talking about seeking "more responsibility" (line 3) and doing "challenges" (line 4), she is implying that she is an extremely driven and competitive person.

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[46] The traditional saying is 'burning the candle at both of its ends' and it refers to being twice as busy and doing things twice as fast as may be considered 'normal'.

She goes on to say that she "was living life to the full or living it to the limit" (line 6), which suggests that she was aware that her lifestyle was stretching her own limitations. However she also says that "she knows a lot of people who do that" (line 7) which indicates that she perceives her behaviour to be 'normal' in the context of her peer or social group. Saying this also seems to remove her from any implied responsibility for causing her illness.

She also talks about having a virus which was disruptive to her normal routine and appeared to linger as "it did take some time to get over it" (line 8) and it seems to be implied that, in retrospect, this event may have been the lead up to becoming ill with ME/CFS.

Unlike Riley (extract 5.1:1) and Dina (extract 5.2:2 below), Tara suggests that she was very much in control of her busy and active life. However, the events that she talks about here can also be interpreted as disruptive and demanding, as even positive events, such as gaining a promotion within the workplace have been recognised as having the ability to be disruptive to normal life. This implies that not all biographical disruption is negative as indicated in much of the previous literature (see Bury 1986; Faircloth et al, 2000; Williams, 2000).

The analysis of these accounts has produced a number of original features. Firstly, it seems that participants experience biographical disruption prior to becoming ill with ME/CFS and that it is not just a consequence of being diagnosed as other research has suggested[47]. Within this analysis the participants are talking about the seemingly ordinary experience of having a virus or an illness which is initially seen as being a 'normal', legitimate reaction to having a stressful working life (Amy, see extract 5.1:2) or being busy (Tara, see extract 5.1:3) which initially does not raise any immediate concern for the participants. It is only as time goes on and they do not get any better from this 'standard' illness in the expected manner, that they become aware that there is a further problem.

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[47] For example Asbring (2001) noted that biographical disruption occurs after diagnosis for pwME/CFS and Locock, Ziebland & Dumelow (2009) found this was also the case for people with Motor Neurone Disease.

Although previous research has noted that participants describe being ill with a 'virus' before developing ME/CFS (See Clements, Sharpe, Simkin, Borrill & Hawton, 1997) and that sufferers describe busy and hectic pre-illness lives (Gray and Fossey, 2003; Horton-Salway, 2001) it does not explore the depth and extent of disruption associated with this stage of the illness. This analysis demonstrates that the unanticipated disruption begins prior to an ME/CFS diagnosis when life does not return to normal following a 'normal ill' as may be expected.

Secondly, the way that the participants talk about life events they experience prior to becoming ill is also of significance. They suggest that they were extraordinarily busy with hectic working and social lives before they became ill, which in itself can be perceived as being disruptive. However, at the same time, these 'busy life' accounts also help participants to present themselves as a being diligent, hardworking people and effectively head off any implications that they are workshy or malingerers; a criticism often levelled at pwME/CFS.

Finally, it seems that biographical disruption occurs throughout a number of different stages before, during and after they become ill. The first disruption seems to occur before they become ill through busy or stressful life events; the second when they become ill with a 'standard' illness. The third stage of disruption is when their illness fails to abate, and the final biographical disruption is when they finally become diagnosed with ME/CFS.

The following analysis focuses on how the participants talk about trying to manage their illness once they have received a diagnosis and enter a different stage of the illness experience and encounter an additional form of biographical disruption.

5.2 Treatment without a cause

The above analysis suggests that participants identify with some form of biographical disruption before they become ill with ME/CFS. This second theme highlights how they try to manage their health effectively and improve their ME/CFS in the second stage of biographical disruption. As the title of this theme suggests, pwME/CFS face a dilemma

because there is no definitive 'cause' for ME/CFS which makes it a difficult illness to treat.

Laura has been talking about her view of the difficulties in treating ME/CFS in general. She then moves on to talk about her experience of attending a local NHS mental health outpatient clinic, the only provision for ME/CFS sufferers in her area. In doing so she focuses on an issue that was raised as a problem for participants in a number of interviews.

Extract 5.2:1 Laura (Group 1 – pwME/CFS)

1	That this clinic in (location) continues to base
2	its whole approach around this very flawed research
3	makes me very angry really and upset that so little care
4	and notice is being taken of the real issues around chronic fatigue
5	and you're just, sort of fobbed off with a half-baked theory
6	that doesn't have much scientific substance to it

 (Laura, Data set 1: lines 425-429)

Laura expresses some dissatisfaction with the clinic that she attends, saying it bases "its whole approach around this very flawed research" (line 2), suggesting that she does not hold the clinic in high regard. She talks about feeling "very angry really and upset" (line 3) and this strong emotive response may also suggest that her expectations of *how* the medical profession could or should be helping her to manage her illness have not been met. It is noticeable that she uses extreme case formulations (ECFs) here, which Pomerantz (1986) claims are typically employed to achieve one of three aims: firstly to present the strongest version of events possible, particularly in situations whereby the speaker's versions of events can be discredited; secondly to indicate a cause of an event or phenomenon and finally, to categorise a practice as fair or unfair or right or wrong. Laura's use of 'whole' and 'very' help to emphasise the reality and factual nature of her experience and disappointment from her interaction with the medical profession.

She goes on to imply the medical profession are out of touch by suggesting that there are "real issues about chronic fatigue" (line 4). "Real issues" which she as a sufferer is aware of but the implication here is that the medical profession are not. She talks of being "fobbed off with a half baked theory" (line 5), implying that ME/CFS sufferers are unduly dismissed or cast aside without much regard. She also implies that this "half baked theory" science behind the ME/CFS treatment that she receives falls short of medicine's own rigorous standards and does not have "much scientific substance to it" (line 6).

Overall it seems that this situation can be interpreted as being liminal because Laura's interaction with the medical profession is contrary to what she, and others, may generally expect. At the same time it highlights that having ME/CFS presents an additional disruption that participants have to manage. It seems that there is a disruption to any expectations they may have of successful illness management, advice or treatment being guided by the medical profession, as it is implied by Laura that they do not appear to understand the illness or its treatment. This finding concurs with previous research which demonstrates that pwME/CFS struggle to access medical care (DeCarvelho-Leite, Drachler, Killett, Kale Nacul, McAurthur et al (2011). However it highlights the additional disruption which can be seen as a consequence of being in a liminal situation, of being in-between being 'ill' and being 'well' which is described in chapter 4. It also draws attention to a further apparent disruption as in the absence of medical guidance, pwME/CFS become responsible for managing their own health which is portrayed as being problematic.

In the extract below Tara talks about her experiences of trying to find ways of managing her ME/CFS more effectively.

Extract 5.2:2 Tara (Group 1 – pwME/CFS)

1	you can be overwhelmed by the information
2	because what works for somebody doesn't work for somebody else
3	erm an- it- it- and it's really really well
4	it's just really hard to know which way to turn
5	I currently have a little erm a plan of all the things I plan to investigate

6	and I've got I think twelve different therapies or investigations
7	that I want to have a go at see if they'll work for me
8	I did quite a bit of research on them
9	thought oh yeah they might work for me
10	but you have to do one thing at a time
11	otherwise you never know when something's working
12	so that that y'know I could see that taking two to three years
13	to get through that lot

(Tara, Data set 1: lines: 1029-1045)

Tara suggests that trying to self-manage her illness and find ways to improve her health is not a straightforward or easy process but one that presents a host of dilemmas and potential disruptions that have to be addressed. She says "it's just really hard to know which way to turn" (line 3), implying that the process of deciding what to do is made more complex by the combination of having a variety of possible 'treatments' to choose from and the lack of any guidance to help her navigate them.

She indicates that there is a level of risk associated with trying to improve her illness, saying "you can be overwhelmed by the information" (line 1), which reinforces her earlier claim that this is not an easy task to undertake. It can be inferred here that becoming 'overwhelmed' would affect Tara's ability to cope and manage her day-to-day life and have a further detrimental impact on her health. She seems to address this dichotomy by creating "a plan of all the things I plan to investigate" (line 4) suggesting that she needs to form an organised, logical and presumably time consuming approach towards tackling the abundance of information.

She talks about trying to improve her health as something she takes very seriously as she uses the word 'investigates' as well as saying she did "quite a bit of research on them" (line 7). As there is often a considerable amount of work involved in 'research' this process can, presumably, become intrusive or disruptive. She seems to anticipate and expect that her process of trial and error will present a longer term on-going

disruption to her life as she says "I could see that taking two to three years to get through that lot" (line 10).

It appears that trying to improve her health is perceived as being a difficult and complex process that requires a long-term, on-going commitment from Tara and presents an on-going disruption to her life. It could therefore be construed that pwME/CFS have to manage this additional disruptive burden of having to explore potential treatment options for themselves, rather than being guided by the medical profession, as people with medically recognised illnesses are. This situation presents an unusual paradox as in an effort to find ways to improve their health in order to help them address the biographical disruption caused by becoming ill in the first place, they incur a different on-going disruption.

Gemma talks about how she manages an on-going dilemma between her desire to mitigate the biographical disruption caused by becoming ill in the first place, by finding a way to manage daily activities, and her compulsion to try and improve her overall longer term health.

Extract 5.2:3 Gemma (Group 1 – pwME/CFS)

1	I find it really hard as well as to know what to do to get better
2	people well they expect you to do something to get better don't they?
3	'what are you doing to try and get better?' erm and
4	there are lots of things out there to try but you kind of think
5	but it oh I don't know I just think if there was a some wonderful cure
6	y'know then people would be ha doctors ha and the whatever
7	would be suggesting you try things I mean I appreciate
8	that some things work for some people don't they?
9	out of all these different therapies and treatments and whatever
10	but I kind of think well if I took something on board again
11	it would be a bit like taking on a job
12	although it would it would hopefully be shorter term
13	I kind of think how would I manage everything else?
14	I've just about got things okay now

Gemma is talking about her experience of finding "it really hard as well as to know what to do to get better" (line 1). She goes on to mention having to manage the expectations of other people whom she perceives as demanding to know "what are you doing to try and get better?" (line 3). So it appears that Gemma feels under some pressure from others to be seen to be doing something to improve her health.

She implies that the situation presents her with a dilemma because "if there was a wonderful cure" (line 5), she would get to know about it via "people...doctors and the whatever" (line 6). This could be construed as a common sense deduction, that is, if a cure were found it would be well publicised and she would be appropriately directed towards it by the medical profession.

She talks about there being "lots of things out there to try" (line 4) and presents a three part list of "different therapies and treatments and whatever" (line 6) which helps to show that there are endless possibilities of treatment options that she could pursue. It seems telling that she demonstrates a general awareness of the type of things that may be available, but does not give any specific detail as she continues to explain that her decision not to undertake them has been carefully considered. She likens exploring potential Complementary and Alternative Medicines and Therapies (CAMTs) to being "a bit like taking on a job" (line 11), a description which suggests that she is aware that it would require an on-going and long-term commitment of time and energy on her part. It also suggests that Gemma would find this situation both taxing and disruptive as she says "How would I manage everything else? I've just about got things okay now" (lines 13 & 14).

So Gemma seems to be in a quandary here. She is aware that trying to improve her health would require a commitment from her, but also that making the commitment could jeopardise her ability to cope with her day-to-day life and cause a further level of disruption that would impact upon her and her family. Like Tara (extract 5.2:4) she

recognises that embarking on improving her health is difficult and complex but for Gemma it seems that the possible benefits do not appear to outweigh the potential costs.

From the above analysis it seems that because of the contested nature of ME/CFS, participants are faced with managing an additional burden of having to try to find ways of managing their illness themselves. Although research to date has recognised that self managing is something that people with contested illnesses (Bury, 1986) and ME/CFS (De Carvalho-Leite, Drachler, Killett, Kale, Nacul, McAuthur et al, 2011) do and that having to undertake treatments can be disruptive for people with medically recognised illnesses (see Thompson, 2007; Williams, 2000 for example), it would appear that there is something different happening for pwME/CFS here. It seems that being charged with this real or perceived responsibility for improving their health is taxing: it requires an investment of their time, effort and energy to try and tackle the wealth of available information in order for them to be able to decide what to do.

The way participants talk about approaching this problem is fascinating, because they present themselves as being knowledgeable about the process, talking about "flawed research" (Laura extract 5.2:1) and conducting research (Tara extract 5.2:2). They also seem to view it as being a difficult task to embark on, as Tara talks about adopting an organised, logical approach to testing potential CAMTs in order to ascertain if any are effective or whether they could be disruptive to her everyday life. Gemma on the other hand seems to perceive the task to be too great and as disrupting her ability to manage her current daily routine. Yet she remains aware that there is an expectation for her to be seen to be doing something to try and improve her health, which may suggest that this will play on her mind.

Receiving a diagnosis of ME/CFS appears to present even more dilemmas to manage and trying to establish a system of self-management or a 'treatment *without a cause'* seems to be perceived as disruptive to the participants' day-to-day way of life because it is drawing on their already limited energy and resources.

The third theme looks at how people who claim to be partially recovered from ME/CFS manage the disruption caused by ME/CFS alongside maintaining aspects of their normal life.

5.3 Better the disruption you know

The first two themes have demonstrated that pwME/CFS experience biographical disruption before, during and after diagnosis (theme 5.1) and that embarking on improving their health, without any guidance, is viewed as being a further disruption (theme 5.2). The following analysis focuses on those participants who claim to be partially recovered and how they manage the disruptions that ME/CFS causes in order for them to be able to participate in aspects of normal life (for example, work).

In the extract below Dina is talking about her experience of having acupuncture for a knee injury and the surprising, unexpected effect it had on her ME/CFS.

Extract 5.3:1 Dina (Group 2 – partially recovered from ME/CFS)

1	I remember saying to them (the hospital) when they said
2	Y'know 'how's this.. has this worked for you?'
3	and I said well not really not with my knee I said
4	but I do have ME and it has changed it
5	and it had given me an extra hour erm in the daytime often
6	and so I was pottering about 'til six o'clock
7	and I said ha ha to I remember saying to her erm erm I said
8	'I daren't carry on because you'll steal my afternoon nap' ha ha
9	I said I've have got quite used to it going to bed at 5 or 6 o'clock
10	and but but I have erm tried to in quotation marks push myself
11	through it sometimes that six 'til seven slot and invariably
12	it it has a negative consequence either that night or the next day

(Dina, Data set 1: lines 795-805)

It is immediately striking here that Dina says her acupuncture treatment "changed" (line 4) her ME and rather than saying that she noticed an improvement as she goes on to explain that "it had given me an extra hour" (line 5) and any reduction in necessary resting time could be construed as an improvement. However, it seems that the possibility of missing her afternoon nap presents a dilemma because, as noted in the previous chapter (see extract 4.3:2), Dina's daily routine helps her to maintain a balance between being ill and participating in a normal life.

Dina recalls saying jovially to medical staff "I daren't carry on because you'll steal my afternoon nap" (line 8), and it is noteworthy that she uses the world 'steal' here as this implies that it is something of value that could be taken away from her. Although Dina says of her nap time "I've have got quite used to it" (line 9) she goes on to justify that it is the best way for her to manage her health effectively, which acts to head off any insinuations that it is any form of laziness on her part. She draws on her own experience of managing her illness to further justify her need for an afternoon rest saying she has "tried to in quotation marks push myself through it" (lines 10 & 11) implying that it is not something that she manages to do easily. The language she uses to express this is fascinating because 'pushing through' is a phrase that commonly appears in the ME/CFS support group literature to describe occasions when people temporarily draw on additional resources when they should actually be resting. Also, it seems that for Dina doing this causes disruptions to her routine as "invariably it has a negative consequence either that night or the next day" (lines 12).

So although her daily rest period can be perceived as disruptive as she does not have a 'normal' day, Dina seems to view this as being a controllable, manageable disruption, which enables her to manage other aspects of her life in a way that can be considered to be 'normal'. It is argued in the literature that other factors can mediate the effects of biographical disruption caused by illness[48] and it is possible that Dina perceives the way she lives her life now as being much less disruptive to being ill with ME/CFS

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[48] Such as the number of 'normal crises' (Pound, Gompertz & Ebrahim, 1998) or age (Bury, 1982).

symptoms. This concurs with other research which has found that people assess the extent of any new disruption against what life was like before (e.g. Ciambrone, 2001). To abandon her routine may be seen as inviting unpredictable consequences and perhaps different life disruptions that could be more debilitating to her overall. It appears that her current lifestyle, although disruptive, is a disruption she knows and is manageable for her because it allows her to manage her life in a way that she is happy with: *'better the disruption you know'*.

In the following extract Sally, who manages her life by working full time hours on four days and then spends the other three days "intensively resting" (transcript line 800), talks about her experiences of managing this routine in order to be able to work.

Extract 5.3:2 Sally (Group 2 partially recovered)

1	I spend a lot of weekends in bed
2	don't really mind doing that but after a while it gets really boring
3	I have latterly started socialising again it's that constant balance
4	really and then of course week week nights y' know
5	I haven't been able to socialise a lot weeknights ha ha after work.
6	ha ha yeah yeah one of my goals for next year is to start
7	just having much more social weekends erm
8	being able to go and see my family and stuff like that
9	my family none of them are in (location) so that's been a big
10	difficulty actually of having a job that was a bit too busy this year
11	and erm not just not seeing my sister which y'know
12	just like a bit of a pain but not the end of the world
13	but you don't want it to go on forever
14	there's definitely some consequences
15	but even those it's probably a balance I'm quite happy with
16	still quite a big difference between what I can handle at weekends
17	and what a well person could is that probably
18	I probably work as hard as anybody would during the week.

Sally indicates here that her ability to live a 'normal' life is limited by her illness. She talks about spending "weekends in bed" (line 1), not being "able to socialise a lot week nights" (line 5) and "not seeing my sister" (line 11), seems to suggest that working full time is disruptive for her as she needs to make a number of sacrifices in order for to be able to do it. Yet at the same time Sally seems to imply that despite these sacrifices, her limited social life is acceptable as she says: "don't really mind doing that" (line 2) and describing it as "a bit of a pain but not the end of the world" (line 12).

She talks about "that constant balance" (line 3) and having "a balance I'm quite happy with" (line 15), from which it may be inferred that Sally either expects or anticipates that she would have to make sacrifices in order to be able to work full time. It seems, like Dina (extract 5.3:1), the disruption she knows is better as Sally is able to manage by adopting an extreme routine of activity and rest which allows her to work. By structuring her week in this way, Sally says she can "work as hard as anybody would during the week" (line 18) and only her social life is negatively affected by her ME/CFS.

So although having ME/CFS seems to be disruptive to her life as she is unable to socialise, Sally seems to be able to actively manage this disruption by deciding when and where to engage in illness behaviours and engage in a 'normal' working life. In essence it seems that she is presenting herself as being either 'ill' or 'well' which also implies that she is managing a liminal situation.

Dawn has had ME/CFS for 4 years and in the extract below talks about her experiences of managing her illness and trying to participate in a 'normal' life.

Extract 5.3:3 Dawn (Group 2 – partially recovered)

1	I think I'm still recovering and I think also I'm still learning how to
2	I'm still learning how to manage it at every stage along the way
3	because life changes change is the only constant isn't it really in life
4	so as life changes I change how I'm managing and what I'm doing

5	so, almost it's almost like if I'm if I'm having a rebellious period
6	like I've had for three weeks and I'm like sod it I'm better
7	I can do what I like Yeah? and that was a really strong phase I've just had
8	and then suddenly it's like this thing it's like actually no you're not
9	you still need to be careful and it's like a real reining in

(Dawn, Data set 1: lines 593- 610)

Despite aspirations to the contrary ME/CFS continues to be disruptive to Dawn's day to day life. It is of particular interest here that Dawn says "I'm still learning how to manage it at every stage along the way", because she is directly addressing the notion that different stages of being ill with ME/CFS present new dilemmas that pwME/CFS have to manage. Dawn suggests that she manages her illness by adopting a flexible approach, saying "as life changes I change how I'm managing and what I'm doing" (line 4). This may indicate that she perceives there to be a circular relationship whereby life changes can impact upon her ability to manage the illness and changes in the illness can impact on her life. What she has expressed so far implies that she has a carefully considered approach to balancing being ill and her 'normal' life.

However, she then goes on to present this as something that is difficult for her to do as she talks about "having a rebellious period" (line 5), where she perceives herself to be free from the constraints of having to manage her illness as she says "sod it I'm better I can do what I like" (line 6). This implies that being 'rebellious' goes very much against the 'norm' of being very careful and controlled over her choice of activities. Although Dawn does not propose that she manages her illness behaviour on a daily or weekly basis, she does suggest that she is forced to be receptive to the needs of her illness which is disruptive. She says that at times when she fails to do this she is made to realise that "you still need to be careful" (line 9). It seems that she then has to curtail her activities and return to carefully managing what she does, which she tellingly describes as being "like a real reigning in" (line 9).

So it seems that for Dawn becoming partially recovered continues to be disruptive because, paradoxically, she still has to curb the level to which she would like to participate in things in order manage her ME/CFS effectively. This means that her life is still disrupted by having ME/CFS.

The analysis suggests that partially recovered participants do not seem to regard the disruption to 'normal' life caused by having ME/CFS as an unsolvable problem. Instead it appears that they are able to focus on addressing a specific area of their lives and participate in it almost 'as normal', but in order to do this they have to make sacrifices elsewhere. This can be seen very clearly in extract 5.3:2 where Sally devotes all of her time and attention to ensuring that she can work full time, to the detriment of other areas of her life. What is engaging about this research is that the participants seem to be actively managing the biographical disruption that ME/CFS causes in a way that enables them to retain aspects of a 'normal' life.

It is intriguing that, unlike people with medically recognised illnesses, pwME/CFS can exercise some control over how and when to engage in illness behaviours as this seems to be an effective overall approach to illness management. However, it also seems to be that retaining elements of a normal life and managing ME/CFS on an on-going basis is perceived as something that requires a great deal of on-going effort and attention and not something that the participants can effortlessly engage in. Therefore, rather paradoxically, this in itself also appears to be disruptive.

The following theme explores how fully recovered participants describe their daily life now that they are free from the constraints of being ill with ME/CFS.

5.4 Out with the old and in with the new

The analysis presented below presents the accounts of fully recovered participants of how they manage to return to a 'normal' life once they have made a 'full recovery'.

In the extract below, Nigel, who was ill with ME/CFS for 5 years and says he has been recovered for 6 years talks about how he now looks back on suffering with ME/CFS.

1	to be honest I don't sort of even think about erm that period now
2	it was erm a long time ago erm and I say I am fully recovered
3	I erm y'know I'm probably not as fit as I would have been
4	had I not had years of erm not being active
5	and certainly when I- if I get a virus now on occasion it can be prolonged
6	erm but usually I recover in the normal way
7	I'm certainly active enough to play cricket and tennis and y'know
8	do everything that a 42 year old bloke erm should should be able to do
9	y'know I mean I'm not don't run marathons
10	but I erm play sport to erm quite an intense level
11	and work very very hard often under intense pressure

(Nigel, Data set 1: lines 205-216)

It is noticeable here that Nigel refers to being ill as "that period" (line 1) which was "a long time ago" (line 2), from which it could be inferred that for him, ill health is purely historical and something that he now distances himself from. It also seems that talking about being ill is something that he does not like to do, as he quickly reaffirms: "I say I am fully recovered" (line 2).

However he goes on to explain that some aspects of his life have been affected by once having ME/CFS as he says "I'm probably not as fit as I would have been" (line 3) and "if I get a virus now on occasion it can be prolonged" (line 5). The implication here is that Nigel would be physically fitter and more resilient to viruses if he had not previously been ill. ME/CFS therefore, seems to have created an on-going disruption for him that affects his current life.

Nigel seems to play down any problems caused by having ME/CFS though and instead emphasises things that he is now able to do as a 'recovered' person, which presumably he could not do whilst he was ill. He says he is "certainly active enough" (line 7) to engage in sporting activity, but he also talks about being able to "do everything that a 42 year old bloke...should should be able to do" (line 8). This is intriguing because it

suggests that Nigel perceives himself to be meeting his own expectations of the type of activities that he 'should' be doing and perhaps provides an insight into how he defines being 'recovered'.

He also suggests that he is able to "play sport to quite erm an intense level" (line 10) and that he can work "very very hard often under intense pressure" (line 11). His use of 'very very' and 'intense' suggest that Nigel is trying to assert his claim to be recovered in the strongest way possible (Pomerantz, 1986), and possibly expects his claim to be recovered to be called into question.

Therefore, even though Nigel claims he is no longer affected by once having ME/CFS, it seems that he is still left with some biographical disruption such as not being quite as physically fit as he would have liked, which is a disruption he still has to manage.

In the following extract Eve, who had ME/CFS for 5 years and has been recovered for six months, talks about how she manages her day-to-day activities. She has been talking about her observation that being on the Internet for long periods of time had a detrimental effect on her ME/CFS symptoms. She then goes on to talk about how she manages this now.

Extract 5.4:2 Eve (Group 3 – fully recovered)

1	I had a day like that yesterday where I spent too much time on the Internet
2	then erm I noticed this morning when I was doing my meditation
3	that it was very hard to relax
4	and that my brain was going chatter chatter chatter
5	see I don't watch television so I wonder if television does the same thing
6	I don't know I suppose we are used to fast cuts in editing aren't we?
7	so I wonder if it moves everything up a few gears
8	I don't I don't know exactly yeah I mean I really noticed it this morning
9	and it made me a bit apprehensive y' know I'm still y' know occasionally
10	I have to keep using the lightning process anyway
11	but I am well I mean I'm I've even been going running
12	I went running the day before yesterday

13   and I have been doing sit ups every morning

(Eve, Data set 1: lines 1221-1235)

Eve is talking about experiencing some on-going problems, saying "I had a day like that yesterday where I spent too much time on the Internet" (line 1), suggesting that she still has to be careful about what type of mundane activities she engages in. She explains that if she is not careful, she finds it "very hard to relax" (line 3) and experiences things that she cannot control, such as her brain "going chatter chatter chatter" (line 4). Her description of how this affects her is very similar to how other pwME/CS talk about experiencing symptoms after seemingly innocuous activities, which prior to being ill they would manage without any problems.

Although Eve seems to try and find a common sense explanation for why she should feel the way she does after using the Internet (lines 5-8), she also talks about being "a bit apprehensive" (line 9), presumably in case her experiences are indicative of her ME/CFS returning. It appears that Eve may be constantly concerned about the possibility of her ME/CFS symptoms returning as she says "I have to keep using the lightning process anyway" (line 10), which implies that the state of recovery is something that she has to constantly and actively maintain. The lightning process is an alternative therapy devised by Phil Parker (2002), which aims to help people become more mindful of themselves and how situations and events might affect them. A number of the participants in this study engaged with this form of therapy and found that this was helpful in managing the symptoms of their illness no matter what their stage of illness or recovery.

What is most notable here is Eve's assertion of "but I am well" (line 11), which seems to contradict what she has said so far. This is similar to how other recovered people talk about this stage, (see Nigel 5.4:1). It is possible that she is aware of this; she presents a three part list (lines 11-13) emphasising how physically active she has been following her recovery. Like Nigel it seems that Eve is providing evidence of her

recovery by emphasising her involvement in physical activities that may not have been possible for her previously.

Despite claims to be 'well' it is notable that Eve has a number of disruptions as a result of having had ME/CFS that she has to manage. For instance, she still has to be very careful about her choice of activities and engage in illness behaviours when necessary in order to keep any symptoms at bay.

In the last extract below, Pip, who had ME for 2 ½ years, and has been recovered for 18 years, talks about how he manages his day-to-day life and the threat of a possible relapse to having ME/CFS again. He is talking about advice that he would provide to ME/CFS sufferers in the extract below.

