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**A LIFE LIVED DIFFERENTLY: AN EXPLORATION OF HOW LIVING WITH CHRONIC
FATIGUE SYNDROME/MYALGIC ENCEPHALOMYELITIS (CFS/ME) IMPACTS UPON
PEOPLE'S IDENTITY**

REBECCA ELIZABETH MURRAY

A thesis submitted to the University of Huddersfield in partial fulfilment of the requirements for
the degree of Doctor of Philosophy

The University of Huddersfield

November 2016

In loving memory of my late father, David (1944-2010)

For my beautiful Mum, Margaret, without whom, I would not have been able to survive the years of intolerable illness. I will never have the words. xxx

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Firstly, I would like to thank my truly wonderful participants, without whom the current research would not have been possible.

In life, and whilst in pursuit of my PhD, I have been blessed by the love and support of my precious husband, Troy, who has always been there for me and who has always had faith in me. xxx

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During my final year, two out of three of my supervisors moved on from the University of Huddersfield and in so doing, had to leave the supervisory team. When Jane was forced to take time off just a few months before I was due to submit, I became a team of one, until Dr. Berenice Golding stepped into the breach! Many thanks, Berenice for helping me to reach the finish line.

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ABSTRACT

Existing literature provides an insight into CFS/ME, but it is fractured, in that it does little to serve understanding, empathy or coping. Moreover the experiences of people with CFS/ME are under theorised. The literature demonstrates that issues of identity appear central to the lived experience of chronic illness, yet the mechanisms underpinning identity are not fully explored. Consequently there is little understanding of the crisis of identity in CFS/ME. Therefore, the aims and objectives of the current research endeavoured to examine identity within the context of the lived experience of CFS/ME.

Drawing upon Wenger's (1998) 'Communities of Practice' theory (CoP), the current research aimed to make transparent the mechanism of identity by exploring the lived experience of identity in chronic illness; specifically CFS/ME. It is argued throughout, that a millennia of meaning underpins the crisis of identity in CFS/ME and that CoP, whilst predominantly a social theory of learning, was re-conceptualised here to illuminate the crisis of identity in chronic illness.

Data were gathered via a closed Facebook group; cfsid, which was created for the purpose of the current research. Participants (n. 37) contributed over time and in depth and in so doing revealed the complex foundation of their shifting identities. The data was analysed using a theoretical thematic analysis (Braun and Clarke, 2006).

Aligned with CoP, the key findings indicate that the mechanism underpinning the crisis of identity in CFS/ME is the changing nature of participation. The history of CFS/ME is one defined by scepticism and as such the controversy surrounding CFS/ME interacted with the lived experience of the illness for participants. The lived experience of CFS/ME for participants was reliably defined by their inability to participate in either life or self. Lives and selves were unrecognisable, but all was not lost as acceptance and adjustment allowed participants to negotiate ways in which they could participate despite their CFS/ME. Participants' experiences of participation emerged within the analysis as a journey to finding a new way to be in the world. On looking to the future, if people with CFS/ME are to be better supported and enabled within their lived experience of chronic illness, the burdening history of CFS/ME needs to be replaced by legitimacy, and the importance of the negotiation of participation in chronic illness needs to be illuminated further.

PROLOGUE

My CFS/ME story; a brief overview

I became ill when I was 18. One day I was a healthy teenager, and the next I was housebound. My life was literally stopped over night. At first the doctors thought I had some sort of virus, but when weeks passed with no improvement, they arranged a series of blood tests to rule out anything 'sinister'. All tests came back clear, so it was concluded that I must be suffering post viral fatigue, and that with time I would recover. I was struggling to cope with being so ill, so utterly incapacitated. I was desperate to get better, to get back to my life, but there appeared no end to my suffering as every day was Groundhog Day; no change and no improvement. I found it very difficult to accept that the world was continuing to turn whilst I was frozen in time, frozen in what felt like a living nightmare. Not only was I trapped inside the four walls of my parents' home, but I was also trapped within my body as I could no longer be myself in any way at all, I even struggled to talk due to the chronicity of my fatigue. However, during every appointment with my GP, I was told that with time I would feel much better, but I never felt better. I was becoming increasingly desperate as life for me was becoming increasingly unbearable and I was scared, really scared as it felt like I had been abandoned, like I had been left to rot.