Extract 5.4:3 Pip (Group 3 fully recovered from ME/CFS)

1	that's another thing that can be communicated that if you do
2	when you're healthy and you relapse as long as you spot it soon enough
3	and you rest you can get back to normal
4	yes I have been back twice from relapses
5	and y'know I bounce back and I'm completely fine again
6	y'know so y'know it's I now know I know that I've got the confidence
7	to know that if it happens again I know that
8	I'm hoping that I'll bounce back again
9	though always at the back of my mind I'm thinking I might not I might not
10	but the fact is that that you know that you you know
11	you can bounce back from far better coz you're
12	you're looking out for those symptoms
13	so much y'know because they are so burnt into my brain
14	now y'know having had that for like two and half years

(Pip, Data set 1: lines 933-944)

Pip seems to suggest that relapsing is an expected or anticipated element of recovering from ME/CFS as he talks about recognising symptoms saying "as long as you spot it soon enough and you rest you can get back to normal" (lines 2 & 3). This implies that for him there are relapse signatures to watch out for, these may indicate a return of ME/CFS that he needs to remain vigilant for and he goes on to suggest that he has previous experience of this situation (lines 4-8). It is contradictory that on one hand he suggests that because of his experiences he has "got the confidence" (line 6) in his ability to deal with any relapses that may occur in the future and "bounce back" (lines 5 & 8) but on the other hand he seems to be equally as uncertain, saying "it's always at the back of my mind I'm thinking I might not" (line 9). It seems that he attributes his success at recovering from two relapses to being able to be "looking out for those symptoms" (line 12) and he suggests that doing so is almost second nature for him as they are "burnt into my brain" (line 13). The metaphor he uses is powerful because it depicts images of being branded by his experience. It also indicates that the fear of experiencing an unrecoverable relapse is disruptive. This awareness appears to be always with him and he remains vigilant for any signs that a relapse may occur. So although Pip seems to be free from the disruption caused by ME/CFS symptoms, he has a new form of disruption to manage in remaining watchful for any sign of it returning.

This final theme highlights some additional aspects of suffering with ME/CFS. The analysis demonstrates that biographical disruption is a feature of the recovery experience, something which has been neglected in the literature to date. It is worthy of note because it seems that biographical disruption is not eradicated once a 'recovery' takes place, but continues to persist after this time, but in different ways. Firstly, it seems that participants have to manage consequences caused by the disruption that was caused to their lives by becoming ill in the first place, like Nigel, who talks about not being as physically fit as he may like (Extract 5.4:1). Secondly, participants talk about having to be careful about their choice of activities, like Eve (Extract 5.2:2) who is careful not to spend too much time on the Internet or like Pip (Extract 5.2:3). They both have to monitor for any signs of the illness returning. Recovery for these participants does not seem to indicate a carefree return to 'normal', but instead appears to be affected by a series of on-going disruptions.

5.5 Summary

The four analytical themes that have been presented in this chapter have focused on how the participants' experience disruptions to their lives throughout the different stages of ME/CFS, specifically: pre-diagnosis, post- diagnosis, partial recovery and full recovery. By focusing upon these different stages of the illness experiences, the analysis presents some novel findings in previously unexplored areas.

The first theme, '*Disruptive lives and troublesome ills*' demonstrated that biographical disruption was a feature of the participants' lives before they became ill. The way the participants talk about this period portrays it as being characterised by disruptive working and social schedules (see extracts 5.1:2 and 5.1:3), which could be construed as being difficult and troublesome. It has been noted in the literature that pwME/CFS typically talk about having an extraordinarily busy pre-illness lifestyle, a feature which has been considered to be an exaggeration in order to emphasise the contrast between pre and post morbid abilities (see Whitehead, 2006). However, it seems that something different is happening here. The way that the participants talk about this period implies that these life events are only regarded as troublesome in retrospect, it seems that the participants managed them until they became ill with a 'normal' virus. According to previous research Lindsay (2009) argues that people with chronic illnesses have a 'disruption threshold' whereby they are able to cope with an increasing number of disruptions up to a certain point where it becomes impossible to manage anything else and they become unable to cope. However, in this study, it was found that participants describe becoming unable to cope with their busy active lives once they perceived what they term a 'normal' virus to become unexpectedly troublesome.

The way that they describe the process of becoming ill with ME/CFS is particularly significant to their construction of events, because it portrays ME/CFS as something surprising and unforeseen. Typically they propose that they initially became unwell with a 'normal', recognisable illness, which they perceive to be an expected or anticipated response to their busy and hectic lifestyles. Yet this ordinary ill becomes troublesome when it fails to abate in a manner that would usually be expected and it therefore becomes troublesome. It is during

this period of disruption caused by the troublesome ill that the illness changes into ME/CFS. Riley (see extract 5.1:1) illustrates this very succinctly by suggesting that his 'normal' virus "morphed" to become ME/CFS. This analogy also implies that the ME/CFS was somehow sneaky and that participants are unable to exercise any control over becoming ill with it. By describing their ME/CFS in this way participants are grounding its onset in a physiological complaint, albeit a 'standard' one like a virus that became deviant. The analysis also suggests that the way the participants structure their accounts helps their story to appear more credible as they are suggesting that the 'ordinary' event of a virus became extra-ordinary[49].

By stressing the busy, active nature of their pre-illness life, the participants also present themselves as being hardworking and conscientious which helps them to counter any possible claims of malingering or being work shy[50]. How an individual interprets the onset of chronic illness and makes sense of the biographical disruption which occurs in their lives is also mediated by the type of person that they believe themselves to be. Williams (1984) argues that chronically ill people reconstruct or add additional emphasis to particular aspects of their pre-illness lives in order to give some contextual meaning to the event of becoming ill. It could be argued that a similar thing is happening here as the participants illustrate how tremendously busy and active they used to be prior to becoming ill. A crucial difference seems to be that the participations do not seem to making claims of causation based on how busy they used to be, Instead they seem to emphasising what a devastating impact becoming ill had upon their lives and sense of self.

The findings of this theme represent a deviation from previous biographical disruption research as rather than biographical disruption being a consequence of becoming diagnosed as Bury (1982) suggests it seems that life disruptions were already a feature of the participants' lives. Therefore ME/CFS itself is presented as a disruption within a disruption and the onset of ME/CFS is constructed as being unusual.

In the second theme, '*Treatment without a cause*' the participants are describing the disruptions that are caused by ME/CFS's status as a contested chronic illness, which they indicate leaves them with additional problems and dilemmas that they have to manage.

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[49] Reminiscent of Wooffitt's (1992) 'at first x and then y'.
[50] There is also identity work going on here as the participants also talking about 'who they are'. Their sense of self is the subject of Chapter 6.

Laura (extract 5.2:1) summarises the 'problem' described by people with ME/CFS, which is that 'treatment' or 'care' is not forthcoming from the medical profession in the way that the participants may expect or anticipate. This means that they have to manage the real or perceived responsibility for improving their health.

The analysis suggests that the participants construe this process as being disruptive for two reasons (see extracts 5.2:2 & 5.2:3). Firstly, because navigating the extensive literature on ME/CFS is difficult without any guidance and secondly because evaluating the potential effectiveness of any treatments involves a process of trial and error. These scenarios require a significant investment of time, effort and energy from the participants and this causes an additional dilemma because it could jeopardise their current ability to manage their day-to-day lives (see extract 5.2:3) and inadvertently cause a further life disruption which they become unable to manage. So the struggle for the participants here seems to be how to present themselves as being *responsible* and as taking responsibility for managing their illness and improving their wellbeing, without further damaging their health. Again this seems to be presenting a different type of disruption to that which has been previously documented as people with medically recognised illness find submitting to a treatment regime dictated by the medical profession disruptive (Thompson, 2007). In comparison pwME/CFS appear to have control over how to manage and improve their health. However, this illusion of control is constructed as being an extremely disruptive process because of the sheer volume of potentially helpful options they could possibly explore. In addition embarking on this process could be seen to be detrimental to their health and ability to cope with their day-to-day life.

The third theme, '*Better the disruption you know*', explored a similar dilemma amongst people who claimed to be in a partial recovery and are able to take part in some 'normal' activities by carefully managing their time. Becoming partially recovered did not seem to indicate a reduction in necessary illness behaviours as it was found that participants still needed to engage with these in order to be 'well'. Illness behaviours are defined as strategies or techniques that people employ in order to maintain their health and for pwME/CFS examples include meditation and the Lightning Process.

Instead, it seems that they deemed themselves to be more in control of this process and able to decide when, where and how to engage in necessary illness behaviours in order to manage the ME/CFS symptoms. Sally (see extract 5.3:1) and Dina (see extract 5.3:2) actively manage the disruption that illness behaviours cause by establishing a daily or weekly routine which allows them to ensure that they can engage in their chosen activities. So although on one hand it may be inferred that the effects of disruption are minimised by their efforts because they can take part in day-to-day life, on the other hand their illness is still disruptive because they are unable to manage 'normal' life without their illness management strategies. Dawn (see extract 5.3:3) indicates that this process is difficult by using the term 'reigning in' to describe employing a level of self-restraint which allows her to participate in 'normal' life without making herself ill again.

In essence it seems that the dilemma they face is similar to that of pwME/CFS (see '*Treatment without a cause',* 5.2 above) in the sense that they have a real or perceived responsibility to keep themselves well and engage in 'normal' life. The key difference here is that these participants perceive themselves to be in control of these activities and are able to strike a balance between being ill and being well which allows them to participate in 'normal' life.

The final analytical theme, '*Out with the old and in with the new'*, presents an area of research that has been neglected to date and explores how disruption occurs in the accounts of people who claim to be fully recovered. This is new territory as chronic illnesses are considered to be life-long conditions. It could be construed that people in recovery from ME/CFS should be symptom free, which would suggest that they no longer experience any form of disruption. However, the analysis has revealed that the participants experienced both on-going and new disruptions, a finding that was unexpected. On-going disruptions were residual consequences of being ill with ME/CFS in the first place, such as not being as fit as one may have been (see Nigel extract 5.4:1) or being aware that certain activities may now be problematic (see Eve extract 5.4:2). Again this presented difficulties that the participants had to come to terms with and manage, as they were no longer able to engage in activities in a carefree manner.

The way participants talked about this stage of their ME/CFS journey also implies that there are new disruptions which revolve around continual worries and concerns that their ME/CFS may return. Nigel, Eve and Pip (extracts 5.4:1, 5.4:2 & 5.4:3) described monitoring or restricting their activities and being watchful for any symptoms that could become troublesome, activities which can be viewed as being disruptive to a 'normal' life. The vigilance that the participants undertake here can be seen as a result of the contested nature of ME/CFS because they seem to perceive themselves as being solely responsible for managing and maintaining their own health. It is telling that ME/CFS is again suggested to be something sneaky, that it can emerge unexpectedly from the most mundane of activities (see extract 5.4:2) if one does not watch out for it. This accords with the analysis presented in theme 2, *'Treatment without a cause'*, which suggested that the illness emerged in circumstances that the participant appeared to have had little control over.

Recovery from ME/CFS does not seem to represent a carefree return to a normal life, but rather presents a new stage of uncertainty and disruption which has to be managed. Even participants claiming a full recovery who do not have to engage in illness behaviours to the extent of pwME/CFS or those in partial recovery, still appear to be actively doing something to maintain their good health. So it seems that they are not completely 'well' either but fall into that liminal state of being in-between sickness and health.

In summary, this chapter has highlighted that the ME/CFS experience is characterised by disruptions at each stage of the pre-illness to post-recovery journey and in addition has presented a new and different dimension to the ME/CFS and chronic illness literature. It also complements and supports the findings of the previous chapter (Chapter 4), which found that the way the participants describe their lives can be interpreted as being liminal as they are stranded between being 'ill' and being 'well' and this state in itself can be seen as disruptive. However, this chapter has focused on how the participants describe events that happen to them throughout the different stages of their journey in order to show how they perceive the disruptiveness of their illness. It is noticeable that when participants talk about these disruptions to their lives they are also talking about issues that relate to their identity and how their sense of self is affected by ME/CFS and the following chapter explores how participants perceive their identity and how this has been affected by their illness.

Chapter 6

Identity and the self

Introduction

The previous two chapters have focused on how the participants describe their experiences of life at various stages of having ME/CFS. Chapter 4 proposed that the participants' experiences could be interpreted as being liminal because they seem to be unable to fully identify with the categories of being ill or being well. Instead their experiences of becoming ill, managing the illness and becoming fully or partially recovered fall between these social categories leaving them stranded or 'betwixt and between'. The analysis suggested that the participants transcended the categories of being ill and being well in order to try to manage their illness effectively and to engage in some aspects of a 'normal' life. However, by switching between categories they found that they became the subject of suspicion and intrigue and attracted negative reactions from other people. Chapter 5 focused on the participants' descriptions of how their lives are disrupted by ME/CFS at each stage of the pre-illness to post recovery journey. The analysis suggests that the participants perceive these disruptions to be exacerbated by the contested nature of their illness as it causes additional problems and dilemmas that they have to manage. Yet they also imply that by actively managing the disruption this allows them to participate in aspects of normal life although they are continually required to exercise caution over their choice of activities even some time after 'recovery'. So the analysis presented so far illustrates that the subjective experience of suffering with ME/CFS is complex and trying to manage the illness and lead a 'normal' life requires a considerable input of time, effort and energy from the participant.

As shown in Chapter 4 and Chapter 5, participants' accounts of events are often structured in a way which acts as a defence against any perceived claims that they are being lazy or malingering. In other words they are addressing issues relating to their identity. The purpose of this chapter is to explore how people with ME/CFS talk about their identity and their sense of self throughout the various stages of their illness to recovery journey.

This chapter embraces the definition of identity proposed by Erickson (1980) who argues that it "connotes both a consistent sameness within oneself (selfsameness) and a persistent sharing of some kind of essential character with others" (Erikson, 1980, p109). Identity is therefore portrayed as being within oneself, whilst at the same time being something that evolves within a social context. The consistent self-sameness that Erikson refers to is explained by Charmaz (1987) as being a 'core' identity. It refers to characteristics such as personality, which are considered to be relatively stable and unique to the individual person. At the same time identity is seen as being inherently social as it is constructed within and informed by social frameworks. According to this view, identity is a social construction and is something that a person actively 'does' via the process of interaction.

The self is a complex concept which is influenced by social representations of the social group that the individual is part of. Moscovici (1984) argues that social representations provide a framework that allows people to people to understand their social world and communicate information about it. As discussed in Chapter 2, social representations of concepts or phenomena are negotiated and agreed within a group setting and they form a constituent part of the groups social identity, which in turn has a psychological effect on an individual's sense of self (Charmaz, 1987). People infer meaning about their 'selves' from the social groups that they are part of and by comparing the status of their group (the 'us') to other groups in the social hierarchy (the 'them'). Such comparisons have consequences for an individual's self-worth and self esteem.

However, Burr (2002) notes that the self is commonly regarded to be "the property of the individual, firmly located in the mind". That is to say that the self is made up of internal values, attributes and emotions which the individual person perceives as being unique to them and forming an integral part of who they perceive themselves to be (Charmaz, 2002). This perception is also influenced by the physical body as physical characteristics or the capability of the body impact upon how people perceive themselves (Reynolds, 2003). It is proposed that the self is continually constructed by the individual through the experiences that they encounter as they pursue their personal life goals such as educational attainment or working in a particular industry (Charmaz, 2003; Christiansen, 2000). In this sense the self

can also be understood as an on-going, consecutively ordered narrative of life events which illustrate 'who I really am' and provide a way to convey the story of oneself to others.

Identity therefore is the framework that people draw upon in order to interpret and explain their experiences of ME/CFS. These same experiences can be regarded as being crucial to informing and shaping the on-going development of the self. As the self is formed in a social setting, the social representations of health and illness are also relevant to this chapter.

Herzlich (1973) identified three specific lay representations of illness which were: Illness as a destroyer, illness as a liberator and illness as an occupation. Firstly, for people who attribute meaning to their lives through being busy and active, illness is often construed as destructive because as noted in the previous chapter it causes a disruption to their day-to-day activities and longer-term biography (see Chapter 5). However conversely, for those who are burdened by responsibility or overcommitted Herzlich notes that illness can be regarded as a liberator because it provides a remit for relief of these obligations. This concept has also been interpreted as liberation of the 'self' for some people as their identity becomes enhanced when they talk of fighting the illness which Murray (2000) interpreted as liberation of their former subdued selves. Finally, for some, illness would become an occupation as they immersed themselves in finding information or trialling solutions and remedies in an attempt to improve their health. Herzlich also highlighted the importance of how 'health' as a concept is socially represented and found that it, unlike illness, was considered to be within the person's control. Being healthy was deemed to be dependent on a person's attributes, such as strength of character and exercising self-control, which could also be used as a resource to defend against the threat of ill health that is believed to exist within society. Subsequent research has supported the view that people view illness as an external event and health as an internal attribute (Blaxter, 1990; Murray, 1997; Williams, 1983).

Furthermore Herzlich (1973) found that there were specific representations of health amongst lay people: the absence of illness or disease, having health in reserve or as equilibrium. Health as the absence of disease originates from the biomedical view of illness (see Murray, 2000), which simply infers that in the absence of biological evidence to the contrary health must prevail. Health in reserve suggests that people are equipped with the

strength to take part in life activities but also that they are able to 'store' good health and keep it in reserve for future occasions when the demands of society threaten ill health. Finally people stated that establishing an equilibrium whereby they are happy, relaxed in life and enjoy strong, positive relationships, as being a sign of good health. In recent years Flick (2000) has added a further category of 'health as a lifestyle' to Herzlich's work, which reflects the societal change towards public engagement in 'healthier' behaviours. These behaviours may include self-examination, self-medication and commitment to diet and exercise programs which lay people become increasingly involved in (Eisenberg, 1998; Hughner, 2004). The point is that being classed as 'healthy/well' or 'unhealthy/ill' communicates something about the type of person someone is: it says something about their identity.

The previous chapter (Chapter 5) found that participants encountered continual biographical disruptions throughout their pre-illness to post recovery journey and these same disruptions are highlighted in this chapter as also disrupting the participants' sense of self. Bury (1982) argues that an ill persons narrative, whereby they construct their past, present and future, is disrupted when they become ill and they often become detached from their identity and sense of self. As a result they have to reconsider their biography and their self-concept and formulate a response to the disruption by recognising and mobilising their resources in order to try and regain control of their symptoms. The way that Bury describes the consequences of biographical disruption and the self resonates with the motivated, pro-active manner that the participants in research have displayed in order to address their liminal status and the disruptive effects of ME/CFS (see Chapters 4 & 5). Thus it seems appropriate that these participants will be equally as motivated to respond to issues relating to their identity and sense of self.

As discussed in Chapter 2 the chronic illness literature to date suggests that 'loss of self' is an undeniable consequence of becoming ill (Bury, 1982, Charmaz, 1983) and that overtime people are able develop ways of dealing with the disruptions to their sense of self and derive some positive meaning from their experiences (Ware, 1999). It has been proposed that the key to achieving this positive meaning lies with how the person perceives the construction of their 'new' self in relation to previous selves (Carricaburu & Pierret, 1995; Charmaz, 1987). For example, people who perceive their attempts to address the disruption to their

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biography to have constructed a self that is the same as, similar to or superior to how they used to be, describe having these positive effects.

Chapter 2 also outlines Charmaz's (1995) proposal that people order the possible outcomes of their identity work in the following hierarchal order of preference: Firstly the 'supernormal identity' whereby they will become able to complete extraordinary feats, if and when they can recover. This identity was considered to be an aspirational one that people who were very ill talked about in the unlikely event of them recovering. Secondly people desired a 'restored self' where previous identities can be reconstructed and life was the same as before and thirdly a 'contingent self' where possible identities are questionable because the course of illness is unpredictable, and therefore the future identity was unknown. Finally, 'the salvaged self' whereby people are able to retain some, perhaps small, aspects of a previous identity despite deteriorations in their physical health.

In comparison Yoshida (1993) claims that changes to identity are more fluid and illustrates a 'pendulum effect' whereby people move between the former self, which is being able to do what they could before; the disabled identity as an aspect of the total self, whereby people were aware of limitations but enjoyed a life as normal as possible; the 'supernormal identity', which is managing to do much more than one could before, and the disabled identity whereby the disability dominates any identity that the person may have had. Unlike Charmaz's model, Yoshida proposed that people could experience any of the identities in any order and for an unspecified amount of time.

It has already been noted (see Chapter 2) that only a limited amount of research looks specifically at how ME/CFS affects people's sense of identity or self with notable exceptions being Asbring (2001), Clarke & James (2003) and Whitehead (2006). Asbring (2001) proposes that pwME/CFS are stuck in a pattern of moving between their illness identity and trying to return to their former identity before they eventually move on. Establishing a new, positive identity allows them to retain some aspects of their former self and former identity. The emphasis for Asbring's participants was on finding new ways of doing things or finding different activities that concur with their perception of their identity.

The purpose of this chapter is to expand the above research by focusing on how participants perceive their identity and sense of self at different points of the pre-illness to post-recovery journey. The focus here is upon how the participants talk about changes that have occurred and how they describe them as being a consequence of their illness or as a result of being 'recovered'. With this in mind the research also draws upon social representations of health and illness as set out by Herzlich (1973). The analysis aims to explore the participants' descriptions of their experiences in relation to the concepts outlined above and this is presented in the following four themes. The first theme, *'The self propelled self'* focuses on how the participants retrospectively construct their pre-illness identities and the meaning that these descriptions hold for them. Secondly, *'The self under siege'* looks at how the participants talk about the effect that becoming ill has upon their sense of self with a particular emphasis on how they *know* that their experiences are a consequence of the condition. The third theme, *'A self divided'* explores how participants perceive their identity when they become able to manage their illness and participate in normal life but are not yet 'recovered'. Finally, *'A return of health, a return of self'* focuses specifically on how people in recovery construct their identity now that they are claiming to be free from their ME/CFS.

6.1 The self propelled self

This theme explores how the participants retrospectively construct their pre-illness selves and their former identities as they describe the type of things that they used to do before they became ill. The first extract within this theme highlights the relevance of 'the self' and 'identity' to the participants' subjective experience of ME/CFS. Prior to this Tara is talking about how busy and active she used to be until she became ill with ME/CFS "almost overnight" (transcript line 14), whereupon she suddenly became too ill to continue with her activities. She has described having to stop working, socialising and relinquish her sporting activities because she was needed to sleep for twelve hours a day.

Extract 6.1:1 Tara (Group 1 –PwME/CFS)

1   The problem with having this [ME/CFS] is especially if you've been

2   quite an active or a social person active physically and at work

3   your identity is suddenly challenged because

4   you cannot be the person that you used to be

5   so, I have found a lot of problems that I've had are emotional related

(Tara, data set 1; lines 223-226)

Tara talks about the onset of ME/CFS from what seems to be a general perspective, conceptualising what she defines as "the problem with having this" (line 1) which seems to be a very profound statement when considering the extensive range of practical problems that becoming ill can cause. Her use of the pronoun 'you' is evident here[51] and it suggests that this issue is of particular importance to Tara and other pwME/CFS. She relates the problem to the type of person "you've been" (line 1) and she describes herself as being a motivated and active person who propelled herself through life (line 3) and describes it as "your identity is suddenly challenged (line 4) which points to an abrupt step change as she becomes unable to do the activities that that she lists on line 2. By talking specifically about her identity it seems that she regards her ability to do these things as encompassing 'who she is'. Interestingly she goes on to suggest that ME/CFS also has a profound effect on her sense of self as she says "you cannot be the person that you used to be" (line 4) which is again quite profound because it strongly implies that Tara somehow becomes detached from her sense of self and it in a situation that she has little control over. This situation has a considerable impact upon her as she suffers additional "emotional related" (line 6) problems.

The way that Tara talks about suggests that she may be grieving for her 'lost' self as Charmaz (1983) notes that people with chronic illnesses experience continual losses of self because their former actions, lives and selves are no longer available to them. It also echoes the findings of Dickson, Knussen & Flowers (2008) as their research claims that sufferers experience a form of bereavement from their former identity. Her description of her experiences can also be likened to Herzlich's (1973) metaphor of

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[51]Dickson, Knussen & Flowers noted that pwME/CFS talk in this way but did not offer an explanation as to why.

'illness as a destroyer', as it has curtailed her ability to participate in life events and limited her social interactions with other people. However, Tara seems to intimate here that there is a deeper concern as the disruption goes beyond the effects of not being able to do things but strikes at the heart of 'who she is'.

It is notable that Tara constructs her pre-illness self as being busy, active and illustrates enjoying a full and active life as previous research suggests that chronically ill people often play down the positive aspects of their past identity in order to make their current identity more favourable (Baumeister, Tice and Hutton, 1989). Instead it seems that her account of who she has 'been' is important to her.

In the following extract Holly is talking about her pre-illness life. She has explained that her life had been stressful as she had been unhappily married before, had two children and divorced when she was 24. She then moves on to talk about the type of things that she used to do before she became ill.

Extract 6.1:2 Holly (Group 1 –pwME/CFS)

1   I mean my next door neighbour used to call me super mum

2   because I was so busy I mean when I was married the first time

3   I carried on working even though I had a baby

4   I worked in a pub in the evening y'know to get some extra cash

5   while he he looked after the baby and so I was busy busy busy busy

6   and I'd never been ill as a child

7   in fact I got an attendance award at school and I was always well

8   I mean I had the usual childhood illnesses bits and pieces

9   but I'd never had anything operations nothing

10   the only operation I ever had was a caesarean

11   so I was renowned for being very energetic I was quite sporty

12   I loved to walk I loved to run

13   I used to play tennis I used to play hockey

14   I did lots of things. I was always full of beans

(Holly, data set 1; lines, 149-166)

It is immediately striking here, that Holly talks in the past tense throughout this extract which implies that she is no longer the same and that things have changed since she became ill. She talks about being known as "super mum" (line 1) in the past which invokes images of maintaining a level of activity over and above what could be considered to be 'normal'. She strongly emphasises how busy she used being saying "I was so busy" (line 2) and "so I was "busy, busy, busy, busy" (line 5). Her use of repetition here seems to reinforce her determination to convince others of just how active she was.

It seems that Holly is acoustically reflecting the repetitiveness of her activity and the fast, hectic pace that she used to have. So Holly has constructed herself as someone who was driven and propelled herself into being a busy, responsible working wife and mother during her early adult life and she goes on to talk about her prior good health.

She intimates that she had particularly good health throughout her childhood as she says "I'd never been ill" (line 6) and "I was always well" (line 7), and uses 'never' and 'always' to emphasise her claim. She also says "I got an attendance award at school" (line 7) and there is an implicit implication that her attendance was exceptionally good, perhaps exceeding an 'ordinary level', for it to warrant an award. However, Holly does not present herself as completely impervious to illness and admits to having "the usual childhood illnesses" (line 8), but these are played down as "bits and pieces" (line 8) from which it can be construed that they did not cause any considerable disruption to her life. It seems that Holly is stressing that she used to be a particularly healthy person during her childhood and early adulthood and these claims help to portray her as someone who is not a 'sickly' person.

She goes on to suggest that she used to be "renowned for being energetic" (line 11) and claims to be emphatic about even seemingly mundane things saying "I loved to walk I loved to run" (line 12)[52] as well as being "quite sporty" (line 11), which again suggests that she was driven and propelled to do things. She says "I did lots of things I was always full of beans" (line 14), depicts Holly as being a lively, energetic person who is enthused about life and who is continually 'on the go'.

It is noteworthy that Holly presents such a convincing account of busy, healthy and energetic she used to be and like Tara (see extract 6.1) she implies that she propelled herself into a full and active life. Rather paradoxically promoting positive aspects of the pre-illness identity, as Holly has here, is considered to be detrimental to the sufferer's current illness identity (Wilson & Ross, 2001), and ill people typically play them down in order to make the contrast between the two identities less stark (Baumeister, Heatherington & Tice, 1993). Yet, from the way that Holly constructs her account seems reminiscent of Charmaz's (1983) description of a supernormal pre-illness identity, with the important difference being that she is speaking of 'who I was' rather than someone she desires to be in the future. By focusing on how busy and active she used to be Holly may also protecting herself against any perceived accusations of malingering or being complicit with the illness, as she is emphasising characteristics which oppose this.

Both Tara and Holly have described how busy and active they used to be before their illness and appear to suggest that they experienced an enforced step change in their identity when they were no longer able to carry out their active lives and were forced to take on more sedentary activities.

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[52]The way that Holly talks about this is also potentially interesting as although she uses a 6 part list (lines 19-21) to support her claim to have been extra-ordinarily busy, she constructs this differently to the way that Jefferson (1991) notes is common in everyday speech. Rather than two three part lists, Holly's speech is constructed in pairs as she says "I loved to walk, I loved to run" (line 19), "I used to play tennis, I used to play hockey" (line 20), "I did lots of things" and "I was always full of beans" (line 21). It may be the case here that Holly is attempting to present her activities as both plentiful and varied as the rhythmic way that her speech is organised (lines 19 and 20) seems to extenuate each individual activity.

In the following extract Riley talks about the challenges that ME/CFS presents to his pre-illness identity. He has previously explained that because his parents made considerable financial sacrifices in order to fund his private education, he felt pressurised to be academically successful when he was a child. He goes on to talk about how this may have impacted upon his identity and possibly his ME/CFS.

Extract 6.1:3 Riley (Group 1 –pwME/CFS)

1   I think without knowing it in my early kind of years

2   I carried a burden of expectation erm and then certainly because

3   I tend to be quite good at things anyway erm that I then translate that

4   into a burden of expectation that I place on myself erm

5   and I was talking earlier about being very competitive

6   and the will to win and it's always kind of drive drive drive

7   and I don't do anything unless I'm very good at it and

8   if I do something I don't that I'm not immediately very good at then

9   I'll practice and practice and practice and practice

10   until I am very good at it and so it's this kind of

11   constant drive constant kind of self criticism I suppose

12   I think that's one of the major things

13   I think when that carries over into your professional life which it did

14   erm and once you kind of deliver a lot at work which I did

15   then people come to expect that of you and in order to continue

16   delivering it erm you have to step it up more and more and more

He talks about having a "burden of expectation", which was unwittingly imposed upon him when he was a child and suggests that he is now compelled to behave in a certain way because of it. He describes himself as "being very competitive" (line 5) and as having "the will to win" (line 6) suggesting that he has an ingrained compulsion to succeed or even excel. He seems to perceive this original burden as manifesting into something that he now places on himself (line 4) and he appears to be relentless in

trying to meet his own high standards saying "it's always kind of drive drive drive" (line 6). Using the ECF of 'always' here and his repetition of the word 'drive' creates the impression that he is continually motivated to move forwards.

Gaining recognition for being high achieving or successful seems to be important for Riley as he will "practice and practice and practice and practice" (line 9) until he becomes good at things. The use of repetition here seems to reflect his relentless and dogmatic approach towards striving for success. Yet, he suggests that his determination to be successful makes him a victim of a continual cycle of "constant drive constant....self criticism" (line 11) whereby he strives to do well and then places himself under pressure by self-critiquing his performance. He also talks about being under pressure to meet what he perceives as the continually increasing expectations of others saying he is compelled to "step it up more and more and more" (line 15). His repetition implies that this behaviour is compulsive and it seems that being 'driven' is an intrinsic part of who he is which means that he cannot help but continue to repeat the same patterns of behaviour.

So Riley, like Tara and Holly (extracts 5.1:1 &5.1:2), perceives himself as the type of person who is naturally industrious and it seems that gaining recognition for this is important, but what is particularly notable is that Riley is talking in the present tense, suggesting this is still representative of 'who he is' even though he is unwell with ME/CFS and his ability to participate in events is limited. By continuing to assert himself as someone who is still incredibly driven to succeed, despite his current poor

health, hints at his activity being over and above what may be considered 'normal', which resonates with Charmaz's (1983) concept of a supernormal identity which is intriguing because it also depicts that his fundamental sense of self remains unchanged.

From the above analysis it seems that the participants consistently highlight how motivated, driven and active they used to be before they became ill and how they were able to propel themselves through life. It seems that the way they talk about this period of their lives accomplishes a number of things for pwME/CFS in terms of conveying their sense of self to others.

The literature to date suggests that chronically ill people typically play-down the positive aspects of their pre-illness identity in order to make the contrast between what they used to be able to do and their current abilities less stark. In turn this boosts the illness identity and makes it seem less inferior to their pre-illness identity (Baumeister, Tice & Hutton, 1989). However the participants in this study seem to be doing the opposite here as they talk about their pre-illness selves in such revered terms that it seems akin to descriptions of a 'supernormal identity'. This in itself is important because Charmaz (1983) suggests that the supernormal identity is an inspirational one that people with progressive chronic illnesses talk about becoming if they are able to recover from their illness as it represents being more than they were before. Yet it seems that for Tara, Holly and Riley the supernormal identity, whereby they managed an extraordinarily busy life, epitomises the person that they still believe themselves to be. It seems that retaining a rich, clear and vivid account of what they used to be able to do and the type of person they used to be is of importance to their overall sense of self. This is particularly apparent in Riley's extract above (see extract 6.1:3).

By emphasising how motivated and driven they used to be and how busy their lives were the participants are also implying that that they were healthy, robust people. This emphasis functions as a way of negating any connotations of being considered apathetic, a malingerer, or a 'sickly' person. In other words they are addressing the social representation of ME/CFS and constructing themselves to be very different from what this may suggest. Therefore it sets the scene for their ME/CFS being an

unwarranted, surprising event and introduces the notion that that the contrast between the hectic lives they describe above and life with ME/CFS causes conflict.

The following theme explores the how the participants talk about this sudden step-change that they experience when they are ill with ME/CFS.

6.2 Self under siege

The extracts above suggest that the initial period of becoming ill presents an acute challenge to a persons' identity or sense of self. The following analysis focuses on participants' accounts of the impact that ME/CFS has upon their lives and their sense of self and the way that they talk about this likens it to being under siege.

Izzie is talking about how she became unable to look after herself when she became ill, a situation which eventually meant that she had to leave university and return home so as her mother could care for her. In the extract below she talks about what her life is like now and how she has been affected by ME/CFS.

Extract 6.2:1 Izzie (Group 2- partially recovered)

1	I would sort of look at what everyone else was doing
2	erm and focus on you know all I get you know
3	I'm never gonna have a job
4	I'm never gonna you know finish university
5	erm yeah I'm never gonna be able to hold down a job
6	and I don't know when I'm gonna get better
7	or if I'm gonna get better erm and am I gonna get married
8	and am I gonna have chil… y'know things like that
9	and y'know at that age as well you look at your friends
10	and they're all finishing university and kinda going travelling
11	and going off and not having to think about
12	sort of you know being ill or you know what they eat
13	or is that gonna make them ill or if they do too much

14   is that gonna make them ill

15   and I think I used to sort of like sit there

16   and wish I was absolutely knackered from doing

17   like a really busy days work or just being really busy

18   rather than just being knackered just for the sake of it

(Izzie, data set 1; lines 196-208)

Izzie talks about becoming an observer of other peoples' lives rather than being an active and busy participant in her own life as she says "I would sort of look at what everyone else was doing" (line 1). She goes on to rather dramatically suggest that her ability to participate in life events as limited by her illness. She presents a list of things she feels that "I'm never gonna" do (lines 3, 4 &5) which indicates her immediate concerns such as finishing university and getting a job. She the gives another list of things that she may not be able to do "am I gonna" (lines 5-7) which relates to her future concerns of other events such as getting married and having children. The way that she structures this emphasises that her life is full of uncertainties since she became ill because participating in future 'normal' life events seems to become impossibility. ME/CFS seems therefore place restrictions on the things that Izzie may be able to do in the future and the type of person that she may be able to become. It seems that she is being held in limbo a new and different state of liminality.

Izzie then goes on to talk about watching the activities of her peers who are embarking on a new, busy and exciting life experiences by "finishing university and kinda going travelling" (line 10) and this presents a stark contrast with her own situation as she "used to sort of like sit there" (line 15). This suggests that for her peers, life and life events were continuing, and they were going on around Izzie, but because of her ME/CFS she was relegated to only being able to observe them. She makes a considerable comparison between her own abilities and that of her friends as they were "going off and not having to think about sort of you know being ill" (lines 12& 13) which suggests that her illness is the primary focus in her own life and overshadows anything else that she may like to do.

So it seems that Izzie is well and truly under siege because her illness has completely changed her current and future life and she seems to be 'stuck' as life continues around and without her. In this sense it seems that she becomes identity-less or that her identity is somehow suppressed because of the illness.

In the following Ann describes the effect that her illness has upon her ability to participate in social events and activities that she used to enjoy in a manner which seems to depict being under siege.

Extract 6.2:2 Ann (Group 1 –pwME/CFS)

1	so it does sort of y'know it's changed the way you are
2	you don't – self preservation and I can't see a lot of people
3	I wanna see my friends and coz I'm just not well enough
4	and I can't cope with talking erm or listening ha ha
5	I mean one of my friends I see just every few months now
6	she talks a lot and much as I like to see her I'm not well enough
7	so it changes everything in your life everything that you enjoy
8	going out meals out you can't do any of that
9	because your just not well enough
10	there's no it's not that you don't want to
11	you just can't you're not well enough
12	to sit with loads of people with the lights the sounds
13	everything is just too much for the system your brains somewhere
14	you want to cope with it but your symptoms get worse
15	your concentration goes you feel worse
16	you can't sit there you can't stand you need to lie down
17	you don't know it's not a conscious thing it just happens

 (Ann, data set 1; lines 840-851)

Ann talks about ME/CFS having a dramatic and devastating impact on her identity as she says "it's changed the way you are" (line 1) and "it changes everything in your life everything that you enjoy" (line 7), which suggests the effects of the illness are all encompassing. ME/CFS seems to challenge both her ability to be part of life events and her fundamental perception of who she is as a person as she talks about being obliged to behave in way that is different to what she actually wants to do. She illustrates this conflict when she says "I can't see a lot of people I wanna see my friends" (lines 2 &3), which suggests that she is forced to restrict her activities in order to avoid aggravating her illness.

She, like Izzie (extract 6.2:1 above), implies that even mundane everyday activity becomes problematic because of the illness, saying "going out meals out you can't do any of that" (line 8) and it is interesting to note that she suggests that her ability to manage simple, possibly taken for granted, aspects of interaction also become impaired as she says "I can't cope with talking … or listening"(line 4) and even seemingly inconsequential things in her surroundings such as "the lights the sounds" (line 12) become difficult to cope with because of her ME/CFS.

She talks about needing to exercise "self preservation" (line 2) by limiting the extent of her social activities, however she strongly emphasises that this not something that she wants to do but something that she has to do because she is "not well enough" (lines 3, 6, 9 &11). She also presents the perceived repercussions to socialising as being outside of her control as she says "everything is just too much for the system your brains somewhere" (line 13), her use of 'system' could evoke comparisons with an errant computer program that is difficult or impossible to control which eventually shuts down to protect itself as she also goes on to say "it's not a conscious thing it just happens" (line 17). She talks about the effect that this has upon her physical and mental being saying "your concentration goes you feel worse" (line 15) and "you can't sit there you can't stand you need to lie down. This suggests that she is completely undersiege as both her body and mind become difficult to operate and she has become mentally and physically disempowered. In one sense it appears that the illness disrupts Ann's ability to be herself by preventing her participation in social events. However, rather poignantly it also seems that her concept of who she is remains

unchanged because she still wants to do the same things that she has always done, but her ability to do them is suppressed by her ME/CFS.

What is compelling here is the way that Ann depicts the illness as being powerful enough to render her incapable of basic functions such as talking or listening as it resonates with the feeling of powerlessness that pwME/CFS have previously expressed (see Clements, Sharpe Simkin, Borrill & Hawton, 1997). It also resonates with Clements et al's finding that pwME/CFS distinguish between the 'illness' and the 'symptoms' with the latter being described as unpredictable and uncontrollable.

In the following extract Dawn also explains how difficult it can be to socialise as she talks about going out for a meal with her extended family.

Extract 6.2:3 Dawn (Group 2- partially recovered from ME/CFS)

1   I didn't really say anything didn't really interact

2   couldn't really understand the conversation at lunch

3   just felt like I was sitting in this little glass bubble

4   and reality was happening on the other side of it

5   felt really distant and I just think in a way when you're ill

6   your body just puts up these defences and says

7   well actually you can't deal with reality at the moment

8   so you're not going to you're not going to be there y'know

9   you're just kind of sat there and things happen around you

10   but you don't feel like you're part of it and looking back now

11   I think yeah actually that's what I needed to do

12   but at the time it's very very hard because you don't

13   I didn't really fully understand what was happening.

14   So it's that whole mixture of Oh I'm just sitting here

15   I'm trying to eat lunch and I'm and I know that there are

16   all these people talking about very clever interesting things

17   but I couldn't I couldn't join in it's a bit like sitting at a

18   sitting at a table with people speaking a foreign language

19   you can understand what they're saying but you can't [laughs]

20   you can't speak the language yourself it's a bit like that

21   That's the closest I can come to explaining what it was like

22   y'know you have all these ideas flying around

23   and you really want to join in but you just can't

(Dawn, data set1: lines 352-375)

Dawn talks about experiencing problems with basic taken for granted elements of being sociable as she says "I didn't really say anything didn't really interact, couldn't really understand the conversation" (lines 1 &2). Her experience appears to be similar to Ann's (see extract 6.2:2). She explains that she "felt like I was sitting in this little glass bubble" line 3) and she strongly suggests that she felt detached from reality, as she is fully aware of what was happening around her but at the same time she was unable to participate in it (line 4 & 5). She goes on to explain: "you're just kind of sat there and things happen around you" (line 9) which, like Ann, implies that life is continuing to happen around her but she is completely incapable of joining in. She portrays her inactivity as being the result of an involuntary, automated process whereby her body "just puts up these defences" (line 6) thus creating a protective sphere in order to protect her from any negative repercussions caused by socialising. Dawn suggests that although she is incapable of communicating, her desire to do so remains the same, saying "you have all these ideas flying around and you really want to join in but you just can't" (lines 22 &23). Throughout the above extract Dawn continually refers to 'you' rather than saying 'I' or 'one' which possibly suggests a claim of generality or solidarity with the listener. This highlights a further stressful characteristic of this frustrating stage of ME/CFS and it involves being resigned to

having limitations imposed on her ability to take part in the most mundane of activities.

Dawn's account powerfully depicts being under siege as she is unable to connect with reality because she is encased in her glass bubble rather than being rendered powerless because of her ME/CFS symptoms. She suggests that this was problematic whilst she was ill (line 12) because she is unable to express her identity and be herself. Yet, in retrospect, it seems that she considers her temporary removal from reality as facilitative to her overall well-being and partial recovery.

The above analysis shows a distinct step-change between *'the self-propelled self'*, the pre-illness self and the mid-stage of the illness when the self is more sedentary and seems to be 'under siege' from the ME/CFS symptoms. It captures something unique in the illness experience of pwME/CFS. Firstly it can be argued that the participants' identity becomes challenged as they become unable to participate in events as they would always have done (employment may be an example of this). Thus from this perspective it seems that their experience accords with the 'loss of self' that other research suggests is a feature of the illness experience (See Asbring, 2001; Clarke & James, 2003; Whitehead, 2006). However, the participants in this study strongly emphasise that they perceive their sense of self to remain unchanged. Instead they indicate that the self is 'suppressed' by ME/CFS and this renders them to be temporarily incapable of participating in life that is going on around them. It indicates that the participants do not completely reject their pre-illness selves as Clarke & James (2003) suggest. In the analysis in this study suggests that ME/CFS holds participants sense of 'self *under siege'*.

The analysis so far has shown that the self-propelled self is associated with an extraordinary level of activity which is reminiscent of a 'supernormal identity' (Charmaz, 1987) but in the mid-stage of illness the self becomes under siege and suppressed by the ME/CFS symptoms.

6.3 A self divided

The dramatic step-change between the pro-active, *'self-propelled self'* (see theme 6.1) and the more sedentary *'self under siege'* (see theme 6.2), has been established. The theme *'A self-divided'* draws upon interviews with participants who have been able to partake in some of the activities that they used to before becoming ill but who still have to balance this with engaging in illness behaviours.

In the extract below, Sally, who claims to be ninety-five percent recovered at the time of the interview, reflects upon her past experiences of illness and 'recovery' and some of the challenges she may expect to face in the future.

Extract 6.3:1 Sally (Group 3- partially recovered)

1	I think the first time I recovered I think I went into therapy
2	because I found I had a lot of anger issues actually
3	just not real- not openly expressing it just feeling very angry
4	I sort of the whole trying I think it's the whole thing about
5	trying to compete on the playing field with well people
6	when you're not you just don't get it
7	and it's an invisible disability
8	I think a lot of people with ME have anger issues
9	I mean like I know someone who used a stick
10	so that people actually realise that she is disabled
11	I mean she's probably like able to function
12	not much more disabled than me
13	you you do get this whole thing about
14	everybody just looks at you and thinks you look fine
15	erm and people don't make allowance

(Sally, data set 1; lines, 645-660)

The way that Sally talks about her partial recovery suggests that it is a reoccurring cycle of illness followed by periods of wellness, so she can never be certain that it will not return and this is something else that she has to mange in terms of her identity. She

talks about finding it difficult to manage, saying "the first time I recovered I think I went into therapy" (line 1) and she specifically mentions having "anger issues" (lines 2 & 8). She goes on to describe being caught in a contradictory situation whereby she may "look fine" (line 14) but because she is not completely well, she is unable to "compete on the playing field with well people" (line 5), which implies that being partially recovered challenges her identity as an employee who is as capable as her peers.

Sally relates the "anger issues" (lines 2 &8) that she and other people with ME experience to her illness being an "invisible disability" (line 7) and says that "everybody just looks at you and thinks you look fine... and people don't make allowance". This is quite telling and presents Sally with a dilemma because it denotes that she wants to be seen as a 'normal' employee but at the same time wants some recognition that her illness is disabling and her abilities are compromised. So she seems to present a '*self divided*', on one hand she is the well worker but on the other hand an ill-person who is struggling in the work place. Thus it appears to be an on-going contradiction that she has to manage. In some ways it seems that Sally's experience resonates with Asbring's (2001) finding the pwME/CFS fluctuate between the illness identity and their pre-illness identity. However, the way that Sally describes this instead points to problems in managing a divided identity, as she in continually aware that her ability to do things is still compromised by being ill.

The notion of managing '*A self divided*' is explored again in the following extract as Riley, who used to be extremely pro-active talks about his ongoing experience of managing life with his ME/CFS.

Extract 6.3:2 Riley (Group 1 –pwME/CFS)

1   I think there are times when those two or three times

2   that I talked about where really I should

3   and today's one of them I should really have stepped back

4   and said I'm having a rest regardless and this can just wait

5   and to hell with it erm and I didn't do that and it was kind of

6   slipping back back a little bit into the old pattern of working

7   erm so it's it's and it's very difficult for me to kind of do

8   the rest and relaxation and the breathing and the meditation

9   because that's not naturally who I am and even despite having ME

10   I'm constantly wanting to be on the go

11   and constantly wanting to be doing things

12   I'd much rather be I don't know playing Playstation or Poker

13   than I would by sitting quietly reflectively and reading y' know

14   so it's it's it's I have to be very disciplined about it

15   and sometimes I'm good at it and sometimes I'm not so good

(Riley, data set 1; lines 422-436)

Riley talks of facing a daily battle because "even despite having ME" (line 9), his fundamental sense of self remains unchanged, as he is still "constantly wanting to be on the go, and constantly wanting to be doing things" (lines 10 & 11), in the same way as he always has. Yet at the same time he seems to be aware that there are a number to times when he "should really have stepped back" (line 3) and suppress his natural instinct to constantly be doing things in order to maintain his overall health. It seems that this is a conflict for him as when he is unable to curb his enthusiasm he talks of "slipping back back a little bit into the old pattern of working" (line 6) which indicates that being sensible about his activities is an ongoing battle for him.

He talks about having to engage in illness behaviours which are thought to be helpful to ME/CFS sufferers such as "the rest and relaxation and the breathing and the meditation" (line 8). The way that he describes these behaviours is in a monotonous tone suggesting that he finds them tedious and possibly laborious and he states that it is difficult for him to do as it because it is "not who I naturally am" (line 9). The need to

restrict his activities seems to impinge on all areas of his life including his choice of leisure activities as he has to avoid strategic, interactive games such as "playing play station or poker" (line 12) in favour of "sitting quietly reflectively and reading" (line 13) although he perceives the latter to be more appropriate to his perception of himself as a driven and active person. The loss of activity that Riley describes here can be interpreted as being potentially isolating and, activity wise, Riley seems to be fluctuating between his previous pre-illness identity and his new illness identity but at the same time recognising that he is presenting *'a self divided'*.

So Riley has to manage this *'self divided'* by balancing being the busy, active person that he feels he is and the new 'ill' Riley who has to be inactive, quiet and disciplined in order to maintain his overall health.

In the following extract Dina also talks about how ME/CFS and becoming particularly recovered has affected her sense of self and led to her managing a divided identity.

Extract 6.3:3 Dina (Group 2- partially recovered)

1   horrible to look back sometimes y' know because

2   erm well I have learned to live with it I suppose

3   and psychologically I didn't think it had affected me

4   but a couple of years ago I thought I'm so angry now

5   that this has robbed me of what could have been a career y' know

6   as a profession I just now I do it occasionally

7   but I can't possibly do the work that I could have done

8   if I had been 100% well at the age I was at sort of thing and so on

9   and and it is very frustrating now to think that y' know

10   other other not necessarily friends but my peers have gone on

11   to do certain things because they didn't have y' know

12   the seven years out of their life y' know where they had to rest

13   most of the day or whatever and therefore had to give up work

14   and they just carried on erm and they are now looking forward to

15   comfortable pensions in retirement and I'm not and that irks me

16   ha ha erm y' know erm coz I think well Neil has been so good

17   but I can't now suddenly go into a well paid full time job

18   and pay him back I can't do it

(Dina, data set 1; lines 432-446)

Dina is talking about the ongoing psychological impact of having ME/CFS here as she reflects on how having the illness has impacted on her life, she suggests that doing this is not a pleasant experience saying "it's horrible to look back" (line 1) She talks about her realisation that ME/CFS has an ongoing psychological impact on her as well as presenting a biographical disruption to her employment saying "this has robbed me of what could have been a career" (line 5). The way she describes this is telling because it implies that her right to have the career that she wanted has been unfairly and unduly taken away from her because of her illness.

She goes on to suggest that even though she is now 90% recovered she "can't possibly do the work that I could have done" (line 7) which suggests that there is an ongoing biographical disruption and Dina is still unable to be the person that she wants to be and that she has to manage the disappointment of not being able to reach her potential. She highlights the contrast between the future prospects of her peers and herself to demonstrate that there are both current and future repercussions to her life and identity as she says her peers are "looking forward to comfortable pensions in retirement and I'm not and that irks me" (lines 14- 15). It seems that she is facing a different type of retirement to the one she envisaged. Despite being able to manage a 90% recovery, Dina's self is divided. Her ability to be who she wants to be is continually stifled by her ME/CFS although she is partially reacquainted with her previous identity through being able to work in a different capacity.

Dina seems to have *'a self divided'* that on one hand appears very capable of a normal life but on the other she realises that she can never become the person that she may once have been.

This theme shows that pwME/CFS and people in partial recovery experience a continual conflict between their intrinsic sense of self which could be construed as who they perceive themselves to be and an illness self where they are obliged to act differently. From the way they describe their experiences it seems that their sense of self is divided between the type of person they think they *could* or *should* be and the type of person they have to be because of their illness. What is interesting about this analysis is that the self is *divided* rather than the participants presenting dual identities as previous research (Asbring, 2001; Clarke & James, 2003) has suggested. This finding reflects the participant's sense of self is still there but becomes divided in order to accommodate the needs of the illness.

The final theme focuses on how people perceive their identity to change when they become fully recovered from ME/CFS.

6.4 A return of health, a return of self

This theme explores an area that has been neglected in the literature, to date, that is, how people describe the effect that recovery has upon their identity. In the first extract below Janet is talking about how her full recovery has affected her life.

Extract 6.4:1 Janet (Group 3- recovered)

1   I think it irritates Mark [husband] at times because

2   erm yeah I want to do everything ha ha

3   so he'll say slow down woman y'know erm

4   but I've obviously got a lot of catching up to do, haven't I?

5   So I think I do irritate him at times [laughter] but yeah, yeah, it's great

6   I can do all sorts which I couldn't have done before

 (Janet, data set 1; lines 633-640)

Janet implies that she has experienced another dramatic step-change following her recovery because it is such a distinct contrast to her illness identity. She suggests that she once again has boundless energy and the capacity to participate in things to such an extent that others have to tell her to "slow down" (line 2). She also talks about having a "want to do everything" (line 2) which resonates with the natural instinct that pwME/CFS and those who are partially recovered describe struggling with in theme 6.3 above. The way that she describes her identity seems to hint at supernormal qualities as she says "I can do all sorts which I couldn't have done before", which suggests that not only has she returned to a restored self but possibly even a better version of her former self. This accords with Charmaz's (1987) concept of a supernormal identity whereby ill people aspire to be enhanced versions of their former selves, if, and when they recover. It also implies the pwME/CFS do not reject their pre-illness identity and may suggest instead that it remains something that they may return to if they can recover.

It seems that Janet is making up for lost time here and trying to readdress the biographical disruption caused by becoming ill in the first place as she says "I've obviously got a lot of catching up to do, haven't I?" (line 4). She also suggests that the transition into recovery is not entirely smooth as she hints that a second step-change in identity to that of a busy, pro-active person seems to have a disruptive impact on those around her.

Jack also talks about how different his life has become since he has recovered and in the extract below he is describing how his ability to do everyday tasks has improved.

Extract 6.4:2 Jack (Group 3 – fully recovered)

1   I have got the most energy I have had as in proper energy

2   coz I used to use a lot of caffeine when I was at uni

3   and I was waitering 70 hours a week and always that fatigue

4   in the back ground y'know that Oh my God I've gotta get up

5   I have got the most energy since I was 16

6   not like a 16 year old necessarily but as a 37 year old

7   with the amount that I can do now without having that hangover feeling of

8   exhaustion or the headaches or the pain

(Jack, data set 1; lines 815- 821)

Jack talks about having "the most energy since I was 16 (line 5) which hints that a further step change has occurred since he has recovered. This is a thought-provoking interesting statement as many ME/CFS sufferers talk about feeling that they have aged prematurely because their energy levels and capabilities seem more akin to those of elderly people, yet Jack suggests that recovery invokes the other extreme, feelings of having youthful energy. He appears to propose that energy has different levels as he refers to "proper energy" (line 1) which appears to be the ability to take part in activities without using artificial means to boost his abilities. He later implies that he is able to use the energy without suffering from the ME/CFS symptoms (lines 7 and 8). He seems to measure the extent of his recovery by "the amount that I can do now" (line 7) and it seems that being able to engage in activity without any repercussions is perceived to be more indicative of 'who he is' and he is able to manage a lifestyle that allows the return of the self.

Jack seems able to return to a self which is very similar to how he used to be which Carricaburu & Pierret (1995) argue is a crucial element of creating a successful new identity. However, what is strikingly different here is that rather than creating a new identity, Jack seems to be saying that he is returning to who he used to be before he became ill in a sharp contrast to the established view on identity and illness.

In the following extract Eve is talking about the things that she is now able to do following her recovery from ME/CFS.

Extract 6.4:3 Eve (fully recovered from ME/CFS)

1   I live on the top of a very steep hill here

2   all of my neighbours get the bus I walk up the hill every time

3   and I love it every time I'm like YEAH I can walk up the hill!!

4   ha ha brilliant so I'm like striding up the hill at top speed

5   people are like looking at me

6   as I stride past them beaming my head off

7   y' know they are like this mad woman who is she?

8   Ha ha because yes it feels good to be moving y' know

9   I was very physically active before

(Eve, data set 1; lines 1551-1557)

Eve suggests that she is able to engage in levels of activity since her recovery which other people cannot: "all of my neighbours get the bus I walk up the hill" (line 2). She emphases how committed she by describing the hill as being "very steep (line 1) and making it clear that '*all*' her neighbours get the bus apart from Eve who walks "*every time*" (lines 2&3). She also proposes that managing this is both effortless and enjoyable as she says "I stride past them beaming my head off" (line 5).It seems she perceives being able to walk up the hill as testament to her recovery as she says "I love it every time I'm like YEAH I can walk up the hill!!" (line 3). It can be construed that her ability to do this reaffirms that she has indeed recovered as she was "very physically active before " (line 9) and it is possible that the level of activity is more akin to her sense of self as a busy and active person.