I was becoming tired of people intimating that I needed to 'snap out of it', that it was a mind over matter situation and that Myalgic Encephalomyelitis (ME) was 'all in the mind'. The scepticism surrounding my illness cut deep as suffering, as I was, was bad enough without this shadow of doubt that was hanging over me. During one of my GP appointments it all got too much and I broke down, which resulted in a psychiatric referral. A few weeks later a psychiatrist concluded that I was not depressed, a danger to myself or anyone else. I subsequently asked to be referred to the local Chronic Fatigue Service, as at six months in, I feared I had ME. Six months later I was diagnosed with ME and told that I should not expect to recover 100%. I was devastated, but hoped that the referral to their Occupational Therapy (OT) team would help me to get better. I never received an appointment, and 12 months later I was worse than I had ever been. My Mum phoned the OT team to ask for help. I was visited at home as an emergency, told I needed to be admitted, but that I was too vulnerable for the ward on which ME patients were placed; the psychiatric ward. MY OT agreed to continue to see me at home, but when I was unable to make progress, the home visits had to end.

I deteriorated further over the next two years, and as such although I thought I had experienced rock bottom, it transpired I hadn't. I was now existing in a darkened room. I weighed just over 5 stones as I was no longer able to physically chew or swallow food. My Mum had become my full time carer as I was unable to do anything for myself. I looked like a living corpse, I was emaciated, grey, my eyes were dark and sunken and my hair was falling out. My Mum went to see my GP and demanded a home visit. I can still recall the look of shock on my GP's face when she saw me. *"I didn't realise you were so ill"* she said.

I was admitted to a local hospital via the local chronic fatigue service, but thankfully not to a psychiatric ward. My illness had stripped me of 'me', and my self-worth, pride, and dignity. I was unrecognisable, there was no evidence of the girl who had once been so full of life, she lived within, but she was locked away. I spent a number of dreadful weeks in hospital, I felt so degraded by my incapacity and dependence on others, but I committed 100% to my rehabilitation programme as all I wanted was to get better, all I wanted was to be me again. I was told that I was one of the worst patients they had ever seen and that they were unsure if I would be able to recover, but I never gave up hope, I never gave up the fight and as such I did make some progress. When I was discharged I was able to eat, and take a few steps. I had also begun to tackle self care tasks, but the struggle of basic tasks such as dressing, and brushing my teeth etc. illuminated to me the enormity of the challenge ahead, but I hoped that the only way this time, was up.

The following 15 years were defined by painstakingly slow rehabilitation with ups and downs in equal measure. One up has to be graduating from the University of Huddersfield with a 1st in Psychology. It took me six years, and although it was all I could do during those years, I did it, which then enabled me to pursue my PhD dream. I continue to live in the aftermath of ME; I have been scarred both physically and psychologically. I would not wish my ME journey on anyone as the horror of it, the desperation, the abandonment, the scepticism and the relentless suffering is something that only an insider could truly understand, and something that I could not endure again.

I continue to be frustrated by the scepticism surrounding ME and Chronic Fatigue Syndrome (CFS) and the lack of understanding and empathy which burdens those who are already burdened by symptomatology. On considering a focus for my doctoral research, it was a given, following on from my undergraduate project titled 'Experiences of identity transition and Chronic Fatigue Syndrome: A qualitative study', that I would pursue this further. Due to my lived experience of CFS/ME and insider perspective, I was not driven to explore symptomatology or medical outside theorising, I was not interested in reaction to diagnosis or medicalised coping, but I was interested in lived experience.

I wanted to explore the whole process of being in CFS/ME and the relationship between the whole process of being and the shifting identity of those with CFS/ME by exploring the lived experience of participants. The physical hit of CFS/ME is immense, but there is a millennia of meaning underpinning the lived experience of this chronic illness, and a millennia of meaning that underpins the jeopardised identity of those with CFS/ME. I was tired of reading fractured accounts of CFS/ME, overviews lacking in depth and context, reviews focussing narrowly upon the 'psychological component' of the illness once known as 'yuppie flu'; a psychosomatic illness affecting the middle classes (Hodgkinson, 1988). Therefore, if the lived experience of CFS/ME was to be illuminated, I had to provide a more thorough insight into CFS/ME in an attempt to enable the true story of CFS/ME to emerge, a story that I hoped would serve those with CFS/ME who are burdened by the shadow and isolation of scepticism and doubt surrounding the illness.

The current research; my personal journey

One of my unique contributions, as a sufferer, is my understanding of the lived experience of CFS/ME, but on immersing myself in the literature, it became apparent that even I had underestimated the injustice surrounding CFS/ME. I was aware of the scepticism, but I was unfamiliar with the foundation of the scepticism, and the history of the illness. Although I was aware of the scepticism surrounding CFS/ME, I was less aware of the relationship between the said scepticism surrounding CFS/ME, the history of the illness, and the role that patriarchal approaches can have within medicine. I had to accept that I had a lot to learn. I was forced to reflect upon my own CFS/ME story, and as such although I was not aware of there being blanks within my story, unanswered grievances and injustices, it transpired that there were many blanks that I was only now able to see and fill with the knowledge gained from the literature. This was bitter sweet as I was saddened by what I had learnt but also impassioned by it and as such my determination to tell the CFS/ME story intensified after a period of struggle. Although in much better health, revisiting the past and my immersion in the literature was problematic for me. I found it to be quite a painful experience and began to remember all too clearly what those years had been like for me and the clarity and rawness of my memories made me wonder if I had bitten off more than I could chew, if I was in fact playing with fire by immersing myself within and committing to the world of CFS/ME when that was a world that had once ruined me. I had to take some time out as I believed I needed to gain some perspective. I thankfully returned with a clear head and so began to focus on what was important; my participants.