It seems that Eve also did not reject her pre-illness identity and seems to suggest that becoming well is represented by being able to do things that she has not been able to do since she became ill.

It appears that becoming fully recovered presents participants with a further step-change to their identity as they become able to engage in the type of activities that they used to do before they became ill without being constrained by the restrictions of having ME/CFS. They describe being able to do 'all sorts' (see extract 6.4:1), having 'proper energy' (extract 6.4:2) and that it 'feeling good to be moving (see extract 6.4:3) which suggest that they once again experience what it is like to be themselves. This is interesting because it suggests that recovery is represented as being physically capable. However there is also a hint that the transition from being ill to a full recovery may not be smooth as it may prove to be disruptive

to what has become 'normal' (Janet 6.4:2). In terms of the previous literature this is uncommon because Clarke & James (2003) suggest that pwME/CFS completely reject their former pre-illness identities and other chronic illness literature states that a 'loss of self' is an inescapable feature of the illness experience (Charmaz, 2003). It seems here that the participants perceive their sense of self as something that they can resume once the ME/CFS has gone. In terms of the social representations of health and illness for these participants health is represented as once again being able to engage in activities that they used to do. Health is returning to what they used to be. These findings reinforce the notion that illness is seen as an external event that the person is unable to do anything about (Murray, 1990).

6.5 Summary

The analysis in this chapter has focussed on how the illness identity and representations of illness were constructed by the participants at different stages of the journey from pre-illness to after 'recovery'. It has yielded some findings that to date have not been recognised in the current literature.

The participants' construction of their pre-illness identity in the first theme, *'The self propelled self'* were intriguing because their descriptions seemed to reflect Charmaz's (1987) description of a supernormal identity. Previous authors have noted that pwME/CFS claim to have led frenetic lifestyles before becoming ill but claim that these have been exaggerated in order to counter any claims of laziness or malingering (see Horton-Salway, 2001, Wesseley, 1999). However these findings suggest that the participants view this, often extraordinary, level of activity as 'normal' for their pre-illness selves and it is representative of them being in good health. So rather than being something that is aspired to in the future, as is argued to be the case with other chronic illnesses (Charmaz, 1983; Yoshida, 1993), the participants in this study construct this as a representation of 'who I was'. This new perspective perhaps gives an insight into how being 'healthy' or 'well' is socially represented for pwME/CFS.

In terms of identity it was found that participants in this study did not reject their former self as Clarke & James, 2003 argue nor do they play down their former accomplishments as Baumeister, Tice and Hutton (1989) suggest. Instead, it has been found that clearly expressing an elaborate account of how accomplished and successful 'I was' appears to be of

paramount importance. This helps to construct the individuals as people who had a lot to lose by becoming ill and helps to construct the illness as a surprising, devastating event.

Theme 2, *'self under siege'* highlighted the step-change between the pre-illness and illness identity. The analysis presents the notion that although participants are unable to engage in activities that reaffirm their identity (such as employment, sport, leisure, socialising) their sense of self is suppressed rather than lost. The way that the participants describe this illustrates that their sense of self becomes temporarily inaccessible as if it is held under siege by the ME/CFS symptoms. The analysis also conveys the impression that identity is dormant or suppressed rather than lost (see Charmaz, 1983), or adapted into a new identity (Clarke & James, 2003; Whitehead, 2007), which is a new concept for ME/CFS. In fact the participants' identity seems to be ambiguous.

'A self divided', explored the participants' experiences of negotiating a balance between a 'normal' life and illness behaviours. The above analytical findings represent the development of a new model of identity for this stage of ME/CFS as rather than just being a cycle between ill and well identities as Asbring (2001) has suggested, the participants seem to present their *'self divided'.* It seems that although they are able to do some things that are similar to what they used to do they are constantly aware that it is not quite the same. In other words, what they can do falls short of what they were previously capable of and what they may have been capable of if they had never had ME/CFS.

The final theme *'A return to health, a return to self'* explored how participants perceived their identity in recovery and presented an analytical focus on a previously unexplored and neglected area in the literature. It seems key to note that for all of the participants '*A return to health, a return to self'* seems to involve being able to return to their pre-illness 'old self'. This is demonstrated by Jack (extract 6.4:2) and Eve (extract 6.4:3) who both drew comparisons with activities that they used to do and they seem to suggest that being able to do them is indicative of a recovery. The findings of this theme are also supportive of the findings in *'The self under siege'* (theme 6.2). Both themes propose that participants construct their sense of self as being held 'under siege' by the illness and once they become well they are able to resume their sense of self again. It also appears that they are once again

capable of an extraordinary level of activity as both Janet (theme 6.4:1) and Eve (theme 6.4:3) talk about engaging in activities that supersede those of other people.

Of course it is impossible to gauge how true or otherwise this may be but it has a number of implications in terms of the chronic illness literature. Firstly it implies that a loss of self (Asbring, 2001; Charmaz, 1983) is not always a part of the experience of becoming ill and instead presents the possibility that people can protect their sense of self whilst they are ill. Secondly, it strongly implies that pwME/CFS do not always reject their pre-illness identity. The analysis presented in *'The self propelled self'* (theme 6.1) presents the idea that their pre-illness identity is important to the participants and that they retain a strong sense of who they were because it seems to make up who they intrinsically believe themselves to be. It seems that their integral sense of self is somehow protected during the experience of being ill with ME/CFS as suggested in *'Self under siege'*. Partial recovery seems to denote *'a self divided'* whereby it becomes possible for pwME/CFS (Group 2) to reconnect with their pre-illness identity for periods of time but it is also necessary for them to engage with their illness identity.

In *'A return of health a return of self'* it seems that they can reconnect with their sense of self and do things that they used to do which may indicate that it is facilitative for sufferers to retain this strong sense of who they were. It is worth mentioning here that these findings may suggest that encouraging people to formulate positive new identities and create new ones may not always be in their best interests because it seems that holding on to this sense of themselves is actively doing things for pwME/CFS.

Although this small sample cannot be considered representative, the findings are important because it demonstrates that identity related issues arise from pre-illness through to recovery, whereas the majority of focus tends to be upon the 'illness-identity'. It is argued here that the heavy emphasis on the importance of 'who I was' seems to inform representations of being 'well', rather than merely being a way to negate any perceived criticisms (Horton-Salway, 2001, Wesseley, 1999). It also appears to be a focus for the participants as returning to this 'supernormal self' is the epitome of recovery, as being unable to return to this leaves the impression that the identity is stranded and dormant. By

imparting an awareness of these issues it is hoped that pwME/CFS and recoverees can be better supported by service providers.

Chapter 7

Ghosts of ME/CFS: Past, present and future: A longitudinal view.

Introduction

This final analytical chapter draws upon the longitudinal aspect of this research and focuses entirely on the follow-up interviews (Data set 2), which were conducted a year after the initial interviews. It explores how the participants themselves perceive their ME/CFS to have changed over the course of a year. This includes accounts from people who are claiming a full or partial recovery, a stage of ME/CFS that has been excluded from literature to date.

It has been noted in Chapter 2 that investigating concepts such as 'improvement' or 'recovery', in terms of ME/CFS, is difficult and can be considered as being controversial and it seems to date this is something that has been omitted from research. Some of this difficulty stems from ME/CFS's status as a chronic illness, as chronic illnesses are, typically, constructed as being lifelong conditions by the medical profession and many, such as Rheumatoid Arthritis (Bury, 1986) or Parkinson's Disease (e.g. Olanow & Tatton, 1999) are associated with being progressively degenerative over time (Bury, 1986). The nature of this type of condition means that long-term improvements in health or 'recovery' are not perceived to be medically possible which makes it difficult to compare with ME/CFS. It is also difficult to draw comparisons between the experiences of pwME/CFS who are claiming improvement or recovery and people suffering from diseases that have a definitive medical basis such as cancer or Multiple Sclerosis because there are no biological markers to confirm the presence or absence of ME/CFS. It seems that recovery from ME/CFS is similar in nature to 'recovery' from alcoholism or mental health conditions because it is reliant on the individual to self-monitor and report their state of heath. Yet, all of these remain problematic as ME/CFS is different because it is regarded as having both a psychological and physiological component to it (Hossenbaccus & White, 2013). This means that the participants' subjective experience of ME/CFS may include elements that are consistent with the experiences of people from each group, those with degenerative conditions and other 'invisible' illnesses. This chapter recognises that the concepts of 'improvement' or 'recovery' are problematic, but does not attempt to align the participants' experience with any

particular domain. Instead, the primary concern is to explore how the participants talk about their experiences and how they describe changes in their illness such as 'improvement' or 'recovery'.

As discussed in Chapter 2, longitudinal research focusing on people who are ill with ME/CFS has shown that the illness is characterised by intermittent periods of relapse, followed by remission (Crowhurst, 2005; Jason, Bell, Rowe, van Hoof, Jordan & Lapp, et al, 2006; Shepherd, 1998). It was also noted that gathering information about peoples' experiences and the illness course of ME/CFS was problematic for a number of reasons. Firstly, because the use of diagnostic criteria has been inconsistent, which may have inadvertently caused an overlap between ME/CFS and other illnesses. This means that data collected may not relate specifically to pwME/CFS. Secondly, there is no way of medically verifying that a person has recovered from ME/CFS and instead this is reliant on a person's self-reports. Thirdly, in the UK, it seems unless pwME/CFS are being treated by the NHS, the progress of their condition over long periods of time is not recorded. Fourthly, even on programs that have been reported to facilitate recovery, how and when medical professionals' follow-up with pwME/CFS to monitor their progress overtime is not consistent between studies. This latter point is particularly relevant to Cognitive Behavioural Therapy treatment programs, where a certain criterion, such as returning to education or employment (Knoop, Bleijenberg, Gielissen, van der Meer, White, 2007), maybe presented as being representative of a 'recovery'. This type of research neglects the participant's subjective experience of what they understand an improvement in their condition, or a recovery, to be and how they subjectively experience it.

The previous analytical chapters have already illustrated that many participants are extremely pro-active in their attempts to manage their ME/CFS. They have described adopting a methodical approach to researching potential treatments and therapies and devise their own ways of 'treating' their ME/CFS. In other words they have a self-driven approach towards finding ways of managing the illness. Some participants claim to have fully or partially recovered through using these techniques, yet the true extent of improvements or recovery which occurs outside the realms of the medical profession is unknown as there is no consistent method of collecting the data. Moreover, little is known about how pwME/CFS

understand the concept of improvement or how 'recovery' endures over time for people who use a self-directed approach, which means that there is a substantial gap in the literature.

Some previous longitudinal ME/CFS research has focused upon issues such as how identity changes over time (Whitehead, 2006) or the role of biographical disruption (Asbring, 2001) and, as discussed in Chapter 2, shows contradictory findings. Asbring (2001), for example, found that pwME/CFS fluctuated between having an illness identity and a pre-illness identity, whereas Whitehead (2006) found that pwME/CFS did not desire to return to a pre-illness identity and formed new 'positive' identities after a period of time instead. It is worth noting that these previous studies focused only on pwME/CFS[53], whereas the present research has purposefully also recruited people claiming a full or partial recovery. It is envisaged that this will expand what is known about the subjective experience of being in 'recovery' from ME/CFS and provides the opportunity to gain a unique insight into a further dimension of this contested condition.

Therefore the purpose of this chapter is to explore how participants themselves perceive changes to their health over a 12-month period and to analyse what this means for them, and it will draw upon the findings of the previous chapters. Six of the selected participants were available to be re-interviewed. Although, for reasons explained in chapter 3, the sample group is small for this chapter adding a longitudinal perspective is argued to be beneficial. Dickson, Knusson & Flowers (2008) note that it is advantageous to conduct interviews longitudinally in order to highlight how ME/CFS fluctuates and changes over time in response to life events. This aspect of research deliberately targeted people who appeared to be approaching a state of fluctuation, such as moving house or moving jobs. The participant's descriptions of their health are interesting and relevant.

The interviewees were Jack who is fully recovered (Group 3), Dawn and Sally who are partially recovered (Group 2) and Petra, Amy and Ruth who are pwME/CFS (Group 1). The analysis below presents four themes: The first of these, '*For better, for worse*' explores how

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[53] Asbring's (2001) sample was women only. Whitehead (2006) employed a mixed sample and the second round of interviews contained a small sample of people claiming to have 'recovered' from ME/CFS during the interim period.

the participants describe things that have happened over the past year and how they perceive their health to have changed. The second theme, *'Re-emergence of 'me'* focuses on how the participants talk about their on-going struggles with ME/CFS. In the third theme, *'Living with shadows of Men*the participants talk about how their lives still continue to be affected by ME/CFS even in full or partial recovery. The final analytical theme, *'To talk or not to talk'* explores how the participants talk about their illness and recovery with other people in an everyday context.

7.1 For better, for worse

In the analysis below, the participants are talking about their how their health has impacted upon their life over the past year. Petra has already spoken about recently realising that she was not able to manage her fulltime working hours as well as studying part time and her subsequent decision to reduce her working hours.

Extract 7.1:1 Petra (Group 1 - pwME/CFS).

1   I think it [ME/CFS] has been slightly worse yeah definitely

2   I can tell when I do too much I have to go back to

3   the pacing and planning and prioritising

4   y'know when I get do too much I do suffer for a few days

5   it wasn't as though I wasn't happy to do as much

6   but I couldn't do as much and I have had to give up

7   because of the things that I do outside of work

8   yeah but I need to get the balance right and I haven't

(Petra, Data set 2:lines 68-73)

Petra describes her ME/CFS as being "slightly worse" (line 1) than it was at the same time last year and she places this in the context of the level of activity that she is able

to do. She talks about experiencing repercussions for doing "too much" (lines 2 &4) and not being able to "do as much" (lines 5 & 6). Her emphasis on 'doing' suggests that she is a naturally busy and active person, despite being increasingly unwell. In other words, it seems that she is still managing on-going challenges to her identity as she talks about having to behave in a manner that contradicts her view of 'who she is'. From her description, it seems that her identity may be under siege as participants have previously described (see theme 6.2).

It is also notable that her perceived deterioration in health since the last interview seems to cause a further disruption to her life and her sense of self too as she says "it wasn't as if I wasn't happy to do as much" (line 5), which infers that reducing her activities was not something that she chose to do, but rather that she had to do. The way that she says "I have to go back to the pacing and planning and prioritising" (lines 2 & 3) is presented in a monotonous tone, which further stresses that she finds it difficult and tedious to curtail her activities. It also implies, that for Petra, a period of good health would mean that she does not have to rely on these techniques and that she can manage without them.

Tellingly, Petra also says "I need to get the balance right and I haven't" (line 8) and it seems that she is managing the same sort of issues that pwME/CFS have spoken about before, specifically the difficulty in striking a balance between necessary illness behaviours and participating in 'normal' life. Her description of this is similar to Asbring's (2001) finding, that pwME/CFS rotate between pre-illness and illness identities. However, it also appears that a change in her condition for the worse has influenced this situation and caused further disruption to her life and she is struggling to find an effective way of managing it.

In the following extract Amy, who is ill with ME/CFS, is talking about how she perceives her health and her level of activity to have changed over the past year.

Extract 7.1:2 Amy (Group 1- pwME/CFS)

> 1   I think I'm probably a bit better at not doing too much

2   mmm I don't know I have to think about it

3   I'm thinking am I really?

4   I don't know [laughter] the thing is one of the things

5   that they say is you should really save fifty to seventy percent

6   of any of your energy on any given day

7   and I think I probably still do as much as I possibly can

8   and probably don't rest as much as I should

9   I think I don't know if I'm really y' know maybe I was worse

10   but I'm still I don't know very difficult to judge really

(Amy, Data set 2: lines 46-54)

One of the striking things about this extract is the level of uncertainty that Amy expresses throughout when she is talking about her the status of her health as she adds "I don't know" (lines 2,4,9 & 10) whenever she is talking about it. She also negates any degree of certainty over what she does to manage her condition by preceding it with "probably" (lines 1, 7& 8). As well as presenting uncertainty this may also illustrate that Amy finds ME/CFS confusing, particularly as she goes on to say she is "probably a bit better at not doing too much" (line 1), yet immediately questions herself by saying "am I really?" (line 3). It seems that her uncertainty arises because the way that she manages to 'do' things (lines 7 & 8) contradicts "one of the things that they say" (lines 4 & 5). She may be referring to lay and some medical advice here, which suggests that pwME/CFS should conserve energy by doing less than they feel capable of, yet despite her awareness of this she says "I think I probably still do as much as I possibly can" (line 7).

This may suggest that Amy is still naturally pre-disposed to being busy and active and, rather like Petra (see extract 7.1:1), she remains unable to be herself because of her ME/CFS. This also indicates that she finds it difficult to maintain a balance whereby she is able to maintain her activities and manage her illness effectively. It appears that she

is experiencing an internal battle here as she seems to revert to her pre-illness way of doing things and using all of her energy even though she knows that this is not the right thing to do.

In the next extract Dawn is describing how her life has changed over the past year. Dawn described herself as being 90% recovered during the first round of interviews and now, one year later, says that her ME/CFS has improved and that she now considers herself to be 99% recovered.

Extract 7.1:3 Dawn (Group 2 - partially recovered)

> 1   Up and down I suppose yeah but more up than down
>
> 2   if you know what I mean?
>
> 3   I'm kind of getting tired because I'm doing more
>
> 4   not because I'm not well and that's quite a big difference
>
> 5   yeah I mean y'know I'm back working kind of eight-hour days
>
> 6   but only kind of once or one or two days a week
>
> (Dawn, Data set 2: lines 3-6)

Dawn says that her health has been "up and down... but more up than down" (line 1) over the past year suggesting that she has still been experiencing periods of relapse and remission, but overall, considers her condition to have improved. She explains that she is "getting tired because I am doing more not because I'm not well" (lines 3& 4), which suggests that she is now attributing her tiredness to factors that are unrelated to her ME/CFS. Instead she constructs her tiredness as being a normal, expected consequence of being "back working...eight hour days" (line 5). It appears that she contradicts herself by saying that she manages to work "once or one or two days a week" (line 6). What is important here is Dawn's emphasis on rejecting any notion that

her tiredness may be due to her illness and the intense importance she places on returning to work which is a contrast to the way Amy (extract 7.1:1) and Petra (extract 7.1:2) talk about this above. Some of the other issues that she mentions, such as the illness being 'up and down' and struggling with tiredness, are commonly raised by pwME/CFS and it seems here that they remain a consistent feature of partial recovery which is intriguing. It would appear that these issues are still disruptive to Dawn's life and that she still has a liminal status because, although she is well enough to work, she is not well enough to work full time.

The way that the participants talk about their health over the past year is worthy of note because their descriptions concur with suggestions that the illness is characterised by periods of relapse and remission (Asbring, 2001; Shepherd, 1988). However, along with changes in their physical condition, it is apparent here that the participants are also continually managing biographical disruptions, challenges to their identity and a liminal status. In addition they are talking about how they attribute symptoms such as tiredness which are associated with ME/CFS and it seems that there is a difference between how people in recovery and pwME/CFS go about this. It is notable that the issues that the participants talk about remain the same regardless of whether or not they perceive their health to have changed 'for worse', like Petra (extract 7.1:1), unchanged like Amy (extract 7.1:2) or changed 'for better' like Dawn (extract 7.1:3). It reiterates the findings in previous chapters, suggesting that ME/CFS continues to be difficult for the participants to manage.

In the following theme the participants talk about their identity and sense of self over the past year.

7.2 The re-emergence of 'me'

The following analysis highlights how participants talk about 'me', in terms of their identity, their sense of self and their illness. The previous chapter (Chapter 6) showed how ME/CFS causes a range of identity related dilemmas and challenges what the

participants have to manage. The following analysis looks at how participants talk about their identity over the past year.

Extract 7.2:1 Dawn (Group 2 - partially recovered)

1   I think it's probably more likely that my condition has changed

2   and that because my condition because I can do more

3   I'm more relaxed about having days when I can't do so much

4   because I'm back at work I think

5   'Well no I'm working so I need to be careful'

6   so the days when I'm having a restful day

7   psychologically I think I'm coping with them a bit better

8   because I'm offsetting them against days

9   when I'm what I would call 're-creating' my adult identity

10   as someone who is working and who is valuable in that way

11   which for a long time was a cause of great stress [laughs] for me

12   when I didn't wasn't able to work

(Dawn, Data set 2: lines 99-113)

Dawn talks specifically about her ability to manage being partially recovered by saying "when I'm having a restful day psychologically I think I'm coping with them a bit better" (lines 6 & 7). This suggests that she has experienced a positive improvement in her mental health, alongside a change in her physical condition. Her wording of having a 'restful day' is intriguing here, as it very much implies that having a restful day is something that Dawn has actually chosen to do rather than being forced to have a restful day. She goes on to explain this further saying that she is "offsetting them

against days when I'm what I would call recreating my adult identity" (line 8 & 9). This is quite a profound and thought-provoking thing for her to say as it suggests that she was prevented from accessing her identity whilst she was ill. She specifically mentions 're-creating', (line 9) which partly portrays her identity as something that has been re-discovered and concurs with the notion that it has been lying dormant or under siege whilst she was ill (as discussed in Chapter 6). However, it also suggests that her identity is something that she has to work on, it has not progressed and needs nurturing, refreshing or rebuilding.

It is also of note that Dawn uses the term "off-set" which draws upon the financial terminology that pwME/CFS have been noted to use when they try to explain their illness to others (see Chapter 4). In financial terms 'offsetting' refers to maintaining a financial balance by countering one transaction with an opposing transaction of an equal value, which seems very apt for how Dawn describes the management of her ME/CFS here.

She also talks about becoming "someone who is working and who is valuable in that way" (line 10), which implies that she previously felt devalued because she was ill and was unable to work. It seems here that although she is not completely well, Dawn is able to maintain a balance between a need to have 'restful' days and 'working', which appears to provide a positive psychological effect. It seems that she is able to manage her ME/CFS more effectively, which in turn means that she has become partially reconnected with 'me' through being able to work which appeals to her sense of who she intrinsically is. Being able to work also provides her with a basis from which it is possible to manage the process of re-creating her 'adult identity'. This is quite an unusual way to look at what happens to someone's identity when they are ill and it seems to concur with the notion of 'being under siege' (see theme 6.2) as Dawn's identity seems to have been stagnant while she was ill but now she needs to re-create her 'adult identity'.

Sally, who one year later still considers herself to be 90% recovered as she was in the previous interview, talks about her reasons for feeling 'happier' in the extract below.

She has already mentioned that she changed her job ten months ago and that she now has a different role in the same company.

Extract 7.2:2 Sally (Group 2 - partially recovered)

1   I've managed to continue being a workaholic pretty much all year

2   [laughs] but I crash out at the weekend

3   so I sort of manage that balance

4   so I would say my career's probably as healthy as it's ever been

5   which is really nice I'm actually for me it's a good trade-off

6   it does mean that life is quite hard

7   and my weekends are for resting y'know and my holidays as well

8   yeah I think I'm happier I think I'm happy with the trade-off

9   I do remember this time last year being quite unhappy

10   and just being quite daunted and overwhelmed by the volume of work

(Sally, Data set 2: lines 36-43)

Sally begins by saying "I've managed to continue being a workaholic pretty much all year" (line 1), immediately suggesting that Sally's 'me' and sense of 'who she is' has remained the same. She has previously explained how important working full time is to her and the considerable sacrifices that she makes in other areas of her life, such as leisure and socialising, so she can do this (see theme 6.2). By describing herself as a 'workaholic', she is suggesting that her devotion to work is extreme and this reaffirms that to Sally, working is very important to her identity and her sense of self. She goes on to say "I crash out at the weekend" (line 2) which is an equally dramatic account of

her need to rest. From her description it seems that Sally fluctuates between the identities of being ill and being well as Asbring (2001) suggests but she is also doing something different by deliberately compartmentalising two areas of her life. She clearly states that she is doing this by saying "it does mean that life is quite hard and my weekends are for resting...and my holidays as well" (lines 6 & 7). By using a three part list here[54]Sally appears to be providing a convincing account of how devoted she is to working and the considerable sacrifices she has to make in order to manage to maintain a working life which may dispel any indications that she is lazy and reinforce her claim to be 'workaholic. However, her description also suggests that her life is still considerably disrupted because she is unable to work *and* maintain social and leisure activities.

Sally presents a sharp contrast to the disruption that she talks about above by saying "my career's probably as healthy as it's ever been" (line 4). Her use of the word 'healthy' is worth noting here because it suggests that health is focused elsewhere and that one aspect of her life can be regarded as 'healthy'. She talks about her lifestyle saying "for me it's a good trade-off" (line 5) and that she thinks she is "happy with the trade-off" (line 8). What is noticeable about this is that Sally's ME/CFS itself seems to remain the same, as she is still talking about having to "manage that balance" (line 3), yet she also reports feeling 'happier'. Her use of terms like 'trade-off' and 'balance' once again draws upon the financial terminology that Dawn (see extract 7.2:1) and other pwME/CFS use to explain how they manage their 'reserves' of energy and the need to engage in certain activities (see Chapter 4. 4.3)

In this extract Sally seems to be referring to her balance as being between sacrificing a social life in favour of working and being able to target her limited resources towards making sure that she is well enough to work as 'normal'. In both Dawn's (extract 7.2:1) and Sally's case it seems that being able to maintain a suitable balance between their

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[54] Jefferson (1990) argues that speakers use three part lists in order to construct a convincing account of their version of events.

working and social lives is important to them and has a positive effect on their sense of self.

It seems that Sally is able to devote more time and attention to her working life, and it may be that this has a positive effect on her identity. She talks about her career being 'healthy', which seems paradoxical because she still seems to be experiencing a significant on-going disruption to her social life. Like Dawn (see extract 7.2:1), Sally's experience can also be interpreted as being liminal because she is unable to work full time without experiencing the disruption to her life.

In the next extract Jack talks about how he has continued to manage his full recovery over the past year.

Extract 7.2:3 Jack (Group 3 - fully recovered)

1   I mean I think when you talk about things

2   like my thought patterns as in I'm you know just want to be perfect

3   just want to live an never let anyone down so all those things

4   like my personality traits still exist

5   but maybe I can just operate slightly below perfection

6   yeah or whatever y'know I can just sort of let

7   maybe a few things will slide or it's just not that important

8   I get it done today I don't know if that's just age now

9   that I'm y' know ten years on yeah y'know

10   but I mean I'm just fine I'm fully I'm better I'm not ill

(Jack, Data set 2: lines 30-37)

Jack talks about the type of person he aspires to be suggesting that he wants to be perfect and to "never let anyone down" (line 3) and "all those things" (line 3). He

seems to further imply these characteristics are representative of the way he has always been as he says "my personality traits still exist" (line 4), suggesting that his personality has survived the experience of having ME/CFS. This could be interpreted as him wanting to be dependable, reliable and well liked or that he is trying to somehow retain these characteristics and continuity with his sense of self. He appears to be emphasising how important these characteristics are to his interpretation of 'who he is' and they also concur with the way that pwME/CFS talk about having a driven and active approach to life before they become ill (See Chapter 5.5.1).

So it seems that Jack is suggesting that he has returned to being 'me' since recovering from the ME/CFS but at the same time becoming well and being 'me' also seems to present him with some problems to be managed saying that "maybe I can just operate slightly below perfection" (line 5) and "maybe a few things will slide" (line 7). The use of 'maybe' suggests that he is not yet entirely confident in his ability to do this. It also possibly implies that he is not actually completely recovered and that he still has to be careful about his activities in order to remain well. However, Jack seems to defend himself against any such perceived criticisms by inferring that his reduction in activities is normal in relation to his age as he is "ten years on" (line 9) rather than being in any way related to having ME/CFS. This is important because it denotes that he has a different interpretation of these events to the other participants which may be connected to his ability to state "I'm just fine I'm fully I'm better I'm not ill" (line 10). It is intriguing to note that Jack is managing any perceived criticisms of his claim to be recovered and it seems that he has a quandary, because admitting any reduction in his activities could be interpreted as a sign that he is not fully recovered.

The way that the participants specifically talk about an "adult identity" (Dawn 7.2:1 line 9), being "a workaholic" (Sally 7.2:2 Sally, line 1) and about "personality traits" (Jack extract 7.2:3 line 4,) places their 'identity' and their 'sense of self' at the forefront of their experience. It seems that they are describing the 'return of me' as they talk about being able to do things which are consistent with their interpretations of 'who they are'. There are some unusual features emerging from this analysis.