My loyalty to participants never waned. I wanted their stories to be told. Although I had my own story, I always understood that the current research was about them not me. However, when our stories often overlapped, it was sometimes hard to separate the analysis of their stories from the analysis of my own. However, I reassured myself that I was collecting their data, not my own whilst being mindful to avoid the potential for lines to be blurred. Their powerful stories were such that my debt to participants was at times burdening. Many of them were acutely affected by CFS/ME yet they used their precious and limited energy to participate in my doctoral research, which is something I did not ever take for granted. As such I felt so indebted to them, to the generosity of their contribution that the responsibility I felt to do right by them was at times overwhelming. When feelings such as this ensued I drew comfort from the fact that they appreciated my commitment to them as people, my commitment to the telling their stories and my desire for their voices to be heard. I would do my best, and that is all I could do.

Research aims; were there any shifts?

As the current research follows on from my undergraduate project my research aims were well considered, however there were shifts. I was initially driven to explore the shifting identity of those with CFS/ME, something which my provisional research aims reflected:

- Explore the shifting social identity of those living with Chronic Fatigue Syndrome (CFS/ME) and the subsequent impact such shifts have on the sense of 'self' and identity of those living with CFS/ME.
- Explore the utility of Wenger's (1998) 'Communities of Practice' theory in understanding identity in chronic illness.

However, upon closer inspection of the literature, I began to realise the importance of an exploration of the millennia of meaning underpinning the lived experience of CFS/ME. I was subsequently driven to provide an insight into the CFS/ME story, as this story appeared central to the lived experience of the illness. Therefore the following research aims were conceived:

- Widen the knowledge about CFS/ME; and by extension contribute to the chronic illness literature in general, how it (CFS/ME) is experienced, how the person interacts with the illness and the context of the person and the illness.
- Provide an insight into CFS/ME for those who live with CFS/ME who may be unaware of the ramifications of the social construction of CFS/ME but who may be in a position to challenge and negotiate any associated oppression and marginalisation.

The final research aim emerged following a crisis prior to data collection. I worked with a technician at the university to design a forum through which to gather data. Although we discussed at length what I needed from the forum, after a few months, it transpired that what had been designed for me was a blog, not a forum, which did not allow for interactive chat. I believed interactive chat and a user friendly medium (which the 'blog' was not) was essential and so I had to accept that months had been wasted and that I needed to find another way to gather data. I began to consider Facebook due to its usability, its ability to enable private messages, and interactive chat via Facebook messenger. I subsequently created the CFS/ME Facebook group: cfsid through which I gathered all data. Part of my Facebook journey to cfsid involved observations of multiple CFS/ME Facebook groups, and I soon realised how important Facebook was for many people living with CFS/ME. When my data reaffirmed the beneficial role of Facebook I realised that something important was emerging. I subsequently added the following research aim:

- Explore the mediating effect of social media support in chronic illness: CFS/ME.

Theoretical foundation and revised research aims

Not forgetting my overarching research aim being a desire to explore the shifting identity of those living with CFS/ME, I began to contemplate identity theories. A number of identity theories could have provided a theoretical foundation for the current research but it was one in particular that resonated mostly with the illness intrusiveness of CFS/ME: Wenger's (1998) Communities of Practice (CoP) theory. CoP is a social theory of learning and as such is widely used in transition research. However CoP foregrounds the relationship between participation and identity and as the lived experience of chronic illness is synonymous with shifts in identities, a re-conceptualisation of CoP provides an opportunity to unpick and understand the story and personal experience of chronic illness. A

commitment to the fundamental CoP concept being 'identity is participation' in the current research allows an insight into the issues of identity that are indicative of the lived experience of CFS/ME, and by extension an insight into the issues of identity that are central to the lived experience of chronic illness in general. The re-conceptualisation of CoP is therefore of value to the literature, because as far as I am aware this is the first time that CoP has been applied to the lived experience of chronic illness.