Firstly, it seems that the participants construct their identity and sense of self as something that has always been there, but was previously temporarily inaccessible because of the ME/CFS; now, as they are partially or fully recovered, they can access it again. Dawn's (extract 7.2:3) account of this is fascinating as she seems to suggest that her identity has been still and stagnant whilst she had ME/CFS and now she has partially recovered it is something that she needs to nurture and 're-create'. The notion that identity is under siege, suppressed or stagnant whilst people are ill with ME/CFS has already been presented in Chapter 6. However, Dawn's description above highlights the next stage of how pwME/CFS begin to orchestrate *'the re-emergence of me'* and reconnect with their pre-illness selves.

The language that they use to describe managing a balance between maintaining a 'normal' life and managing their ME/CFS is also particularly worth noting here. They talk about "offsetting" (Dawn extract 7.2:1, line 8), having a "trade-off" (Sally extract 7.2:2, lines 5 & 8) and a "balance" (Sally extract 7.2:2, line 3). The use of such financial metaphors has already been noted in Chapter 4 as a regular feature used by pwME/CFS in order to explain the effects of their illness to others and such metaphors are still key and used in order to explain how participants come to terms with their 're-emerging me'.

The implication is that managing their partial recovery is far from being straightforward and requires a constant input from them in order to get the balance right. PwME/CFS may for instance, defend themselves against any perceived accusations of malingering or being lazy and stressing the impact of ME/CFS. Jack is doing the opposite here as he emphasises that any restrictions on his activities have no relation to him once being ill with ME/CFS and instead proposes that they must be due to some other factors such as he says being ten years older. The attention is attributed elsewhere, it is not focused on the illness itself, thus it seems that like Dawn (Extract 7.2:1) being able to attribute symptoms that could be associated with ME/CFS elsewhere seems to allow him to suggest that he has 'recovered'.

The above analysis indicates that the way the participants describe their experiences here is consistent with the notion that their identity and their sense of self have been liberated from being *under siege* and they are able to begin to return to who they were prior to ME/CFS. In other words their 'me' has been able to re-emerge from the illness experience. In the following theme, participants continue talking about how ME/CFS continues to influence their lives.

7.3 Living with shadows of ME/CFS

As the above analysis has revealed, participants have indicated that they are striking a balance between managing their ME/CFS and participating in a normal life. In the following extracts they go on to talk about the disruptive effects that they continue to experience despite being fully or partially recovered.

In the first extract Sally is talking about the lingering doubts that she has over her decision not to undertake 'The Lightning Process', an alternative therapy, which was becoming popular in some areas of the ME/CFS domain around the time of the interview. It is worthwhile to reiterate here that Sally manages her ME/CFS in a way that she is happy with because it enables her to work (see extract 7.2:1)

Extract 7.3:1 Sally (Group 2 – partially recovered)

1   I do sometimes think about whether I have sold myself short

2   by not doing things like the Lightning Process

3   I just don't fancy it do you know what I mean?

4   I I psychologically I it sort of doesn't really fit with my philosophy

5   and though I mean I do do other psychological work

6   to support my health definitely but I kind of look at the lightning process

7   and think 'Oh I can't be arsed'

8   and I've kind of got enough in terms of my quality of life

9   I'm very happy with it but I do I do sometimes think

10   have I sold myself short could I actually be all the way better?

11   but y' know I guess the point is

12   you pays your money and you takes your choice

13   and y'know I'm actually happy with the level I've got

(Sally, Data set 2: lines 356-367)

Sally seems to present some lingering doubts here about her choice of lifestyle as she says "I do sometimes think about whether I have sold myself short" (line 1) which she repeats again in lines 9-10. Her use of 'sold myself short' implies that she has let herself down or not been all that she may be able to be. Having the option to undertake Complementary or Alternative Medicine or Therapies (CAMT's) appears to cause Sally some conflict because on one hand she says "I've...got enough in terms of my quality of life" (line 8), but on the other hand she wonders "have I sold myself short could I actually be all the way better?" (line 10). She stresses that she does not reject things like the Lightning Process[55] out of hand, by saying "psychologically I it sort of doesn't really fit with my philosophy" (line 4) which implies that she has given it a great deal of thought and consideration.

Although she says "you pays your money and you takes your choice" (line 12), another financial type colloquialism that can be interpreted as being prepared to live with the consequences of her decision, she also stresses that she is "actually happy with the level I've got" (line 13). However, it seems that her decision not to pursue the possibility of a full recovery casts a shadow over her life by presenting her with on-going doubts about whether or not she could ever be completely well. This appears to be a re-occurring quandary for her. It seems that Sally is concerned because she can currently manage the disruption that ME/CFS causes to her life by using her compartmentalised routine of working and resting. The dichotomy seems to be that if

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[55]The Lightning Process is a psychological therapy developed by Phil Parker which is popular amongst some ME/CFS support groups. See www.lightningprocess.com

she were trying to pursue CAMTs in the hope of a full recovery it could undermine the balance between work and illness behaviour that she has worked so hard to achieve. In other words it could present a further and more serious disruption to her life which would become more difficult to manage.

In the next extract, even though she is now 99% recovered, Dawn talks about areas of her life that still remain difficult.

Extract 7.3:2 Dawn (Group 2- partially recovered)

1   So yes there are if I was being really honest

2   I would say there are days in the week where I still struggle

3   I mean otherwise I would be working five days a week if I could

4   but I can't so and there are times when obviously

5   I find it frustrating that I'm still having you know

6   but I I'm realistic I'm still playing the same game

7   but I'm just playing it in a different at a different level now

8   I'm thinking Oh well I'm driving to (location) on Monday

9   so I don't really want to go and do exercise on Friday

10   and it's that kind of level of consideration rather than thinking

11   Oh God I've got two loads of washing to do on Monday

12   so therefore I can't do the dusting today it's a different

13   it's the same decisions but it's about different a different level of task

14   so I mean that's the difference

(Dawn, Data set 2: lines 74-86)

Dawn presents a paradoxical situation here as she suggests that even though her illness has improved "there are days in the week where I still struggle" (line 2) and she says "I would be working five days a week if I could" (line 3). This is surprising in some ways as it implies that ME/CFS has a considerable impact upon her way of life and seems to contradict her claim to be 99% recovered. It is notable that the way she talks about this seems similar to the way that pwME/CFS describe the disruptive effects the illness has upon their lives and it appears that Dawn herself is aware of this when she goes on to say "I'm still playing the same game but I'm just playing it...at a different level now" (lines 6 & 7). She seems to suggest that some things, such as being careful about how many activities she takes on, have not changed much and that she is still managing her illness and her activities in the same way she always has. Yet she stresses that as her condition is improved, she is managing "a different level of task" (line 13) and for her, this seems to be the difference between being 90% and 99% recovered.

It seems that Dawn's life is still overshadowed by ME/CFS; she still faces disruptions to her way of life and her identity, and she is very much between being ill with ME/CFS and being recovered from it. Therefore she still has a liminal status that she has to be managed and she is in a constant cycle of trying to strike a balance between being ill and being well.

In the following extract Jack, who is still fully recovered from ME/CFS, talks about how he feels he has changed over the past year and about his plans for the future.

Extract 7.3:3 Jack (Group 3 - fully recovered)

1   the only probably difference between now and back then

2   is just my confidence is back so that that's the main thing

3   so physically I'm the same but I'm just confident

4   both in my health and confidence socially

5   and financially and professionally

6   I'm raising [my] expectations all the time just sort of

7   I'm probably going back to where I always wanted to get to

8   and maybe pushing myself too hard towards that

9   I haven't got children at the moment so I think

10   I have to put in all the hard hours now

11   to try and get it sort of like catch-up

(Jack, Data set 2: lines 254-261)

Jack talks about the ways in which things have improved for him over the over the past year saying "my confidence is back" (line 2) and he outlines the positive effect that this has had on specific aspects of his life (lines 4 & 5). He goes on to explain that because of his increased confidence he is "raising [my] expectations all the time" (line 6), which suggests that he does not perceive his capabilities to be restrained by ME/CFS in any way. He says "I'm probably going back to where I always wanted to get to" (line 7), suggesting that his life is now back on track and that he is able to address the biographical disruption that was caused by becoming ill in the first place. However, there is a suggestion here that by "maybe pushing myself too hard towards that" (line 8), Jack may be causing a new form of biographical disruption, because he claims that he is able to do things without any physical limitations, although, paradoxically, he does seem to experience them (see extract 7.3:2) but he ascribes them to something else. He also talks about having a need to "catch-up" (line 11) on things that he may have missed out on by being ill, which concurs with the notion that people who are recovered from ME/CFS appear to want to engage in an extra-ordinary level of activity (see theme 6.1). It also complements the finding that pwME/CFS construct themselves as being extra-ordinarily busy before they become ill (see theme 5.1) and it seems that they want to return to this way of being again, once they become well enough.

So for Jack it seems that ME/CFS overshadows his life in a different way. For him, becoming recovered is prompting him to increase his level of activity and he is trying to make up for the opportunities that he has missed out on. Therefore, his current life is still influenced by having ME/CFS, even though in order to construct himself as being 'recovered', he emphasises that ME/CFS does not have a disruptive impact upon the way he lives his life. So there appears to be a contradiction between what Jack is saying and how the illness appears to still affect him.

From the analysis of the above extracts, it is clear that ME/CFS still has a considerable impact upon the participants' lives, even though they claim to be fully or partially recovered. The analysis also captures the various ways that the participants' lives are overshadowed by their ME/CFS and reveals issues such as lingering doubts about whether one should try to make full recovery and participants' concerns about whether or not this would be successful (see Sally extract 7.3:1). It is suggested that people in a partial recovery stage continue to face the same challenges and dilemmas, even when their abilities increase, as they are still trying to maintain a balance between managing the ME/CFS and taking part in a 'normal' life. This appears to be Dawn's experience (see extract 7.3:2), as she claims to be 99% recovered and in comparison, Jack, (see extract 7.3:2) who is fully recovered, seems to suggest that although he is no longer constrained by being ill, he is busy trying to address the biographical disruption caused by having ME/CFS in the first place, which may in turn prove to be disruptive too.

It seems recovering from ME/CFS is a complex and intricate process which, regardless of the level of recovery that they achieve the participants are never completely free of the illness. In other words, it overshadows their lives in a number of different ways.

The final analytical theme brings another difficulty that the participants experience to the fore: broaching the subject of their ME/CFS and their health with other people.

7.4 To talk or not to talk

It has already been noted in Chapter 2 that pwME/CFS typically find it difficult to talk to people about their illness because of the controversy and stigma that surrounds it. In the following extracts, the fully and partially recovered participants talk about their experiences of this.

Dawn talks below about a situation that occurred when she recently returned to work and her boss unexpectedly asked her to explain what ME/CFS is and how it affects her.

Extract 7.4:1 Dawn (Group 2 - partially recovered)

1	If you try and talk to someone who's got no experience of it
2	and hasn't really kind of looked on the Internet
3	because they don't have time they've had no reason
4	to look on the Internet they've had no reason to consider
5	it as a possibility of something that could happen
6	they just don't they don't understand and they also don't understand
7	that psychologically talking about it is hard
8	and I actually said in an email to him after he'd gone
9	I said oh I'm sorry if I preached about being unwell
10	but I it is a very difficult subject for me to talk about
11	because I feel that I fail to communicate what it's like
12	and that's really hard because I'm a very verbal person
13	as you gather I do most of the talking [laughter]
14	because you're one person you're one of the few people
15	who I've met along my journey if you like who goes
16	'oh yes I understand' and I know that you do
17	and that's why I find I mean what do you say to somebody?
18	I've been unwell for five years but I've done all these things

19   outside of work y'know

20   I couldn't drive I couldn't do this I couldn't do that

21   but there's no it's like I'm never going to be in remission

(Dawn, Data set 2: lines 337-344)

Dawn explains the difficulties she encounters when she tries to talk about her illness and her partial recovery and she points out that unless people have had some prior knowledge or experience of ME/CFS "they just don't understand" (line 6). She says that not only do they not understand her experiences of suffering from the illness, but they also don't realise that for her "psychologically talking about it is hard" (line 7).

She says "I feel that I fail to communicate what it is like" (line 11), and she goes on to describe herself as "a very verbal person" (line 12) which emphasises how incredibly difficult this condition can be to talk about, even at her advanced stage of 'recovery'. It also presents the notion that ME/CFS remains an isolating kind of illness because she is unable to explain what has happened to her and make people understand how it continues to affect her. She goes on to suggest that being able to talk to someone who knows something about ME/CFS is unusual by saying to the researcher "you're one of the few people who I've met along my journey if you like who goes 'oh yes I understand' and I know that you do" (lines 14-16).

It seems that it is explaining the contradictory nature of the illness that causes a problem for Dawn as on one hand she says "I've done all of these things outside of work" (lines 18 & 19), which infers that she is referring to sporting or leisure activities. On the other hand, she has to convey the extent to which the illness affected her by explaining "I couldn't drive I couldn't do this I couldn't do that" (line 20) and the use of a three part list here helps her to present a convincing account of the extent of her previous incapacity. So far it can be understood that Dawn's description of her illness may infer scepticism from others, but she also seems to imply that telling others that she is now almost completely recovered adds a further level of difficulty as she says:

"I'm never going to be in remission" (line 21). This may suggest that there is little she can do to convince others that she is almost recovered as, like talking about being ill with ME/CFS, she is reliant upon other people understanding the illness.

So talking about having ME/CFS and becoming partially recovered from ME/CFS is constructed as being difficult. Sally outlines her experiences of doing this in the following extract.

Extract 7.4:2 Sally (Group 2 - partially recovered)

1   I can't talk about my illness to people who have ME

2   because it's like y'know it's nothing

3   and the well people don't really understand

4   I do I do try and be open about the scale of my health issues

5   but you can tell they never really get it

6   because they look at you and think you look fine y'know [laughs]

7   so it is difficult actually talking about how it affects you

8   it's the sort of you're in the grey area in between the two

(Sally, Data set 2: lines 754- 750)

Sally seems to indicate here that being partially recovered from ME/CFS is isolating as she can't even "talk about my illness with people who have ME" (line 1) and implies that her concerns are dismissed as being "nothing" (line 2) by the ME/CFS community. It is possible to infer from this that Sally is excluded from the ME/CFS community and being in exile is a feature of the liminal experience. However, Sally goes on to say "well people don't really understand" (line 3), suggesting that she is also unable to share her experiences with well people because they are also unable to understand that she is still affected by ME/CFS despite appearing to be 'well'. She explains the problem that she faces in her working environment saying that "they look at you and think you look fine" (line 6). This is an issue that pwME/CFS commonly talk about, as the discrepancies between their subjective feelings of being unwell are not reflected in

their appearance as they look 'normal'. It seems that this issue continues to have a detrimental impact upon Sally's attempts to talk about her health.

These two extracts highlight the difficulty that pwME/CFS, a controversial and misunderstood chronic illness, have with communicating, not only with people in the ME/CFS community but with other people in their social and working lives. This adds a further burden to living with their illness. The illness is contentious at so many levels because although it is labelled as chronic it seems that recovery is possible and there is so little understanding of this concept and the process that it involves even within in the medical community it thus makes it hard to talk about and validate the illness. What is intriguing here, is Sally's explanation of why she thinks her ME/CFS is hard to talk about as she says "you're in the grey area between the two" (line 8), by which she may be referring to the two groups of people she is trying to talk to, being suspended between being ill' and being 'well' or both. So Sally is describing herself as being in a liminal situation whereby she appears to feel is isolated and excluded from both social groups, i.e. pwME/CFS and 'well' people

It seems that being partially recovered adds a new dimension to the difficulties of talking about ME/CFS, as it appears that participants become as equally unable to share their experiences with people who are ill with ME/CFS and with well people. In the following extract, Jack talks about how he broaches the subject of once being ill with ME/CFS, now that he has recovered.

Extract 7.4:3 Jack (Group 3 - fully recovered)

1   I did probably [talk about it] for the first twelve months

2   after getting better now there's no point

3   I don't even think about it anymore I mean

4   I got a bit stressed telling my girlfriend for the first time

5   because it was that was hard y' know

6   I was only really just getting back on my feet

7   first proper girlfriend since the ME

8   she thought I was going to say that I was married [laughter]

9   so it was fine and she's got no problem

(Jack, Data set 2: lines 224-229)

For Jack it seems that talking about his health and his ME/CFS is something that he no longer needs to do as he says there is "no point" (line 2). He explains that since he has recovered he doesn't "even think about it anymore" (line 3), which strongly suggests that it does not play any part in his life and that he genuinely perceives himself to be recovered. However, he also says "I got a bit stressed telling my girlfriend for the first time" (line 4) and it could be construed here that he is wary of her reaction because of the stigma that surrounds ME/CFS. There is also a suggestion here that Jack felt that he was vulnerable because of this situation. Therefore, although he no longer *has* to talk about ME/CFS, doing so is presented as being difficult and stressful and he infers that for him it a subject best avoided.

This final theme has highlighted an original feature of the experience of becoming partially or fully recovered by focusing on the difficulties that the participants describe when they try to talk about their health. The way they construct their accounts likens their experience to being liminal and they become isolated from others with ME/CFS and 'well' people. In some ways, this is similar to the experiences that pwME/CFS (group 1) describe, as they find convincing others that they are unwell difficult. However, it seems here that becoming partially recovered adds a new dimension to the difficulties because it presents the participants with an additional experience that is equally as difficult to quantify and to explain. Recovery seems to be equally as controversial as the illness itself and incurs the same level of stigma, disbelief and difficulty, which in turn makes it difficult to talk about and share. There seems to be a continual need for partially recovered participants to justify not only their recovery but also their claim to have been ill in the first place.

This also suggests that they incur a further level of scepticism and have to defend themselves against any insinuation that their claims to be fully or partially recovered may not be genuine.

The above analysis has identified that the experience of recovering is constructed as being an isolating for the participants and this is a particularly valuable finding as it has not been presented in the literature before.

7.5 Summary

The analysis of the data has produced some unique findings which have not been explored in the literature to date. The first theme, '*For better, for worse'* introduces the notion that the participants continue to experience on-going disruptions to their life because of their illness and it appears that they remain in a liminal state between being ill and being well. It seems Petra (extract 7.1:1) and Amy (extract 7.1:2), who are pwME/CFS (Group 1) describe ME/CFS to be disrupting their ability to be themselves which may suggest that their identity remains under siege (see theme 6.2). Amy (7.1:2) also seems to indicate that she has become completely disempowered by ME/CFS as she is unable to talk about how her health has changed over the past year and how she manages the illness. It seems that all of the participants experience difficulties talking about having ME/CFS regardless of whether they are suffering with it, partially recovered or fully recovered. However, both Petra and Amy seem to present themselves as being 'stuck' and unable to move on because of their condition. The description of events accords with Asbring's (2001) finding that pwME/CFS fluctuate between pre-illness and illness identities, however partially recovered participants seem to present '*a divided self'* (See Chapter 6.6.3) instead which reflects the liminal status that they appear to occupy.

What is of interest here though is that Dawn (extract 7.1:3), who now claims to be 99% recovered, talks about experiencing problems with 'tiredness' and other things that pwME/CFS often talk about, yet she appears to perceive her identity to be liberated as she is able to return to work. Rather like Jack (extract 7.3:3) the focus of Dawn's account moves away from her illness and instead her problems (i.e. tiredness) are now related to being a

consequence of working. Although she still appears to be in a liminal situation, stranded between illness and health in a similar manner to the other participants, it seems that she is moving away from her illness identity.

It is of note here that the participants are all in a similar situation to where they were a year ago in terms of their liminal status, the biographical disruption that they encounter and challenges to their identity regardless of whether they perceive their health to have changed *'For better or for worse'.* However, what is key here is that they all continue to express a desire to return to their pre-illness identities rather than rejecting this identity as other research has suggested (Asbring, 2001: Whitehead, 2006). Instead it seems that in particular, Dawn is able to become partially reacquainted with her pre-illness self and is rejecting her illness identity, by strongly asserting her claim to be 99% recovered. This may imply that the transitional stages of recovery are quite complex and raises similar issues and dilemmas to those that pwME/CFS also have to manage.

In the second theme,' *The re-emergence of 'me',* participants talk more specifically about how they have remained connected with their intrinsic sense of 'who they are' over the past year. They use some significant and telling phrases such as "recreating my adult identity" (Dawn, extract 7.2:1), "I've managed to continue being a workaholic" (Sally extract 7.2:2) and "my personality traits still exist" (extract 7.2:3) which suggest the following. Firstly, that these aspects of their identity have always been there, but suppressed or dormant, which is consistent with the notion of being 'under siege' that has been explored in Chapter 6 (see 6.2). Secondly, it implies that the participants have been building stronger links with their pre-illness selves over the past year. Thirdly, it hints that the participants are reunited with aspects of their 'self' that are important to them; once they reach a particular level of 'recovery', their 'me' can re-emerge. This has important implications in terms of the previous identity literature and expands the suggestion that the pre-illness identity is somehow important to participants (see theme 6.1). It has already been noted that participants do not reject their pre-illness selves, as other research suggests pwME/CFS do (Asbring, 2001; Whitehead, 2006). From the analysis in this chapter, it seems that maintaining continuity with aspects of the pre-illness self may be a crucial part of becoming fully or partially recovered for people who self-direct the management of their illness. It is worthwhile to note here, that previous research has focused on pwME/CFS who are in a hospital or

treatment setting and who therefore may be encouraged to address their identity issues in a certain way as part of the treatment process. However, it raises the possibility that being encouraged to relinquish a pre-illness identity may not always be facilitative to partial or full recovery.

The language that the participants use to describe their experiences is also important to note as they use financial type metaphors such as "offsetting" (Dawn extract 7.2:1) and "trade-off" (Sally extract 7.2:2). PwME/CFS also use when they try to explain their illness to others as it is a way of conveying to other people that they only have a limited amount of resources available to them. However, it seems that the participants may be stressing that they have made an investment in trying to strike a balance between their ME/CFS and their participation in normal life. Overall this implies that recovering from ME/CFS is an intricate and complex process that requires a considerable amount of effort on their part.

Whilst '*The re-emergence of 'me'* theme suggests that the participants have found a way to manage the condition that allows them to live a 'normal' life, *'Living with shadows of ME/CFS',* focuses on how the participants go on to talk about aspects of their lives that they continue to struggle with. It seems that a primary on-going concern for the partially recovered participants here is managing to continue to balance a 'normal' life and accommodating the illness and this manifests itself in various ways. For Sally (extract 7.3:1), it seems that she is plagued with doubts about whether she could ever be fully better and how she may go about this. The issue here seems to be similar to the one that participants have previously described (see theme 5.2), yet it also has implications for her identity and sense of self as there is the possibility that she would be able to work harder and do more than she is at the moment. Dawn (extract 7.3:2) suggests that her life is still disrupted by ME/CFS, even though she is now 99% recovered. The way that she manages her illness has not changed at all, so everything that she does appears to be overshadowed by her ME/CFS. Finally Jack, (extract 7.3:3) suggests that he feels compelled to "catch-up" on things that he missed out on whilst he was ill, which suggests that ME/CFS is, albeit subtly, still overshadowing what he is doing. This also seems to hint at a return to a zealous, perhaps supernormal identity, which has been seen amongst other people who claim to have recovered from ME/CFS (see theme 6.4). Overall it appears that the partially recovered participants have to manage similar problems ones that pwME/CFS encounter, such as being

liminal, experiencing biographical disruptions, and challenges to their identity. However, it is also apparent that they are able to negate some of the effects of these by maintaining a routine that allows them to participate in a 'normal' life. Paradoxically though, this routine itself is disruptive and although in some ways it seems liberating for the participants as described above, in other ways it seems to keep them in a liminal state, suspended between being ill and being well. In other words it appears to become a quandary, which the participants still have to manage.

The final theme, *'To talk or not to talk',* focuses on how the participants explain their experiences of talking about their illness or recovery from ME/CFS, with other people and the analysis revealed that this was constructed as being problematic. Dawn (extract 7.4:1) suggests that describing what the illness is like and how it affects her is difficult, but that trying to convey that she is now almost recovered makes the situation much worse. It seems that the issue of 'recovery' may be just as controversial as being 'ill' with ME/CFS and that trying to convince others of either is fraught with problems, such as misunderstandings and doubt. Sally (extract 7.4:2) presents a similar account of the problems she had with communication, particularly when talking to 'well' people. What is surprising is that she specifically mentions that pwME/CFS are dismissive of any of her concerns, as it mirrors the way that sufferers talk about their experiences with the medical profession (see theme 4.1), who they perceive as being unduly dismissive. From the way participants describe these experiences, it seems that they are isolated and in a liminal situation, rather like pwME/CFS. The difference though is that unlike pwME/CFS, they are also ostracised from the ME/CFS community and therefore do not have that support network available to them. This suggests the possibility that the liminal status of people in partial recovery is more profound.

It is also worthwhile to mention here that Jack, (extract 4.4:3) who claims a full recovery, seems to avoid talking about ME/CFS, but it seems that in certain situations where he has to, he is still concerned about how the stigma of once suffering with it may affect him.

This final theme highlights the notion that 'recovery' from ME/CFS adds an additional level of controversy and stigma to the illness experience that people have to find a way to manage. Issues such as being in a liminal situation, managing on-going disruptions and challenges to one's identity still feature in the participants' experiences.

This concluding analytical chapter has explored the participants' subjective experience of their health over the interval of a year. It includes the accounts of people who describe themselves as partially and fully recovered and who have been excluded from the literature to date. Therefore this chapter presents unprecedented findings about how to understand a new and exciting dimension to the experience of suffering with a chronic illness such as ME/CFS. The analysis reveals that a number of additional issues continue to plague people in recovery regardless of claims to be able to participate in a 'normal' life. It proposes that the controversial nature of ME/CFS remains problematic at all levels and all stages, from pre-diagnosis to post recovery as it does not follow the trajectory of other chronic illnesses.

Chapter 8

Conclusions

As I explained in Chapter 1 my interest in ME/CFS stems from the experiences of my husband, who has now had the illness for 12 years, and a desire to highlight some of the problems and dilemmas that he, and other people affected by ME/CFS have had to manage. Over the duration of my PhD, I have been fortunate to build strong relationships with other ME/CFS sufferers, carers and people claiming a recovery who have been happy to share their experiences informally as well as volunteering to participate in the research process. Members of the ME/CFS community have been involved at each stage throughout the research process. Firstly they assisted with the recruitment of participants, as many people who described themselves as being fully or partially recovered or pwME/CFS who did not attend support groups were recruited by participant driven sampling. Secondly, as described in chapter 3 the participants' views on quantitative research lead to this research becoming adopting qualitative rather than mixed methods design. Taking note of how the participants described themselves as 'partially recovered' or 'recovered' informed the grouping of interviewees into 'pwME/CFS', 'partially recovered' and 'recovered'. Thirdly all participants were provided with a 'rough pass' copy of their transcript and invited to make amendments where they deemed it necessary as a form of 'member checking'. As the research developed emergent concepts and themes were discussed with small number of the ME/CFS community and some claiming a recovery, including some who did not participate in the research.

The ongoing dialogue and professional relationships that I established with the people in the ME/CFS community have helped to ensure that the research has remained grounded in first-hand experience and that it reflects issues, dilemmas and experiences that are representative of how people describe different stages of the pre-illness to post recovery journey. Therefore I present the conclusions below with added confidence that they are representative of issues that the participants want to emphasise as being relevant to their subjective experiences of ME/CFS.

8.1 The analytical approach

The thesis draws upon the theoretical frameworks of both social constructionism and grounded theory and adopts an analytical approach which draws upon constructivist grounded theory (CGT) as both a theory and a method. The analytical framework allows the researcher to present data which is grounded within the participants experience as well as attending to how categories such as being 'partially' or 'fully' recovered are constructed by pwME/CFS. It is proposed that CGT is appropriate for this research because it is flexible enough to allow engagement with emergent concepts and as it is data driven it provides an opportunity to explore the data in a different way. For example, it was possible to comparatively examine the experiences of people across the three different groups; people with ME/CFS (group1); people partially recovered from ME/CFS (group 2) and people claiming a full recovery from ME/CFS (group 3). This in itself was unusual because chronic illness literature and ME/CFS research to date has focused on people who are ill with ME/CFS and has not included the other two groups. By adopting an approach that is grounded in the participants' experiences, the researcher was able to pursue unexpected findings that emerged from the data set. This was particularly useful when participants' began to talk about being 'partially recovered' rather than being 'ill' or 'well' as it signified a separate and distinct category which could be identified and the subjective meaning explored.

It was also possible to explore points of interest within the data in greater depth for instance it was of note that that the participants used financial terminology to explain how the illness affected them and their struggle to manage it effectively. This way of talking about ones' illness seems to be unique to pwME/CFS and signifies something new within the chronic illness literature.

The type of analysis undertaken here also allowed an insight into the different ways that the three participant groups construct their subjective accounts of suffering with ME/CFS or being partially or fully recovered. As discussed in more detail below, all of the participants talk about similar issues, but the *way* that they talk about them differs considerably and this approach makes it possible to highlight these distinctions.

It is argued that using this specific analytical approach makes it possible to perceive ME/CFS as an ongoing pre-illness to post-recovery journey, but at the same time allows specific poignant features to be illuminated. It has led to new and exciting conceptual insights which are surmised below.

8.2 Research Design

This research was initially conceptualised as having a mixed methods design, however for reasons more fully documented elsewhere (see Chapter 3 and appendix B) pwME/CFS indicated that they were uncomfortable with the quantitative element of the research. After further discussions with the ME/CFS community and some deliberation I decided that it would be advantageous and beneficial to change the research design to and conduct purely qualitative research. I realised that building rapport and gaining the trust of the ME/CFS community was important and demonstrating that I was listening to, and acting upon, their concerns would be an important part of this process.

The research also adopts a longitudinal design which successfully demonstrated that the dilemmas and challenges that participants face at different stages of their illness are enduring and representative over time, despite being hampered by a low number of participants. After the first round of interviews were complete, twelve participants who had implied that they would experience a life event within the next year (such as changing jobs) were asked to participate again in a year's time. Unfortunately, for a variety of reasons (see chapter 3 for more detail) only six were contactable and although they all took part this has had a detrimental effect on the impact of the chapter.

8.2.1 Participant recruitment

The participants were recruited by a number of different methods including via self-help groups and participant driven sampling from areas across the UK. There were definite advantages to using these methods. One such advantage of recruiting people from a number of different places is reducing the possibility of a local group consensus about how to talk about the illness influencing the findings of the research. Previous research has suggested that people who are members of 'groups' tend to develop established and accepted ways of talking about their illnesses and experiences (Hoffmann, 2003). In chapter two it is noted

that the majority of previous ME/CFS research draws participants from hospital clinic settings or from a single support group setting and it is suggested that this could influence the nature of the participants' responses. By recruiting from a wide geographical area, people at different stages of their ME/CFS journey and who were presumably adopting different methods of managing the illness this research was able to minimise any influences of recruiting from a particular setting.

8.2.2 Grouping Participants

I noted early into the research process that some participants clearly classified themselves as being 'partially recovered' or 'recovered' and that they interpreted their status as being different to having ME/CFS. It was clear that these self-classifications were important to the participants and pertinent to their perception of themselves and their ME/CFS. Therefore the participants were divided into three groups; pwME/CFS, people in partial recovery and people who are fully recovered.

8.2.3 Participant sample

The sample size for this research was relatively large consisting of 36 people. 20 of these were pwME/CFS, 5 people described themselves as being particularly recovered and a further 11 declared themselves to be fully recovered. Six people were interviewed a year later (2 pwME/CFS, 3 claiming a partial recovery and 1 fully recovered participant. The ME/CFS literature presented in chapter 2 predominantly draws upon small sample sizes therefore the sample sizes presented here are deemed to be adequate for the purposes of the research. Participants were recruited from a number of different sources including support groups and by participant driven sampling rather than being drawn from one or two hospital or support group settings. This means that the findings presented represent a broader set of sources and experiences than might have been achieved from a study based on a particular clinical group.

8.3 An introduction to the findings

The findings of this research present an alternative perspective to some of the literature which I outlined in Chapter 2; these are presented below in relation to the existing literature and the wider theoretical categories of Liminality, Biographical Disruption and Identity. The findings are organised to reflect the stages of the participant's journey which are pre-illness and diagnosis, mid-stage, partial recovery and full recovery.

8.3.1 Pre-illness and diagnosis

This research found that the majority of sufferers described becoming ill with a flu-like virus, which they initially perceived to be ordinary until it failed to abate in an anticipated or expected way. It was noted that the participants seem to suggest that the ordinary, recognisable virus somehow mutates into something more sinister which then goes on to become ME/CFS. This adds an additional dimension to existing research and sets the scene for ME/CFS being regarded as liminal because participants describe feeling 'unwell' but are unable to find any medical reason for this to be the case.

Existing research has found that suffers often talk about experiencing a virus of some type before they become ill with ME/CFS and it suggested that this often leads to a belief the illness is physiological in nature (Clarke & James, 2003; Clements, Sharpe, Simkin, Borrill & Hawton, 1997). However it argued within this thesis that it also sets the scene for the way that participants perceive the virus as somehow sneaky or deviant and for ME/CFS itself to be viewed as something that is 'out of the ordinary'. It can be therefore inferred that, as ME/CFS is perceived to be extra-ordinary, it has a liminal status as the participants are 'betwixt and between' socially mandated categories of being ill and well.

This thesis also found that sufferers describe having busy and active lives prior to becoming ill with ME/CFS, which has already been noted in literature to date (Soderlund & Malterud, 2005) yet alternative explanations of why this occurs is proposed in this research. For instance it has been suggested that the emphasis on an active pre-illness life may be used to ward against any perceived accusations of laziness or malingering (Horton-Salway, 2001). Literature on chronic illnesses (Baumeister, Tice & Hutton, 1989) often proposes that ill people typically play down their pre-illness identity once they become ill in order to make

the difference between illness and pre-illness identity less stark. Consequently, the finding that participants are doing the opposite in this research is all the more interesting. This research proposes that detailed descriptions of pre-illness identity are important to the participants because they are indicative of the type of person that they intrinsically perceive themselves to be regardless of their state of health. Later in the research, when considering the concept of partial and full recovery the significance of this proposal is clearer.

Other noted features of the experience of becoming ill with ME/CFS such as difficulties in obtaining a diagnosis, problems with accessing medical care or treatment and managing the condition (Anderson, Jason & Hlvatay, 2014; DeCarvello, Leite, Drachler, Killett, Kale Nacul & McArthur, 2011; Clarke & James, 2003). These finding were replicated in this research and are proposed in this thesis to place the participants in a liminal position. This is because they describe engaging in laborious, time-consuming processes of self-diagnosis and self-management in order to try and manage their health which people with medically recognised conditions possibly would not have to consider.

The thesis further proposes that these processes are disruptive for the participants because they seem to involve painstakingly researching, resourcing and trialling different techniques and therapies. This approach requires an ongoing commitment from the participants, drawing upon their already limited resources of energy. The view that these processes are disruptive in themselves is one that has not been covered in literature to date as it focuses upon disruptions to identity and life events that occur once someone is ill (e.g. Asbring, 2001).

It is suggested in this thesis that biographical disruption plays a significant part in the process of discovering one has ME/CFS, as the disruption caused by a 'normal ill' failing to abate seems to alert participants to the possibility that something else is wrong. It also demonstrates that ME/CFS is disruptive following diagnosis in terms of life events including employment, education, identity and relationships which is in line with previous research (See Asbring, 2001; Dickson, Knusson & Flowers, 2008). As suggested in Chapter 2, previous research presents a complex picture of identity whilst ill, suggesting a divided identity (Asbring, 2000), a rejection of previous identity (Clarke and James, 2003) or a lack of rejection of the previous identity (Whitehead, 2005). The findings from this research suggest

that participants present the experience as a sharp step-change from being the 'person they used to be' when they become ill which corresponds to the change from an active to a sedentary lifestyle.

Accordingly, the pre-illness and diagnostic phase is examined in some detail for this thesis and it explores some areas which are referred to but not explored in literature to date, such as the belief that the illness originates from a virus. The thesis argues that these early experiences are an important part of understanding how pwME/CFS perceive and experience their illness and that this is perpetuated throughout the remainder of their ME/CFS journey.

8.3.2 After diagnosis

Once they have a diagnosis participants enter a phase whereby they try to address their ill health. Often this involves turning to alternative and complementary therapies and techniques (CAMTS) as Bury (1986) has suggested is the case for other chronic illnesses and Clements et al (1997) for ME/CFS. The thesis suggests that the need to research, trial and undertake therapies in a self-driven manner places participants in a liminal state, as it may be assumed that for medically recognised illnesses therapeutic and restorative activities are usually managed by the medical profession. Furthermore in the perceived absence of definitive medical guidance participants describe negotiating a confusing array of information in order to try and find something that may help them to manage their ME/CFS. The participants are therefore left in a grey area of having a diagnosis but not receiving medical treatment at a level which they may ordinarily expect.

It is also proposed in this thesis that being charged with finding ways to self-manage ME/CFS potentially adds a further level of disruption to the participant's lives by threatening to undermine the status quo of their current routine. On one hand participants suggest that their illness already causes a level of disruption to their lives but indicate that they can manage this disruption enough to partake in some activities that are consistent with having a normal life. Yet on the other hand they are aware of all of the potential 'treatment' options that could help them to manage the illness better in the long run. Thus they face a considerable dilemma over whether or not to disrupt the 'balance' of their normal life. The challenges and dilemmas associated with trying to self-manage the illness have not been

noted in the ME/CFS literature to date even though they seem to form an important part of the subjective experience.

The way participants talk about the impact ME/CFS has upon their identity at this stage of the illness is fascinating. Research to date explores how participants' identity is affected after an ME/CFS diagnosis and there are suggestions that participants reject the pre-illness identity (Clarke & James, 2003), or; that participants fluctuate between 'well' and 'ill' identities for a period of time (Asbring, 2000). However participants in this study seem to allude to their identity being suppressed by their illness, the way they describe it implies that the ME/CFS is perceived to be powerful and controlling and they are powerless to prevent it from taking over their ability to control their own body, preventing basic functions such as walking and talking. This fits well with previous research which suggests that pwME/CFS perceive the illness as being powerful and difficult to control (Clements et al, 1997). Although from the analysis presented here, participants appear to be identity-less at this stage of the illness which seems to contradict previous findings and suggests that something different may be going on.

8.3.3 Partial recovery.

Some participants made a definite distinction between themselves, as people who were in recovery from ME/CFS and other ME/CFS *'sufferers'.* Partially recovered participants described fluctuating between times of being 'ill' and times of being 'well' leaving them in limbo between the two categories. Although it has been suggested that pwME/CFS can pretend to be 'well' at times (Dickson, Knusson & Flowers, 2008) it seems that something different is happening here. The participants alluded to actively and deliberately organising their time into periods of 'well' behaviours and 'ill' behaviours in order to participate in aspects of normal life such as work. The analysis demonstrates that committing to these routines was challenging and disruptive for the participants as they describe being faced with dilemmas and having to make sacrifices in order to be able to 'do things'. The interesting yet paradoxical thing is that the participants are managing any potential disruption caused by their ME/CFS by embracing a regular day-to-day disruption which allows them to keep their symptoms under control. It implies that being able to keep one's symptoms under control is the key to becoming partially recovered.

In terms of identity the partially recovered participants describe transcending between the identities of being an 'ill' person or a 'well' person on a regular basis in order to maintain aspects of a 'normal' life. It seems that to enable episodes of being 'well', engaging in 'normal' life and being 'oneself' requires the person to engage in periods of 'illness' behaviours such as resting. Although Asbring (2001) noted that people with CFS switch between identities of being ill and being well, the findings presented in this research suggest that participants can and do actively manage both identities in order to take part in 'normal' life events. It also seems that rather than rejecting their pre-illness identity as previous research suggests (Clarke & James, 2003) maintaining a connection with their previous identity is of paramount importance to the participants and forms a crucial part of being in recovery.

8.3.4 Full recovery

'Recovery' is a concept that has been mentioned in the ME/CFS literature (e.g. Whitehead, 2005) yet how pwME/CFS come to define themselves as recovered and what it means to them has not been explored to date. The notion of recovering from a chronic illness is problematic because by definition such illnesses are considered to be 'lifelong'. For medically recognised illnesses recovery is usually consistent with the absence of disease which is verified by the medical profession (see Sibbett, 2005). With ME/CFS this is different because the presence or absence of the disease cannot be medically verified.

The thesis found that even people claiming to be fully recovered appear to be in a state of liminality because of ME/CFS. The way that the participants talked about being fully recovered on the one hand but, on the other hand, having to remain watchful for any sign of their ME/CFS symptoms indicated that they were in a grey area between being 'ill' and being 'well'. Further analysis demonstrated that there were other features reminiscent of an ongoing liminal status for 'recovered' people such as limiting the type and extent of activities they engage in order to try and minimize any risk of the illness returning. Participants also described encountering stigma and disbelief from others when they talk about being recovered, which is also indicative of having a liminal status and something that that pwME/CFS encounter when they talk about being ill. What is surprising about this is the recovered participants' perceptions of being ostracized from the ME/CFS community. It is

argued that this places recovered people in an enhanced state of liminality as they are unable to share experiences with or draw support from the ME/CFS community or from 'other people'. Broadly speaking this means that they are unable to share their experiences of recovery with either group. So although they are 'recovered' in some ways the participants still seem to have a liminal status that they have to manage.

Being recovered is also disruptive as participants describe measuring and cataloguing their activities in a meticulous way in order to be watchful for any sign of their ME/CFS symptoms returning. Even for participants claiming to be symptom free it was noted that the extent to which they could engage in activities such as sport or employment were tempered because they once had ME/CFS, which points to an ongoing disruption in terms of careers or earning potential for instance. Participants also described experiencing a need to 'catch up' and somehow try to make up for lost time by working additionally hard to address issues such as a gap in earnings for example. Therefore it seems that recovery itself becomes disruptive.

Despite these ongoing disruptions participants seem to perceive themselves as becoming reunited with their pre-illness identity by describing their level of activity as being similar in both situations. This indicates that maintaining a link with one's pre-illness identity may be facilitative to recovering at a later date, contradicting the findings of previous research. It also demonstrates that participant's descriptions of busy and active pre-illness lives may not be as exaggerated as previous research implies but are in fact representative of who the participants believe themselves to be.

The longitudinal element of this research demonstrates that the findings of this research are not presenting a snapshot of one-off happenings in the lives of pwME/CFS. Instead, as people described encountering similar experiences and circumstances a year after the initial interviews it implies that these findings are enduring over time.

It was interesting to note that all of the participants were sometimes talking about experiencing setbacks but the way that they talked about them differed considerably. PwME/CFS appeared to regard any deterioration in their health as a consequence of having ME/CFS whereas people in recovery considered them to be a result of being active and engaging in life events.

8.3.5 Figures of speech

It is also evident that the participants talk about their ME/CFS in a unique way within this thesis which is compelling. Their perceptions of the illness seems to be reflected in their descriptions of it as phrases such as "it morphed" (see extract 5.5:1) and "it creeps in" (extract 4.3:2) denote that the illness is viewed as being sneaky, deviant and difficult to control. Also throughout the interviews participants used financial metaphors and language to explain how the illness affects them and to illustrate what they could and could not do. They seem to imply that their energy was a form of capital and as an example, one participant talked about a situation of being in 'overdraft' then having to rest in order to explain her routine of working normally for four days and then resting for three (Sally, Chapter 4, Extract 4.3:1). All of the participants talked about managing a 'balance', which involved constantly monitoring themselves in order to ensure that they had sufficient energy reserves to enable them to participate in elements of 'normal' life. Their use of this terminology gives an insight into the way people manage this illness, through a use of checks and balances; of debits and credits. The use of financial language also resonates with their perception that finding and trialling ways to potentially treat their illness is troublesome because it seems that they have to make an *investment* of their limited resources of *capital.* It has previously been noted that people with certain illnesses use certain types of metaphors; Sontang (1991) for instance noted that people with cancer often use military metaphors in order to give the impression of fighting or battling with the illness. Miserandino (2003) adopts the 'spoon theory' to illustrate the limited amount of energy that a person with lupus may have. To the author's knowledge this is the first time this specific way of talking about the illness has been noted with ME/CFS and it seems worthy of further exploration.

8.5 Reflexivity

As I have already mentioned my interest in ME/CFS began when my husband was diagnosed with it in 2002. I have outlined some of the difficulties that we experienced in chapter 1 but suffice to say that we both struggled with having ME/CFS in our lives for different reasons. I embarked on ME/CFS research because I wanted to highlight some of these difficulties and help my husband and others who have ME/CFS to manage the illness and regain their lives.

Some elements of the research, such as the difficulty with obtaining a diagnosis, accessing medical care and experiencing stigma, were, on the whole, consistent with our own experiences. This presented two challenges, one was to ensure that I did not inadvertently assume that our experiences were the same as the interviewees and the second was to be careful not to engage in too much of an information exchange about ME/CFS. I managed to minimize these possibilities by taking notes whilst the participant talked and by paraphrasing what they had told me. When people described situations that differed from my experiences I checked my understanding in order to make sure it was accurate. Even though some of these conversations may have reflected the difficulties, challenges and dilemmas that I had expected to hear I was not prepared for the extent of suffering that some of my participants described. There were two occasions I found particularly moving; a couple with ME/CFS talking about the difficulties of raising two school age children, and; a lady who was in tears at the prospect of losing her job and possibly her relationship because of ME/CFS.

The couple both had quite severe ME/CFS and their ability to leave the house and participate in life events was very limited. They talked to me separately but both talked about the impact that ME/CFS had upon their two school-age children. They talked about how managing the practicalities of being a parent such as getting the children ready for school by providing clean uniforms, preparing packed lunches and then later checking homework and providing a cooked meal was a daily struggle for them. They described feeling guilty and inadequate for not being able to attend school sports days or concerts and for not being able take their children along to parties, parks or out to the cinema or the theatre. Mum explained that her children were fortunate because parents of their school-friends would often extend additional invitations to these kinds of activities and pick the children up and drop them home again. Then she became upset saying that she wanted to be a hands-on Mum and share new experiences with her children rather than "giving them to other people whenever they want to do anything". In his interview the Dad seemed to get upset when he talked about this as he explained that when these situations arise and one or both of the children has been invited out, either he or his wife has to ask one of their parents to pay for the outing because their welfare benefits would not cover the cost.

Their accounts impressed me because I could understand how hard they were trying to care for their children and make sure they have as much of a 'normal' childhood as possible. Yet I

could hear and see how hurt and distressed they were by their situation. Later, I realized my feelings about this were prompted by the way that the couple in question were very competent in their knowledge of ME/CFS and could secure, within reason, the help they needed. Part of my emotive response stemmed from considering the plight of people who were less aware and less capable of securing any assistance.

I also interviewed a lady who was struggling to keep her job since she has ME/CFS as she had been unable to work for nine months and her employers were demanding that she returned. She had described her partner as being unsupportive towards her since she had become ill and as a result she was lonely. She also talked about her fear that losing her job and her income would signal the end of her relationship as she doubted that her partner would financially support her. If this were to happen, as he owned the house and they did not have any children, she feared that she would become homeless as there was nowhere for her to go. At this point she became distressed and tearful, asking "what on earth will I do? If my job goes that will be the end of me". I switched off the recording device and put my hand on her shoulder which she seemed to welcome. We sat in silence for quite some time whilst she regained her composure at which point I offered to make a drink and we talked about the positive steps she had taken to secure her job for the future. This interview was touching because of the sheer desperation the participant was expressing and the obvious emotional effect it was having upon her.

The end of interviews with pwME/CFS were interesting as once the 'official' part was over and the recorder had been switched off people asked me questions. Some were general questions, such as; "What do you think about the XMRV virus research?" which we had a discussion about presenting different perspectives and theories. Other questions were a way of checking that any symptoms that they were experiencing were a feature of ME/CFS such as "Have other people that you have spoken to talked about experiencing problems with their concentration?" I handled these questions more carefully by stipulating that I was not qualified to give advice, saying that I had come across it before and signposting the person towards some ME/CFS literature that may help and *always* advised them to visit a GP if they were uncertain. Finally people sometimes asked personal questions which I wasn't always prepared for. For instance one man I interviewed had talked about having an extremely successful and lucrative career and being happily married before becoming ill. He lost his job

a year later and his wife left him shortly afterwards. At the end of the interview he pointed out that I had asked him a lot of personal questions which he had answered and asked me "Why do you think it is that some relationships survive and some don't? Why didn't you leave your partner when he became ill?" This was difficult to answer, not least because he had described his wife leaving him as being very unexpected, completely devastating and something he did not understand. I skirted the question a bit by saying that I couldn't comment on his relationship, each one is different and that any answer I provided would not necessarily help him understand the breakdown of his relationship any better. Strangely I did feel obliged to say something more meaningful and so I said that to me Adrian is the same person that he always has been, although he can do less, everything that drew us together in the first place is there. At this point the man sunk back into his chair, deflated, and said "I thought you would say something like that". Although I didn't ask what he meant by that we discussed things a bit more and later, rightly or wrongly, I told him that some pwME/CFS had met new partners since they became ill and were very happy. As it happened he had assumed that becoming ill was the end of his romantic life and had not considered the possibility of meeting anyone else at all.

These encounters in particular left a lasting impression on me and I thought about ME/CFS in a slightly different way. Information about being partially or fully recovered was completely new to me though.

One lady was introduced to me as being partially recovered and she prefaced much of what she said with "I am partially recovered now and so" which I found interesting. However it was a difficult stage of illness for me to understand as being distinct from having ME/CFS because they seemed to be so similar. It was only after interviewing a few people that I began to realise what they perceive the difference to be, an increase in activity levels and a 'reduction' in symptoms.

Fully recovered participants were more difficult to find, but again I was introduced to one such person by a member of an ME/CFS group. From my 'knowledge' of ME/CFS I was anticipating that people would talk about experiencing a spontaneous recovery whereby the illness disappears overnight or recovery following a medical intervention such as being treated with high doses of antibiotics. I was very surprised when people talked about

CAMTs, particularly as I had never heard of things like 'Lightning Therapy' or 'The Gupta Technique' and had never used any form of CAMs myself. Initially I found it difficult to comprehend what people were describing and I asked plenty of questions to ensure that I was accurately collecting this information which fell outside of my own knowledge. I was initially quite confused when I came to realise that the majority of 'recovered' people had used a form of CAMTs as I ruminated over what this meant for the physiological/psychological debate over the origins of the illness. I was of the opinion that ME/CFS was physiological but, as with all illnesses, there was a psychological component. Yet some of this information seemed to challenge my perception. What did it mean? I continued to ponder as I progressed with the interviews and gathering information about ME/CFS in the medical, social science and lay domains.

By the end of my quest, the murky waters surrounding these questions is no clearer for me. Instead it seems starkly apparent that there really are no 'answers' to being ill with ME/CFS or no "magic bullet" as some participants had said. Instead it seems that managing the symptoms and becoming recovered are personal and individual processes. Quite how these processes tally with the physiological vs psychological debate represents a larger philosophical question which is not the focus of this research. However, receiving a definitive answer to these questions is not so highly important to some sufferers, whereas finding a way to manage and cope with the condition is. One of the things that the thesis does suggest that may be of help to pwME/CFS is renewed hope that recovery and resuming a 'normal' life is possible.

8.6 Future directions

This research has yielded a number of original findings which would benefit from further research in the future because they have implications, not only for the successful management of ME/CFS, but for other contested and chronic illnesses.

One of the intriguing issues that arose from this research was the participants' extraordinary emphasis on working, being employed and engaging in competitive sporting activities, even when they were talking about being ill with ME/CFS and were unable to do these things. As I

have already mentioned their descriptions went beyond merely trying to address any preconceptions of being 'lazy' instead it seems that an ability to participate in these things was vitally important to them, to their identity and their sense of self. However, the explanation for this does not become apparent to them until they become fully or partially recovered and are able to return, at least in part, to participating in activities that they did before. Then it seems that they can use their past level of activities as a benchmark to measure their level of recovery and to monitor and plot a return to a 'normal' life.

The implications of this are enormous. It seems that being able to return to a working life and become reacquainted with a previous self is conducive to managing the illness successfully or even 'recovering', yet there is so little known about how pwME/CFS manage this transition back into the working world. The participants construct themselves as being diligent, hardworking and responsible people and, perhaps unsurprisingly, they reject the negative, stigmatic connotations that accompany a label of having ME/CFS. Returning to work seems to be a way to demonstrate 'who they really are' and illustrates that they are not, nor have ever been, what a label of ME/CFS can signify or imply. So, although they may still experience on-going problems due to ME/CFS, they are somehow able to manage them more effectively. It seems that being able to do this reacquaints them with their pre-illness selves too and so it seems to help them with addressing disruptions to their identity, which they attribute to being caused by being ill. More needs to be known about this transitional process and conducting further longitudinal research focussing on the role that working and identity play will provide a clearer understanding for medical and health professionals.

Longitudinal research would also provide a greater understanding of what 'recovering' and 'recovery' actually mean for pwME/CFS, but in order to be able to address this in the future it is necessary to look at the widespread use of complementary and alternative medicines or therapies (CAMTs) and self-management techniques in the ME/CFS community, which is not documented in the social science literature so far. CAMTs carry a level of controversy of their own as they are also considered sceptically by many medical doctors and people in the lay arena alike. This presents pwME/CFS with an additional dichotomy because in the perceived absence of any 'treatment' from the medical profession they are charged with the responsibility for improving their health themselves and as Bury (1991) notes is common, the turn to CAMTs. However, in relation to ME/CFS it is proposed that sufferers engaging

with CAMTs are deluding themselves and will prolong ultimately their suffering by searching for an elusive cure (Huibers & Wessely, 2004) which implies that it is the wrong thing for them to do. However, in this research participants who have used CAMTs have described them to be of some benefit to their well being but it seems that their actions are again controversial. It is unfortunate that relevant information about the people using CAMTs is, so far, not officially recorded as it seems to be an important element of the participants', ME/CFS experience. It seems to causes subjective issues and dilemmas which are significant to the experience of having ME/CFS but remain ignored.

To be clear, I am not trying to imply that future research should focus on the merits and efficacy of the multitude of CAMTs and self-management practices available, but it should take into account that they form an integral part of the participants' experiences of ME/CFS and are valuable to our understandings of the subjective experience. One of the major findings about this research was that the vast majority of people actually *wanted* to talk about their experiences of ME/CFS, even after they had recovered, and furthermore that they also expressed an enthusiastic desire to help other people suffering and struggling to manage and live with their illness.

I propose that conducting large scale, longitudinal research would be beneficial to understanding more about the various transitional stages of ME/CFS in order to establish how people can be helped and supported throughout the pre-illness to recovery journey. It would further increase our understanding of what it means to 'recover' from a chronic illness and in addition would highlight some of the psychological and psychosocial issues that being recovered seems to raise. A heightened awareness of these issues would benefit not only pwME/CFS themselves but also anyone who may have interactions with sufferers or recoverees.

References

Acheson, E.D. (1959). The clinical syndrome variously called benign myalgic encephalomyelitis, Iceland disease and epidemic neuromyasthenia. *American Journal of Medicine, 26, 569-595*.

Albisser, A.M., Hodel, A.S., Albisser, J.B., & Wanner, A. (2002). Chronic disease management: a systems model relating outcomes, reporting, monitoring, interventions and satisfaction. *Control Engineering Practice, 10(1), 101-110*.

Anderson, V.R., Jason, L.A. & Hlavaty, L.E (2014). A Qualitative Natural History Study of ME/CFS in the Community, *Health Care for Women International, 35 (1), 3-26.*

Anderson, R., & Bury, M. (1988). *Living with chronic illness. The experience of patients and their families.* London: Unwin Hyman.

Archer, M. (1986). *'The Sociology of Education'* In U. Himmelstrand (Ed.), The Social Reproduction of Organisation and Culture (pp. 59-87): Sage.

Armstrong, P. (1984*). Labour Pains: Women's work in crisis*. Toronto Tavistock. Routledge.

Arroll & Senior (2008). Individuals' Experience of Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis: an Interpretative Phenomenological Analysis. *Psychology and Health, 23 (4). 443 - 458*.

Asbring, P. (2001). Chronic illness – a disruption in life: identity-transformation among women with chronic fatigue syndrome and fibromyalgia. *Journal of Advanced Nursing, 34(3), 312-319.*

Asbring, P, & Narvanen, A.L. (2003). Ideal versus reality: physicians perspectives on patients with chronic fatigue syndrome (CFS) and fibromyalgia. *Social Science & Medicine, 57,(4), 711-720.*

Austin, J.L. (1962). *How to Do Things With Words*. . Oxford, England: Oxford University Press.

Banks, J., & Prior, L. (2001). Doing things with Illness. The micro politics of the CFS Clinic. *Social Science and Medicine, 52(1), 11-23.*

Barker, K. (2008). Electronic support groups, patient-consumers, and medicalization: the case of contested illness. *Journal of Health and Social Behavior, 49(1), 20-36.*

Barsky, A.J., & Boras, J.F. (1999). *Functional somatic disorders. Annals of Internal Medicine, 130(11), 910-9*21.

Baumeister, R.F., Heatherton, T.F., & Tice, D.M. (1993). When ego Threats lead to self-regulation failure: Negative consequences of high self-esteem. *Journal of Personality and Social Psychology, 64(1), 141-156.*

Baumeister, R.F., Tice, D.M., & Hutton, D.G. (1989). Self presentational motivations and personality differences in self-esteem. *Journal of Personality and Social Psychology, 57(2), 547-579.*

Bayliss, K., Riste, L., Fisher, L., Wearden, A., Peters, S., Lovell, K. andChew-Graham, C. (2014). Diagnosis and management of chronic fatigue syndrome/myalgic encephalitis in black and minority ethnic people: a qualitative study, *Primary Health Care Research & Development,15, 143–155.*

Beasant, L., Mills, N. & Crawley, E. (2014) Adolescents and mothers value referral to a specialist service for chronic fatigue syndrome or myalgic encephalopathy (CFS/ME), *Primary Health Care Research & Development;15:134–142.*

Beck, A.T., Ward, C.H., Medelson, M., Mock, J., & Erbaurgh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry, 4(6), 561-571.*

Bell, D.S. (1991*). The Disease of a Thousand Names*. Lyndonville: Pollard Publications.

Bell, D.S., & Bell, D.E. (2010). Definition of recovery in Chronic Fatigue Syndrome. *The Journal of IiME, 4(1), 23-27.*

Bell, E.J., McCartney, R.A., & Riding, M.H. (1988). Coxsackie B viruses and myalgic encephalomyelitis. *Journal of the Royal Society of Medicine, 81(6), 329-331*.

Berger, PL, & Luckmann, T. (1967*). Thesocial construction of reality: a treatise in the sociology of knowledge*. Harmondsworth: Penguin Books.

Bird, C.E. (2010). *Handbook of Medical Sociology*. Vanderbilt: Vanderbilt University Press.

Blaxter, M. (1990). *Health and Lifestyles*. London: Routledge.

Bohr, T. (1995). Fibromyalgia syndrome and myofascial pain syndrome: Do they exist? *Neurologic Clinics, 11, 365-384.*

Bonner, D., Ron, M., Chalder, T., Butler, S., & Wessely, S. (1994). Chronic Fatigue Syndrome: a follow up study. J*ournal of Neurology, Neuropsychology and Psychiatry, 57(5), 617-621.*

Boote, J., Telford, R., and Cooper, C. (2002). Consumer involvement in health research: a review and research agenda. *Health Policy 61, 213–36.*

Brant, A. (2002). Grounding Systems Research: Re-establishing Grounded Theory. *The Journal of Information Technology, Theory and Application, 4(1), 25-42.*

Brown, P. (1995). Naming and Framing: The Social Construction of Diagnosis and Illness. *Journal of Health and Social Behavior, 35(Extra Issue), 34-52.*

Bryman, A. (2012).*Social Research Methods* 4th Edition. Oxford. Oxford University Press.

Buchwald, D., Umali, J., Pearlman, T., Schmaling, K., & Katon, W. (1996). Functional status in patients with chronic fatigue syndrome, other fatiguing illnesses, and healthy individuals. *American Journal of Medicine, 101, 364-370*.

BUPA (2012).*Chronic Fatigue Syndrome*, accessed 10/11/12 from

http://www.bupa.co.uk/individuals/health-information/directory/c/hi-chronic-fatigue-syndrome

Burr, V. (1995). *An Introduction to Social Constructionism*. London: Routledge.

Burr, V. (2002)*. The Person in Social Psychology*. Hove: Psychology Press.

Burr, V. (2003). *Social Constructionism (Second ed.)*. London: Routledge.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness, 4(2), 167-182.*

Bury, M. (1986). Social constructionism and the development of medical sociology. *Sociology of Health and Illness, 8(2), 137-131.*

Bury, M. (1991). The social constructionist movement in modern psychology. *Sociology of Health and Illness, 13(4), 451-468.*

Carricaburu, D., & Pierret, J. (1995). From biographical disruption to biographical reinforcement: the case of HIV-positive men. *Sociology of Health and Illness, 17(1), 65-68.*

Carter, P., Beech, R., Coxon, D., Thomas, M.J. & Jinks, C. (2013). Mobilising the experiential knowledge of clinicians, patients and carers for applied healthcare research, Contemporary Social Science: *Journal of the Academy of Social Sciences, 8 (3), 307-320.*

Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness, 5(2), 168-195.*

Charmaz, K. (1987). Struggling for a self: identity levels of the chronically ill. In J. Roth & P. Conrad (Eds.), *The Experience and Management of Chronic Illness: Research in the Sociology of Health Care* (pp. 283-321). Greenwich: JAI Press.

Charmaz, K. (1990). "Discovering" chronic illness: using grounded theory.*Social Science &Medicine, 30(11), 1161-1172.*

Charmaz, K. (1991). *Good days, bad days: The self in Chronic Illness and Time*. New Brunsick, NJ: Rutgers University Press.

Charmaz, K. (1995). Grounded theory. In J. Smith, R. Harré, & L. Langenhove (Eds.), *Rethinking methods in psychology* (pp. 27-65). London: Sage.

Charmaz, K. (2000). Grounded theory objectivist and constructivist method. In Denzin, N. and Lincoln, Y. (Eds.), *Handbook of Qualitative Research* (pp. 509-535). Thousand Oaks, CA: Sage.

Charmaz, K. (2001). Qualitative interviewing and grounded theory analysis In J. F. Gubrium & J. Holstein (Eds.), *Handbook of interview research: Context and Method* (pp. 675-694). Thousand Oaks, CA: Sage.

Charmaz, K. (2003). "Qualitative interviewing and grounded theory analysis". In J. Holstein & J. F. Gubrium (Eds.), *Inside Interviewing: New Lenses, New Concerns* (pp. 311-330). London: Sage.

Charmaz, K. (2005). Grounded theory in the 21st century: a qualitative method for advancing social justice. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage Handbook of Qualitative Methods, Third edition* (pp. 507-535). Thousand Oaks, CA: Sage.

Charmaz, K. (2006). *Constructing Grounded Theory: A practical guide through qualitative analysis.* Thousand Oaks, CA: Sage.

Charmaz, K. (2008). Constructionism and the grounded theory method. In J. A. Holstein & J. F. Gubrium (Eds.), *Handbook of constructionist research* (pp. 397-412). New York: The Guilford Press.

Charmaz, K. (2009). Shifting the grounds: Constructivist grounded theory methods. In J. M. Morse, P. N. Stern, J. M. Corbin, B. Bowers & A. E. Clarke (Eds.), *Developing grounded theory: The second generation* (pp. 127-154). Walnut Creek, CA: University of Arizona Press.

Cheney, P. (1999). *The most important thing about exercise is not to have (patients with ME / CFS) do aerobic exercise*. Paper presented at the International Congress of Bioenergetic Medicine, Orlando, Florida.

Chew-Graham, C., Brooks,J., Wearden, A. Dowrick, C. & Peters, S. (2011) Factors influencing engagement of patients in a novel intervention for CFS/ME: a qualitative study

Christiansen, C. (2000). Identity, personal projects and happiness: self construction in everyday action. *Journal of Occupational Science, 7(3), 98-107.*

Ciambrone, D. (2001). Illness and other assaults on self: the relative impact of HIV/AIDS on women's lives. *Sociology of Health and Illness, 23(4), 517-540.*

Clark, M.R., Katon, W., Russo, J., Kith, P., Sintay, M., & Buchwald, D. (1995). Chronic fatigue: risk factors for symptom persistence in a 2 ½-year follow-up study*. American Journal of Medicine, 98, 187-195.*

Clarke, A. (1994). What is a chronic disease? The effects of a re-definition in HIV and AIDS. *Social Science & Medicine(39), 591-597.*

Clarke, A.E. (2005). *Situational analysis: Grounded theory after the postmodern turn*. Thousand Oaks, CA: Sage.

Clarke, J.N., & James, S. (2003). The radicalized self: the impact on the self of the contested nature of the diagnosis of chronic fatigue syndrome. *Social Science & Medicine, 57(8), 1387-1395.*

Clements, A., Sharpe M., Simkin S., Borrill J. & Hawton. K.(1997). Illnessbeliefs of patients with chronicfatigue syndrome: a quantitativeinvestigation. *Journal of PsychosomaticResearch42, 615-624.*

Compston, N.D. (1978). An outbreak of encephalomyelitis in the Royal Free Hospital Group, London, in 1955*. Postgraduate Medical Journal, 54, 722-724.*

Conrad, P. (1987). The experience of illness: recent and new directions. *Research in the Sociology of Health Care, 6, 1-31.*

Conrad, P., & Stults, C. (2008). *Contestation and Medicalization. Contesting Illness: Processes and Practices.* Toronto, ON: University of Toronto Press.

Corbin, J.A., & Strauss, A. (2008). *Basics of qualitative research, 3rd ed.* Thousand Oaks, CA: Sage.

Corbin, J.M., & Strauss, A. (1988). *Unending Work and Care: Managing Chronic Illness at Home*. San Francisco: Jossey-Bass Inc.

Corrigan, P.W. (2003). An attribution model of public discrimination toward persons with mental illness. *Journal of Health and Social Behavior, 44, 162-179.*

Craib, I. (1984). *Modern Social Theory*. Brighton: Harvester Wheatsheaf.

Crooks, D.L. (2001). The importance of symbolic interaction in grounded theory research on women's health. *Health Care for Women International, 22, 11-27.*

Crossley, M. (1998). 'Sick role' or 'empowerment'? The ambiguities of life with an HIV positive diagnosis. *Social Health and Ilness, 20, 507-531*

Crowhurst, G. (2005). Supporting People with Severe Myalgic Encephalomyelitis. *Nursing Standard, 19(21), 38-43.*

da Silva, L.C. (2004). Fibromyalgia reflections about empirical science and faith. *Journal of Rheumatology, 4, 828-829.*

Daily Mail (2013). *'The fog of fatigue I lived in for 15 years has lifted at last'* accessed on line from http://www.dailymail.co.uk/health/article-2283390/The-fog-fatigue-I-live-din-16-years-lifted-How-pop-art-legend-Roy-Lichtensteins-muse-conquered-chronic-ME.html

Deale, A., Chalder, T., Marks, I., & Wessely, S. (1997). Cognitive behaviour therapy for chronic fatigue syndrome: A randomised control trial. *American Journal of Psychiatry, 154, 408-414.*

Dean, R.G. (1993). Constructivism: An approach to clinical practice. Smith College Studies in *Social Work, 63(2), 127-146.*

de Carvalho-Leite, J.C., Drachler, M., Killett, A., Kale, S., Nacul, L., McArthur, M., Hong, C.S., O'Driscoll, L., Pheby, D., Campion, P., Lacerda, E. & Poland, F. (2011). Social support needs for equity in health and social care: a thematic analysis of experiences of people with chronic fatigue syndrome/myalgic encephalomyelitis. *International Journal of Equity and Health. 10: 46.* doi: 10.1186/1475-9276-10-46.

Dickson A., Knussen, C, & Flowers P. (2007). Stigma and the degitimation experience: An interpretative phenomenological analysis of people living with chronic fatigue syndrome. *Psychology & health 22 (7). 851-867.*

Dickson, A., Knussen, C., Flowers, P. (2008). 'That was my old life; it's almost like a past-life now': Identity crisis, loss and adjustment amongst people living with Chronic Fatigue Syndrome. *Psychology & Health, 23*(4), 459-476

Douglas, J.D. (1976). *Investigative social research*. Beverly Hills, CA: Sage.

Dumit, J. (2006). Illnesses you have to fight to get: facts as forces in uncertain, emergent illnesses. *Social Science & Medicine, 62(3), 577-590.*

Edwards, D. (1991). Categories are for talking: On the cognitive and discursive bases of categorization. *Theory & Psychology, 1(4), 515-542.*

Edwards, D. (1994). 'Script Formulations: A Study of Event Descriptions in Conversation.' *Journal of Language and Social Psychology, 13(3), 211-247.*

Edwards, D. (1995). Two to tango: Script formulations, dispositions, and rhetorical symmetry in relationship troubles talk. *Research on Language and Social Interaction, 28(4), 319-350.*

Edwards, D., & Potter, J. (1992). *Discursive psychology*. London: Sage.

Edwards, D., & Potter, J. (2005). Discursive psychology, mental states and descriptions. In H. te Molder & J. Potter (Eds), *Talk and Cognition: Discourse, Mind and Social Interaction*. Cambridge: Cambridge University Press.

Eisenberg, D.M. (1998). Trends in Alternative Medicine Use in the United States from 1990-1997 Results of a Follow-Up Study. *The Journal of the American Medical Association, 280(18), 1569-1575.*

Eisenberg, L. (1977). Disease and illness. Distinctions between professional and popular ideas of sickness. *Culture Medicine and Psychiatry, 1(1), 9-23.*

Erikson, E.H. (1980). *Identity and the life cycle*. New York: Norton.

Faircloth, C.A., Boylstein, C., Rittman, M., Young, M.E., & Gubrium, J.F. (2004). Sudden illness and biographical flow in narratives of stroke recovery. *Sociology of Health and Illness, 26(2), 242-261.*

Flick, U. (2000). Qualitative Inquiries into Social Representations of Health. *Journal of Health Psychology, 5(3), 315-324.*

Foucault, M. (1998). *The History of Sexuality Volume 1: The Will to Knowledge*. London: Penguin.

Frank, A. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago: The University of Chicago Press.

Freidson, E. (1970). *Profession of Medicine*. New York: Dodd Mead.

Friedberg, F., & Jason, L.A. (1998). *Understanding chronic fatigue syndrome: An empirical guide to assessment and treatment*. Washington DC: American Psychological Association.

Fukuda, K., Straus, S.E., Hickie, I., Sharpe, M.C., Dobbins, J.G., & Komaroff, A.L. (1994). The Chronic Fatigue Syndrome: A comprehensive approach to its definition and study. *Annals of Internal Medicine, 121, 953-959.*

Gately, C., Rogers, A., & Sanders, C. (2007). Re-thinking the relationship between long-term condition self-management education and the utilisation of health services. *Social Science & Medicine, 65, 934-945.*

Geertz, C. (1973). *The interpretation of cultures: selected essays*. New York: Basic Books.

Geertz, C. (1979). *"From the Native's Point of View: On the Nature of Anthropological Understanding" Interpretive Social Science.* (pp. 225-242). Berkeley: University of California Press.

Gergen, K.J. (1985). The social constructionist movement in modern psychology. *American Psychologist, 40(3), 266-275.*

Gergen, K.J. (1997). The social constructionist movement in modern psychology. *Theory & Psychology, 7(6), 723-746.*

Gergen, K.J., & Gergen, M.M. (1991). From theory to reflexivity in research practice In F. Steier (Ed.), *Method and reflexivity: Knowing as systemic social construction* (pp. 76-95). London: Sage.

Gergen, K.J., & Gergen, M.M. (2008). Social construction and psychological inquiry. In J. A. Holstein & J. F. Gubrium (Eds.), *Handbook of constructionist research* (pp. 171-189). Thousand Oaks, CA: Sage.

Glaser, BG, & Strauss, AL. (1967). *The discovery of grounded theory: Strategies for qualitative research.* New York: Aldine de Gruyter.

Glaser, B.G. (1992). *Basics of Grounded Theory Analysis: Emergence vs Forcing*. Mill Valley, CA: The Sociology Press.

Gluckman, M., & Gluckman, M. (1977). On drama and games and athletic contests. In S. F. Moore & B. Myerhoff (Eds.), *Secular Ritual*. Assen: Van Gorcum.

Goffman, E. (1963). *Stigma: Notes on management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.

Goudsmit, E.M., Stouten, B., & Howes, S. (2009). Illness Intrusiveness in Myalgic Encephalomyelitis. *Journal of Health Psychology, 14(2), 215-221.*

Goulding, C. (1999). Grounded theory: Some reflections on paradigm, procedures and misconceptions. In K. Gilbert (Ed.), *Working Paper Series*. Wolverhampton: University of Wolverhampton.

Grbich, C. (2007). *Qualitative data analysis: An introduction*. London: Sage.

Greenberg, D. (1990). Neurasthenia in the 1980's: Chronic mononucleosis, chronic fatigue syndrome and anxiety and depressive disorders. *Psychosomatics, 31, 129-137*.

Guba, E. &Lincoln, Y.S. (1994). Competing paradigms in qualitative research In: Denzin, N. &Lincoln, Y.S. (Eds.) *Handbook of Qualitative Research*. Thousand Oaks, California. Sage.

Hacking, I. (1998). *Mad Travellers*. London: Free Association Books.

Hammersley, M. (1992). *What's wrong with ethnography? : Methodological Explorations*.. London & New York: Routledge.

Hammersley, M. (1993). *Social research: Philosophy, politics and practice.* London: Sage.

Hammond, C. (2002). A Poorly Understood Condition: Disability Living Allowance and People with CFS/ME*. Social Policy and Administration, 36(3), 254-274.*

Hammond, J. (1986). Yuppies. *Public Opinion Quarterly, 50(4), 487-502.*

Hart, B., & Grace, V.M. (2000). Fatigue in chronic fatigue syndrome: A discourse analysis of women's experiential narratives. *Health Care for Women International, 21, 187-201.*

Heegaard, E.D. & Brown, K.E. (2002). Human Parvovirus B19. *Clinical Microbiology Reviews, 15(3), 485-505*

Henwood, K.L. (1996). Grounded theory: Practical implementation. In J. Richardson (Ed.), *Handbook of qualitative research methods for psychology and the social sciences*. Leicester: British Psychological Society.

Herzlich, C. (1973). *Health and Illness*. London: Academic Press.

Hill, R.C., Cheetham, R.W., & Wallace, H.L. (1959). Epidemic myalgic encephalomyelopathy: the Durban outbreak. *Lancet, 1(7075), 689-693.*

Hoffman, H.C. (2003). Recovery careers of people in Alcoholics Anonymous: moral careers revisited. *Contemporary Drug Problems, 30, 647.*

Holmes, G.P., Kaplan, J.E., Gantz, M.D., Komaroff, A.L., Schonberger, L.B., Strauss, S.E., . Brus, I. (1988). Chronic Fatigue Syndrome: A Working Case Definition. *Annals of Internal Medicine, 108(3), 387-389.*

Holstein, J.A., & Gubrium, J.F. (2008). *Constructionist Impulses in Ethnographic Fieldwork. Handbook of Constructionist Research. .* New York: Guilford Publications.

Honkasalo, M. (2001). 'Pain, self, and the body'. *The American Journal of Semiotics, 17(4), 9-31.*

Horton-Salway, M. (1998). *Mind and Body in the Discursive Construction of ME: A struggle for authorship of an illness.* Loughborough University.

Horton-Salway, M. (2001). Narrative Identities and the management of personal accountability in Talk about ME: A discursive approach to illness narrative. *Journal of Health Psychology, 6(2), 247-259.*

Horton-Salway, M. (2002). Bio-psycho-social reasoning in GP's case narratives: The discursive construction of ME patients' identities. *Health, 6, 401-421.*

Horton-Salway, M. (2004). The local production of knowledge: Disease labels, Identities and category entitlements in ME Support group talk. *Health, 8(3), 329-350.*

Horton-Salway, M. (2007). The ME Bandwagon and other labels: Constructing the authentic case in talk about a controversial illness. *Journal of Social Psychology, 46(4), 895-914.*

Hossenbaccus, Z., & White, P.D. (2013). Views on the nature of chronic fatigue syndrome: content analysis. *Journal of the Royal Society of Medicine, 4(1), 4.*

Howe, A., MacDonald, H. & Little, B. (2006). Ensuring public and patient participation in research: a case study in infrastructure development in one UK Research and Development consortium, *Primary Health Care Research and Development, 7, 60–67.*

Hughner, R.S., & Kleine, S.S. (2004). Views of Health in the Lay Sector: A Compilation and Review of How Individuals Think about Health. *Health, 8(4), 395-422.*

Huibers, M.J.H., & Wessely, S. (2006). The act of diagnosis: pros and cons of labelling chronic fatigue syndrome. *Psychological Medicine, 36(7), 895-900.*

Hunter, K.M. (1991). *Doctor's stories: The narrative structure of medical knowledge*. Princeton: Princeton University Press.

Hutchby, I., & Wooffitt, R. (1998). *Conversation analysis*. Cambridge: Polity Press.

Jackson, J.E. (2005). Stigma, liminality, and chronic pain: Mind? body borderlands. *American Ethnologist, 32(3), 332-353.*

Jackson, J.E. (2007). Rights to indigenous culture in Colombia. In M. Goodale & S. Merry (Eds.), *Transnationalism and the New Legal Order: Tracking Rights between the Global and the Local* (pp. 204-241). Cambridge: Cambridge University Press.

Jacobson, N. (2003). Defining recovery: an interactionist analysis of mental health policy development, Wisconsin 1996-1999. *Qualitative Health Research, 13, 378-393*.

Jacobson, N., & Curtis, L. (2000). Recovery as Policy in Mental Health Services: Strategies Emerging from the States. *Psychosocial Rehabilitation Journal, 23(4), 333-341.*

Jason, L.A., Bell, D.S., Rowe, J., Van Hoof, E., K., Jordanm, Lapp, C.,. De Meirleir, K. (2006). A pediatric case definition for myalgic encephalomyelitis and chronic fatigue syndrome. *Journal of Chronic Fatigue Syndrome, 13(2/3), 75-78.*

Jason, L.A., Corradi, K., Gress, S., Williams, S., & Torres-Harding, S. (2006). Causes of Death Among Patients With Chronic Fatigue Syndrome. *Health Care for Women International, 27(7), 615-626.*

Jason, L.A., Richman, J.A., Friedberg, F., Wagner, L., Taylor, R.R., & Jordan, K.M. (1997). Politics, science, and the emergence of a new disease. The case of chronic fatigue syndrome. *American Psychologist, 52(9), 973-983.*

Jason, L.A., Richman, J.A., Rademaker, A.W., Jordan, K.M., Plioplys, A.V., Taylor, R.R., McCready, W.J.,Huand, C., Plioplys, S. (1999). A community-based study of chronic fatigue syndrome. *Archives of Internal Medicine, 159, 2129-2137.*

Jason, L.A., Torres-Harding, S., Gurgens, A., & Helgerson, J. (2004). Comparing the Fukuda et al. criteria and the Canadian case definition for Chronic Fatigue Syndrome. *Journal of Chronic Fatigue Syndrome, 12(1).*

Jefferson, G. (1990). List-construction as a task and a resource. In G. Psathas (Ed.), *Interaction Competence* (pp. 63-92). Washington, D.C.: University Press of America.

Jerant, J.F., von Friederichs-Fitzwater, M.M., & Moore, M. (2005). Patients' perceived barriers to active self-management of chronic conditions. *Patient, Education and Counseling, 57(3), 300-307.*

Jones, E., & Wessely, S. (2004). War syndromes: the impact of culture on medically unexplained syndromes. *Medical History, 49, 55-78.*

Karp, D. (1996). *Speaking of sadness: depression, disconnection, and the meanings of illness*. New York: Oxford University Press.

Kelly, M., & Field, D. (1996). Medical sociology, chronic illness and the body. *Sociology of Health and Illness, 18, 241-257.*

Kerr, E., Heisler, M., Krein, S., Kabeto, M., Langa, K., Weir, D., & Piette, J. (2007). Beyond comorbidity counts: how do comorbidity type and severity influence diabetes patients' treatment priorities and self-management. *Journal of General Internal Medicine, 10(30).*

Kerr, J.R. (2005). Pathogenesis of parvovirus B19 infection: host gene variability, and possible means and effects of virus persistence. *Journal of Vetinary Medicine, 52(7-8), 335-339.*

Kirk, J. &Miller, M.L. (1986).*Reliability and Validity in Qualitative Research*. Newbury Park California. Sage.

Knoop, H., Bleijenberg, G., Gielissen, M.F.M., van der Meer, J.W.M., & White, P.D. (2007). Is a Full Recovery Possible after Cognitive Behavioural Therapy for Chronic Fatigue Syndrome? *Psychotherapy and Psychosomatics, 76, 171-176.*

Knoop, H., Stulemeijer, M., Prins, J.B., van der Meer, J.W.M., & Bleijenberg, G. (2007). Is cognitive behavioural therapy for chronic fatigue syndrome also effective for pain symptoms? *Behaviour Research & Therapy, 45(9), 2034-2043.*

Komaroff, A.L., Fagioli, L.R., Doolittle, T.H., Gandek, B., Gleit, M.A., Guerreiro, R.T., .Bates, D.W. (1996). Health status in patients with chronic fatigue syndrome and in the general population and disease comparison groups. *American Journal of Medicine, 101(3), 281-290.*

Krein, S., Heisler, M., Piette, J., Makki, F., & Kerr, E. (2005). The effect of chronic pain on diabetes patients' self-management. *Diabetes Care, 28(1), 65-70.*

Lawton, J. (2003). Lay experiences of health and illness: Past research and future agendas. *Sociology of Health and Illness, 25(3), 23-40.*

Le Compte, M.D. Goetz, J.P. (1982). Problems of Reliability and Validity in Ethnographic Research. *Review of Educational Research, 52, 31-60.*

Leininger, M. (1994).*Evaluation Criteria and Critique of Qualitative Research Studies*. San Francisco: Jossey-Bass.

Lincoln, Y.S.& Guba, E.G. (1985).*Naturalistic Inquiry*, Thousand Oaks, California: Sage.

Lindsay, S. (2009). Prioritizing Illness: Lessons in Self-Managing Multiple Chronic Diseases. *Canadian Journal of Sociology, 34(4), 983-1002.*

Little, M., Jordens, C.F., Paul, K., Montgomery, K., & Philipson, B. (1998). Liminality: A major category of the experience of cancer illness. *Social Science & Medicine, 47(10), 1485-1494.*

Lloyd, A.R., Hickie, I., Broughton, C.R., Spencer, O., & Wakefield, D. (1990). Prevalence of chronic fatigue syndrome in an Australian population. *Medical Journal of Australia, 153(9), 522-528.*

Locock, L., Ziebland, S., & Dumelow, C. (2009). Biographical disruption, abruption and repair in the context of Motor Neurone Disease. *Sociology of Health and Illness, 31(7), 1043-1058.*

Lombardi, V.C., Ruscetti, F.W., Das Gupta, J., Pfost, M.A., Hagen, K.S., Peterson, D.L., Mikovits, J.A. (2009). Detection of an infectious retrovirus, XMRV, in blood cells of patients with chronic fatigue syndrome. *Science, 326(5952), 585-589.*

Lupton, D., & Tulloch, J. (2002). Risk is part of your life: Risk epistemologies among a group of Australians. *Sociology, 36(2), 317-334.*

Martin, A., Chalder, T., Rief, W., & Braehler, E. (2007). The relationship between chronic fatigue and somatization syndrome: a general population survey. *Journal of Psychomatic Research, 63(2), 147-156.*

Mayou, R., & Farmer, A. (2002). ABC of psychological medicine: Functional somatic symptoms and syndromes. *British Medical Journal, 325, 265-268.*

ME Action UK (2012). *ME/CFS Symptoms* accessed 10/11/12 from http://www.bupa.co.uk/individuals/health-information/directory/c/hi-chronic-fatigue-syndrome

McCann, T.V., & Clark, E. (2003). Grounded theory in nursing research: Part 2 – critique. *Nurse Researcher, 11(2), 19-28.*

McCrone, P., Darbishire, L., Ridsdale, L., & Seed, P. (2003). The economic cost of chronic fatigue and chronic syndrome in UK primary care. *Psychological Medicine, 33(2), 253-261.*

McEvedy, C., & Beard, A.W. (1970). Royal Free epidemic of 1955: a reconsideration. *British Medical Journal, 1, 7-11.*

Mead, G.H. (1934). *Mind, Self and Society*. Chicago: University of Chicago Press.

Meeus, M., van Eupen, I., van Baarle, E., De Boeck, V., Luyckx, A., Kos, D., & Nijs, J. (2011). Symptom fluctuations and daily physical activity in CFS*. Archives of Physical Medicine and Rehabilitation, 92(11), 1820-1826.*

Mills, J, Bonner, A, & Francis, K. (2006). The development of constructivist grounded theory. *International Journal of Qualitative Methods, 5(1), 1-10.*

Miserandino, C. (2003). *The Spoon Theory*. Accessed 22/10/2012 from http://www.butyoudontlooksick.com

Moscovici, S. (1961). La Psycgoanalyse: *Son Image el son Public*. Paris: Presses Universitaires de France.

Moscovici, S. (1984). The phenomenon of social representations. In R. Farr & S. Mascovici (Eds.), *Social Representations* (pp. 3-70). Cambridge: Cambridge University Press.

Murray, M. (1990). Lay representations of illness. In P. Bennett, J. Weinmam & P. Spurgeon (Eds.), *Current developments in health psychology* (pp. 63-92). Chur: Harwood.

Murray, M. (1997). A narrative approach to health psychology: background and potential. *Journal of Health Psychology, 2(1), 9-20.*

Murray, M. (2000). Levels of narrative analysis. *Health Psychology. 5, 3(337-348).*

National Institute of Clinical Excellence, (NICE). (2007). *Chronic fatigue syndrome / myalgic encephalomyelitus (or encephalopathy): diagnoses and management of CFS / ME in adults and children.* Retrieved 22 Oct 2012, 2012, from www.nice.org

Navron, L., & Morag, A. (2003). Liminality as biographical disruption: unclassifiability following hormonal therapy for advanced prostate cancer. *Social Science& Medicine, 58(11), 2337-2347.*

NHS Choices (2012). *Chronic Fatigue Syndrome*, accessed 10/11/2012 from:
http://www.nhs.uk/Conditions/Chronic-fatigue-syndrome/Pages/Introduction.aspx

Nicholson, M., & McLaughlin, C. (1987). Social constructionism and medical sociology. *Sociology of Health and Illness, 9(2), 107-126.*

Olanow, C. W., & Tatton, W. G. (1999). Etiology and pathogenesis of Parkinson's disease. *Annual Review of Neuroscience, 22(1), 123-144.*

Onken, S. J., Craig, C. M., Ridgway, P., Ralph, R. O., & Cook, J. A. (2007). An analysis of the definitions and elements of recovery: A review of the literature. *Psychiatric Rehabilitation Journal, 31(1), 9-22.*

Parker, I. (1998). *Social constructionism, discourse and realism*. London: Sage.

Parsons, T. (1951). *The social system.* London: Routledge & Kegan Paul.

Patterson, B.L., & Thorne, S.E. (2000). The developmental evolution of expertise in diabetes self-management. *Clinical Nursing Research, 9(4), 402-419.*

Pemberton, S. & Cox, D. (2014). Perspectives of Time and Occupation: Experiences of People with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis, *Journal of Occupational Science, 21 (4), 488-503.*

Pomerantz, A. (1986). Extreme case formulations: A way of legitimizing claims. *Human Studies, 9(2-3), 219-230.*

Potter, J. (1996). Discourse analysis and constructionist approaches: theoretical background. In J. Richardson (Ed.), *Handbook of Qualitative Research Methods* (pp. 125-140). Leicester: British Psychological Society.

Potter, J. (1997). Discourse analysis as a way of analysing naturally occurring talk. In D. Silverman (Ed.), *Qualitative research. Theory, method and practice* (pp. 144-160). London: Sage.

Potter, J., Edwards, D., & Wetherell, M. (1993). A model of discourse in action. *American Behavioural Scientist, 36(3), 383-401.*

Potter, J., & Wetherell, M. (1987). *Discourse and Social Psychology: Beyond Attitudes and Behaviour.* London: Sage.

Potter, J., & Wetherell, M. (1994). Analyzing discourse. In A. Bryman & B. Burgess (Eds.), *Analyzing Qualitative Data* (pp. 47-56). London: Routledge.

Potter, J., & Wetherell, M. (1995). Discourse analysis. . In J. Smith, R. Harré & L. van Langenhove (Eds.), *Rethinking Methods in Psychology* (pp. 80-92). London: Sage.

Pound, P., Gompertz, P., & Ebrahim, S. (1998). Illness in the context of older age: the case of stroke. *Sociology of Health and Illness, 20(4), 489-506*.

Radley, A. (1994). *Making Sense of Illness: The Social Psychology of Health and Disease* London: Sage.

Raine, R., Carter, S., Senski, T., & Black, N. (2004). General Practitioners' perceptions of chronic fatigue syndrome and beliefs about it's management in comparison with irritable bowel syndrome: A qualitative study. *British Medical Journal, 328, 1354-1357.*

Ramsay, A.M. (1957). Encephalomyelitis in North West London. An endemic infection simulating poliomyelitis and hysteria. *Lancet, 2, 1196-1200.*

Ramsay, A.M., & O'Sullivan, E. (1956). Encephalomyelitis simulating poliomyelitis. *Lancet, 270(6926), 761-764.*

Ray, C. (1991). Chronic fatigue syndrome and depression: conceptual and methodological ambiguities. *Psychological Medicine, 21, 1-9.*

Reid, S., Chalder, T., Hotopf, M., Cleare, A., & Wessely, S. (2000). Extracts from clinical evidence: Chronic fatigue syndrome. *British Medical Journal, 320(7230), 292-296.*

Rennie, D.L., Phillips, J.R., & Quartaro, G.K. (1988). Grounded theory: A promising approach to conceptualisation in psychology? *Canadian Psychology, 29(2), 139-150.*

Reynolds, F. (2003). Reclaiming a positive identity in chronic illness through artistic occupation. *Occupational Therapy Journal of Research, 23(3), 118-127.*

Ritzer, G. (2004). *The McDonaldization of Society: Revised New Century Edition*. London: Sage.

Ross, J.S., & Wilson, K.J.W. (2001). *Physiology in Health and Illness* London: Physiology in Health and Illness

Sanders, C., Donovan, J., & Dieppe, P. (2002). The significance and consequences of having painful and disabled joints in older age: Co-existing accounts of normal and disrupted biographies. *Sociology of Health and Illness, 24(2), 227-253.*

Sarbin, T.R., & Kitsuse, J.I. (1994). *Constructing the Social*. London: Sage.

Savely, V.R., & Stricker, R.B. (2010). Morgellons disease: Analysis of a population with clinically confirmed microscopic subcutaneous fibers of unknown etiology. *Clinical, Cosmetic and Investigational Dermatology, 3, 67-78.*

Scambler, G., & Hopkins, A. (1986). Being epileptic: coming to terms with stigma. *Sociology of Health and Illness, 8(1), 26-43.*

Sharpe, M.C., Archard, L.C., Banatvala, J.E., Borysiewicz, L.K., Clare, A.W., David, A., Lane, R.J. (1991). Chronic Fatigue Syndrome: Guidelines for Research. *Journal of the Royal Society of Medicine, 84(2), 118-121.*

Shepherd, C. (1988). *Living with M.E. the chronic / post-viral fatigue syndrome*. Reading: The Random House Group Ltd.

Shotter, J. (1992). Social constructionism and realism: Adequacy or accuracy? *Theory & Psychology, 2, 175-182.*

Shotter, J. (1993). *Conversational Realities: Constructing life through language*. London: Sage.

Sibbett, C. (2006). *Nettlesome Knowledge, liminality and the taboo in cancer and art therapy experiences*. Paper presented to Threshold Concepts in the Disciplines Symposium. University of Strathclyde

Silverman, D. (1985). *Qualitative Methodology and Sociology*. Aldershot: Gower.

Singer, E. (1974). Premature social aging: the social-psychological consequences of a chronic illness. *Social science & medicine, 8, 143-151.*

Skeat, J., & Perry, A. (2008). Grounded theory as a method for research in speech and language therapy. *International Journal of Language & Communication Disorders, 43(2), 95-109.*

Smith, D.E. (1978). K is mentally ill: the anatomy of a factual account.*Sociology, 12(1), 25-53.*

Soderlund, A & Malterud, K. (2005). Why did I get Chronic Fatigue Syndrome? A qualitative interview study of causal attributions in women patients. Scandinadian Journal of Primary Healthcare, 23, (4), 242-7.

Starnino, V.R. (2009). An Integral Approach to Mental Health Recovery: Implications for Social Work. *Journal of Human Behavior in the Social Environment, 19, 820-842.*

Strauss, A., & Corbin, J.A. (1990). *Basics of qualitative research: Grounded theory procedures and techniques.* Newbury Park, CA: Sage.

Tamm, M., &Soderlund, L. (1994*). Vad distriktsl . akare anser om fibromyalgi [General practitioners views on fibromyalgia].* Boden: V (ardh.ogskolan).

Taylor, R. R., Jason, L. A., Richman, J. A., Toress-Harding, S. R., King, C., & Song, S. (2003). Epidemiology. In L. A. Jason, P. A. Fennell & R. R. Taylor (Eds.), *Handbook of chronic fatigue syndrome* New York: Wiley.

Thompson, K. (2007). Liminality as a Descriptor for the Cancer Experience*. Illness Crisis and Loss, 15(4), 333-351.*

Turner, V.W. (1957). *Schism and continuity in an African society: a study of Ndembu village life.* Manchester: Manchester University Press.

Turner, V.W. (1965*). Ritual symbolism among the Ndembu. In M. Fortes & G. Dieterlen (Eds.), African Systems of Thought*. Oxford: Clarendon Press.

Turner, V.W. (1967). *The Forest Symbols: Aspects of the Ndembu Ritual*. Ithaca, New York: Cornell University Press.

Turner, V.W. (1969). *The Ritual Process: Structure and Anti-structure*. Chicago: Aldine Pub.

Van Geelen, S.M., Sinnema, G., Hermans, H.J.M., & Kuis, W. (2007). Personality and chronic fatigue syndrome: methodological and conceptual issues. *Clinical Psychology Review, 27(8), 885-903.*

Van Gennep, A. (1909). *Les Rites de passage* Paris: Picard.

Van Gennep, A. (1960). *The Rites of Passage*. Chicago: University of Chicago.

Van Houdenhove, B., Bruyninckx, K., & Luyten, P. (2006). In search of new balance. *Journal of Psychomatic Research, 60(6), 623-625.*

Vercoulen, J.H, Swanink, C.M., Fennis, J.F., Galama, J.m., van der Meer, J.W.M., & Bleijenberg, G. (1996). Prognosis in chronic fatigue syndrome: a prospective study on the natural course. *Journal of Neurology, Neuropsychology and Psychiatry, 60(5), 489-494*.

Ware, N.C. (1992). Suffering and the Anthropology social construction of illness: The delegitimation of illness experience in chronic fatigue syndrome. *Medical Quarterly, 6(4), 347-361.*

Ware, N.C. (1998). Sociosomatics and Illness Course in Chronic Fatigue Syndrome. *Psychosomatic Medicine, 60(4), 394-401*.

Wessely, S. (1999). "To tell or not to tell": The Problem of medically unexplained symptoms. In A. Zeman & L. L. Emanuel (Eds.), *Ethical Dilemmas in Neurology* (pp. 41-53). Oxford: Harcourt Publishers Limited.

Wessely, S., Chalder, T., Hirsch, S., Wallace, P., & Wright, D. (1997). The prevalence and morbidity of chronic fatigue and chronic fatigue syndrome: a prospective primary care study. *American Journal of Public Health, 87(9), 1449-1455.*

Wessely, S., Nimnuan, C., & Sharpe, M.C. (1999). Functional somatic syndromes: One or many? *Lancet, 354, 936-939.*

Wetherell, M., & Potter, J. (1992). *Mapping the language of racism: Discourse and the legitimation of exploitation*. London: Sage.

Whitehead, L. (2004). Enhancing the quality of hermeneutic research: Decision trail. *Journal of Advanced Nursing, 45(5), 512–518.*

Whitehead, L. (2006). Toward a trajectory of identity reconstruction in chronic fatigue syndrome/myalgic encephalomyelitis: a longitudinal qualitative study. *International Journal of Nursing Studies, 43(8), 1023-1031.*

Williams, K.D. (2001). *Ostracism*: The Power of Silence. New York: Guildford Publications.

Williams, R.G.A. (1983). Concepts of health: an analysis of lay logic. *Sociology, 17(2), 183-205.*

Williams, S.J. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health and Illness, 22(1), 40-67.*

Willig, C. (1991). *Applied discourse analysis: social and psychological interventions.* Buckingham: Open University Press.

Wilson, S. (2007). 'When you have children you're obliged to live': motherhood, chronic illness and biographical disruption. *Sociology of Health and Illness, 29(7), 610-626.*

Wooffitt, R. (1992). *Telling tales of the unexpected: The organization of factual discourse*. London: Harvester/Wheatsheaf.

Yardley, L. (2000). Dilemmas in Qualitative Health Research. *Psychology and Health, 15, 215-28.*

Yawn, B. (2001). Is diabetes treated as an acute or chronic illness in community family practice? *Diabetes Care, 24, 1390*.

Yoshida, K.K. (1993). Reshaping of self: A pendular reconstruction of self and identity among adults with traumatic spinal cord injury. *Sociology of Health and Illness, 15(2), 217-245.*

Zavestoski, S., Brown, P., McCormick, S., Mayer, S., D'Ottave, M., & Lucove, J.C. (2004). Patient activism and the struggle for diagnosis: Gulf War illness and other medically unexplained physical symptoms in the US. *Social Science &Medicine, 58, 161-175.*

Zbinden, R., Kurer, S.B., Altwegg, M., & Weber, R. (1996). Generalized infection with Bartonella henselae following infection due to Epstein-Barr virus. *Clinical Infectious Diseases, 23(5), 1184-1185.*

Zigmond, A.S., & Snaith, R.P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica, 67(6), 361-370.*

Appendix A Literature Review Table

Author (s) (Year)	Location	Data Collection	Recruitment /sample	Criterion	Sample size
Anderson, Jason & Hlavaty (2014)	US	Semi-structured	Community based sample	Fukuda	19
Asbring (2001)	Sweden	Semi- structured interviews	Hospital outpatient clinic/ strategic sample	Fukuda (CFS) Wolfe (FM)	12 13
Arroll & Senior (2008)	UK	Semi-structured interviews	ME/CFS support groups	Not specified	8
Asbring & Narvanen (2002)	Sweden	Semi- structured interviews	Hospital outpatient clinic/ strategic sample	Fukuda (CFS) Wolfe (FM)	12 13
Clarke & James (2003)	Canada	Semi- structured interviews	Local support groups	Not specified	59
Clements et al (1997)	UK	Semi-structured interviews	Hospital 'infectious diseases' department	Oxford	66
De Carvalho Leite, et al (2011)	UK	Semi-structured interviews/ focus group	ME/CFS support groups	Not specified	35
Dickson, Knussen & Flowers (2007)	UK	Semi structured interviews	Alternative therapy clinic (7)/ Personal contact (7)	Fukuda	14

Dickson, Knussen & Flowers (2008)	UK	Semi structured interviews	Alternative therapy clinic (7)/ Personal contact (7)	Fukuda	14
Horton-Salway (2001)	UK	Semi-structured interview	Unknown	Not specified	1 (and Carer)
Soderlund & Malterud (2005)	Norway	Semi- structured interview	Self-help group	Not specified	8
Whitehead (2006) (a)	UK	Semi-structured interview	Hospital setting (10) Support groups (3) Snowballing (4)	Diagnosis not part of criteria	17
Whitehead (2006)	UK	Semi-structured and Longitudinal	Hospital setting (10) Support groups (3) Snowballing (4)	Diagnosis not part of criteria	17

Appendix B Information about changes in research direction and data collection

When I approached the ME/CFS community with the details of how the data would be collected I was forced to re-evaluate this approach. Although the response to my proposed research topic of ME/CFS and employment was positive and welcomed, there was an almost completely negative reaction to the use of quantitative data methods. Further discussions with ME/CFS support group leaders about this topic were enlightening. It seems that some of the ME/CFS community had been involved in the consultations that predated the formulations of the National Institute for Clinical Excellence (NICE) guidelines which were published in 2007. These guidelines were something that the ME/CFS community at large had been eagerly awaiting in the hope that it would finally document the illness in the 'right' way (i.e. as a physical illness rather than a psychological one) and lay the years of debate over its origins to rest. Therefore many offered to help the working party who were in charge of collating evidence to base the guidelines on by offering a 'patient perspective' on what it was like to have the illness and became part of NICE's patient consultation. Group leaders informed me that as part of the consultation group members were sent a significant number of complex questionnaires to complete and return in the post. The burden of this was enormous because the questionnaires related to 'illness' but not specifically to ME/CFS and therefore completing them involved writing numerous, additional explanatory comments and even letters explaining about ME/CFS in more detail. In addition to this there was a very stringent time constraint which put people under pressure to complete them quickly. Subsequently the pressure and exertion made their condition worse. Although this was a taxing process for pwME/CFS they completed it and I was informed that they were pleased to make a positive contribution by championing ME/CFS as a 'proper' medical illness and it was their understanding that it would be recognised as such by the medical community following this input.

The problem, which had a direct impact on this research, it appears, arose when the NICE (2007) guidelines were published as on the whole the ME/CFS community were extremely disappointed with the classification and description of ME/CFS. The classification, they claim, focuses heavily on the notion that the illness is psychological in nature and therefore it does not reflect their experiences of ME/CFS or the information that they provided prior to the formulation of the guidelines. More poignantly the guidelines do not acknowledge the

physical difficulties that are caused by the illness, which members of the consultation group felt they went to great lengths to convey. These scenarios led to a deep distrust of questionnaires in general. There seemed to be a pervasive belief that these were laborious and taxing to undertake and a suggestion any subsequent answers could later be manipulated and misrepresented until they failed to reflect the sufferers' experiences.

Clearly I do not propose to present this anecdotal account as factual chain of events, but nonetheless these perceived happenings had an impact upon my early research plans. This explanation as to *why* the ME/CFS community were reluctant to undertake quantitative research was reflected in several conversations with group leaders and individual ME/CFS sufferers which meant that there was clearly an aversion to answering questionnaires. This led to a rethink of my methodology and in order to retain the trust of my participant I decided to proceed on the basis of interviews only. Although I considered the possibility of approaching the participants after the qualitative analysis was complete in order to develop a quantitive questionnaire designed specifically for pwME/CFS at a later date.

Appendix C- Information for Support Group

From: Kate Butlin [mailto:p04259060@myemail.dmu.ac.uk]
Sent: 04 November 2009 12:23
To: Support Group

Subject: ME/CFS research please help

Dear (removed)

I hope that you are able to help me. My name is Kate Butlin and I am a PhD student at De Montfort University in Leicester. The topic of my PhD is ME/CFS, Employment and Identity and I am interested in the work related experiences of people with ME and also those of people that have recovered from it.

My inspiration comes from my fiancée who has had ME for almost 8 years now and has been in a great deal of pain for most of that time. I'm sure ours is a story that you are familiar with... an unhelpful GP, friends and some family that do not understand, a loss of employment and a general feeling of being unsure of what to do for the best. To me it is apparent that the physical aspect of the illness is exacerbated by the lack of research that surrounds it. I resolved to try and do something about this by conducting some research myself and I have now almost completed the first year of my PhD
As it stands at the moment I have interviewed people who have had ME for many years and have been unable to work for that time, which has proved to be invaluable. However, I would like to contrast this with the experiences of people who feel that they have either completely or almost completely 'recovered' (I know there are problems with definition here) from ME/CFS or who are able to maintain any kind of a working life. All I am asking people to do is tell me about their experiences of being ill and becoming recovered if applicable and how this has affected their working life.

I would be extremely grateful if you could pass my details to any of your current or previous members and invite them to get in touch with me. I have attached my information sheet for participants, which also includes details about the university and how to contact my supervisors if anyone wishes to. I also have a website which is p04259060@myemail.dmu.ac.uk(p04259060@myemail.dmu.ac.uk) (my university email) or kate@cfs-me-study.org.uk . Alternatively if you wish to provide me with provide a telephone number I am quite happy to call and discuss my research with you.
Thank you for your help,
Best wishes,
Kate Butlin

Appendix D Participant Information sheet

Project title: **An Interval study of M.E. Employment and Identity**

You are invited to participate in the above research, which forms part of my MPhil/PhD at De Montfort University, Leicester. Participation is entirely voluntary and this document provides further information about the study to help you make a decision. Please discuss this research with others if you wish and you are welcome to contact either myself or my supervisors if you have any further questions.

The purpose of the study

The purpose of this research is to gather the employment related experiences of people with ME/ CFS. As you will be aware many people are forced to significantly reduce or cease employment once they become ill. PMWE /CFS trying to remain in or return to employment are faced with numerous challenges. These include liaising with employers to ask for accommodation in the workplace, arguably, particularly difficult as employers are not legally required to make adjustments for the illness. Unemployed people have to balance aiming for recovery, and a long term return to work, whilst not jeopardizing their entitlement to pension or state benefits. People returning to the workplace after a long absence struggle to present themselves as capable employees when doctors have attributed characteristics such as, conscientiousness and being high achievers as contributory factors to developing ME/CFS.

It is hoped that this information will highlight some of the difficulties that PWME encounter when returning to or attempting to remain at work, and also identify the type of support that is needed from employers.

I have recovered from ME/CFS – can I still participate?

Yes. Part of the study involves asking people who have recovered to divulge their experiences of employment related support.

Do I have to take part?

No, participation is entirely voluntary. You are also able to withdraw your participation from the study at any time without penalty or prejudice.

What would I have to do?

This is a longitudinal study and you will be asked to complete the following twice with an interval of a year. You will be asked to complete 5 questionnaires, which take approximately 10 minutes each and you may be asked to participate in a semi-structured interview, which will be recorded, lasting about an hour.

When, where and how?

The questionnaires can be completed online, via an especially designed secure website, or using pen and paper. Interviews will be arranged at a time and location which is convenient to you or may take place on the telephone.

What accommodations have been made for my illness?

The researcher understands how the symptoms of the illness may make it difficult to adhere to definite time frames. Therefore please note that the questionnaires can be completed at your own pace, and the website is designed so as they can be saved partially completed. Interviewees are welcome to take breaks as necessary or request that the interview be completed at a later date.

Will my information be kept confidential?

Yes all information is collected and stored in accordance with the principles of the British Psychological Society and in accordance with the Data Protection Act. Your real identity will not be referred to in any of the interviews or questionnaires. Audio recordings will be kept in a secure location and will only be heard by the researcher and the supervisors.

What will happen to my data?

Any data collected will be kept securely. At the end of the study audio recordings will be destroyed. You may request partial or full removal of your data up to three weeks after submitting a completed questionnaire or receiving your interview transcript.

What are the possible disadvantages of taking part?

You will not be asked to do anything harmful. Please note that you are not under any obligation to answer any questions that you are not happy with and interviews can be ceased immediately in the event of you being uncomfortable. The researcher is not qualified to provide advice but will be able to provide details of helpful organisations to contact for assistance.

What if there is a problem?

Your comments, concerns and suggestions are very welcome and will all be addressed. Please contact the researcher in the first instance. If you are unable to do this for any reason then please contact my supervisors using the details below.

What will happen to the results of the study?

This information will be used for my report, which may be published. Please let me know if you would like a summary of the results once this has been completed.

Who has reviewed this study?

The study has been approved by the Research Ethics Committee of the Faculty of Health and Life Sciences at De Montfort University, Leicester.

Researchers contact details

Kate Butlin   Email: p04259060@email.dmu.ac.uk
c/o H0.17a Hawthorn Building   Email: kate@cfs-me-study.org.uk
DeMontfort University
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Supervisors

Dr Rosemary Chapman   Dr Brown
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Tel: 0116 2078411   Tel: 0116 2551551
Email: Rchapman02@dmu.ac.uk   Email: brown@brown.uk.com

Appendix E –Consent form

Date:

I,   state that I am over 18 years of age and that I voluntarily agree to participate in a research project conducted by Kate Butlina PhD Psychology Student, studying at De Montfort University, Leicester.

I understand that this research forms part of a PhD, entitled: A longitudinal study of employment related support for people with ME/CFS in the Midlands.

I have been provided with a copy of 'information for volunteers' and understand that I am being invited to participate in semi-structured interviews which will last about one hour and I agree to the whole interview being recorded and transcribed for the purposes of analysis. I have also been asked to complete of questionnaires and I realise that I am able to complete these online via a specially designed secure website, or via paper copy.

I acknowledge that Kate Butlin has explained the task to me fully; has informed me that I may withdraw my participation at any time without prejudice or penalty; has offered to answer any questions that I might have concerning the research procedure; has assured me that any information that I give will be used for research purposes only and will be kept strictly confidential and anonymous; has informed me that I can request partial or whole withdrawal of my data up to three weeks after receiving my transcript or submitting my data online. I understand that some of the transcripts of the interview may be used in research documents and may be published in scientific journals.

I understand that if I so wish I can have a copy of the summarised results of the study.

------------------------------------   ---------------------------
Signature of student (Researcher)   Signature of participant

Researcher Contact Details:	Contact Details of supervisor
Kate Butlin	Dr Rosemary Chapman
Health and Life Sciences	Health and Life Sciences
De Montfort University	Room H0.17a
The Gateway	De Montfort University
Leicester	The Gateway
LE1 9BH	Leicester
	LE1 9BH
Email: P04259060@learner.dmu.ac.uk	Email: RChapman02@dmu.ac.uk

Appendix F - Interview questions and prompts- pwME/CFS and pirfME/CFS

<u>For people with ME</u>

- Can you tell me a bit about how did you initially found out that you had ME?

- How long have you have had ME for?

- What symptoms do you experience? How do they affect you?

- How has the illness affected your life

- (prompt in terms of work, hobbies, social role?)

- How has it affected your work?

- Have you approached your employers for support at work?

- (prompt What response have you been met with?)

- How do you manage day to day activities?

- Prompt what strategies do you employ (resting, medication etc)

- What do you consider to be the greatest difficulty of having ME/CFS?

- Have you tried any treatments?

- Overall do you think your condition is improving?

- Is there anything that else you would like to add about your experiences?

Appendix G - Interview questions and prompts- people recovered from ME/CFS

- Can you tell me a bit about when you had ME?

- How did you find out that you had it?

- What symptoms did you have and how did they affect you?

- (work, hobbies & social role)

- How did you recover, what happened?

- (medication, CAMTS or medical, timing)

- Do you still have symptoms? What are they and how do you deal with them?

- What is the greatest difference between being ill and being recovered?

- Would you say that your life is similar now to how it was before you became ill?

- What advice would you give to people who are ill and struggling with the condition?

- Is there anything else you would like to add about your experiences ME/CFS or recovery?

Appendix H - Debrief form

Thank you for participating in this research your time is very much appreciated.

Please contact me, using the details below if you have any questions or concerns regarding this research.

Please find attached a list of helpful organisations to contact in the unlikely event that this research has caused you any distress:

Organisation	Telephone number	Email address
The ME Association	01280 818968 (9.30-4.30)	www.meassociation.org
Samartians	08457 909090 (24 hours)	jo@samaritans.org
Disability benefits helpline	08457 123456 (7.30-6.30)	CPU.Customer-Services@dwp.gsi.gov.uk
Advisory Concillation and Arbitration Service for work related advice	08457 474747 (8 – 6)	www.acas.org.uk

Thank you once again for your help.

Kind regards,

Kate Butlin

Kate Butlin
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Leicester

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