Research aims:

- Explore the shifting social identity of those living with Chronic Fatigue Syndrome (CFS/ME) and the subsequent impact such shifts have on the sense of 'self' and identity of those living with CFS/ME.
- Explore the utility of Wenger's (1998) 'Communities of Practice' theory in understanding identity in chronic illness.
- Widen the knowledge about CFS/ME; and by extension contribute to the chronic illness literature in general, how it (CFS/ME) is experienced, how the person interacts with the illness and the context of the person and the illness.
- Provide an insight into CFS/ME for those who live with CFS/ME who may be unaware of the ramifications of the social construction of CFS/ME but who may be in a position to challenge and negotiate any associated oppression and marginalisation.
- Explore the mediating effect of social media support in chronic illness: CFS/ME.

Layout of the thesis

In chapter one (C1) the introduction to CFS/ME provides an insight into the CFS/ME story. The history of ME and the construction of CFS is reviewed which illuminates the millennia of meaning underpinning the lived experience of the illness today.

The conceptual chapter (C2) provides a detailed introduction to Wenger's (1998) 'Communities of Practice' (CoP) theory and in so doing a detailed introduction and rationale for the proposed re-conceptualisation of CoP in an attempt to illuminate the potential of CoP to be applied to the lived experience of chronic illness: CFS/ME.

In the literature review (C3) the CFS/ME and identity literature is presented. Consideration is given to strengths and weaknesses, a consideration which reaffirms the potential value of CoP; the re-conceptualisation in chronic illness research and the value of longitudinal data, which was lacking in many of the studies reviewed.

The epistemology chapter (C4) opens with an introduction to the CFS/ME Facebook group 'cfsid' and the emergence of the virtual quasi ethnography. My ontological and epistemological framework is considered further within discussions of the role of interpretivism, the emancipatory paradigm, critical relative rationalism, hermeneutics and an insider perspective which underpin the current research.

The methodology chapter (C5) outlines the research aims before discussing the journey which led to the Facebook group 'cfsid'. cfsid activity is then discussed as to illuminate the method of data collection before a detailed introduction to the theoretical thematic analysis emerges as to provide a transparent insight into and rationale for all methodological decisions and choices.

The analysis begins with a story: 'Basking in the glory of my evil' (C6) which serves to foreground the commonality and continuity of participants' lived experience of CFS/ME.

The subsequent theoretical thematic analysis is broken up into four themes/chapters:

- 'An introduction to participants' (C7) provides an insight into participants and their CFS/ME stories;
- 'Losing on the swings and the roundabouts' (C8) considers the multiple losses and few gains as defined by the reality of CFS/ME;
- 'It's not just about me' (C9) reflects the millennia of meaning underpinning the lived experience of CFS/ME which is not individualised;
- 'What you going to do?' (C10) provides an insight into coping, and in so doing draws upon the potential for positives in CFS/ME which aligns with the need to 'find a new way to be' in chronic illness: CFS/ME.

The conclusion (C11) begins by reviewing the extent to which the research aims were met.

Consideration is then given to implications and contribution(s) to knowledge: The CFS/ME story; the re-conceptualisation of CoP; longitudinal data; and, an insider perspective. The conclusion closes with discussions around the potential for further research in this area.

CHAPTER ONE (C1)

An introduction to CFS/ME; a review of the history and discussion of the ramifications and implications for those living with CFS/ME today

My intention here is to illustrate how the history of ME and the construction of CFS has contributed to the construction of CFS/ME today and in so doing illuminate the millennia of meaning which encapsulates the evolving understanding of CFS/ME and the CFS/ME sufferer. Although many have provided an overview of the history of ME to introduce various papers on ME and/or CFS, I will provide a depth of insight which goes beyond an overview, one which emphasises the aforementioned millennia of meaning within a critical framework which is designed to illustrate how the history of CFS/ME as defined by multifaceted scepticism, has shaped the lived experience of CFS/ME today. My search strategy, quite simply, involved reading anything that gave me an insight into the history of the illness and my presentation of this literature is as detailed as it is as I did not want the current introduction to the history of CFS/ME to be yet another snapshot.

History of Myalgic Encephalomyelitis (ME)

The prevalence of CFS/ME in the UK is estimated to be 0.2-0.4% (Chew-Graham et al. 2010), however, CFS/ME is an illness that resides beneath a burden of scepticism due to the controversy surrounding CFS/ME regarding a lack of proof that CFS/ME is 'real'.

Between the 1930's and 1980's there were 47 epidemics pertaining to the symptomatology of Myalgic Encephalomyelitis (ME) in the US, Switzerland, Iceland, Australia, UK, South Africa and Europe (Appendix 1). However it is the epidemics which occurred in the US and UK which provide the greatest insight into the history of ME and the construction of Chronic Fatigue Syndrome (CFS). ME first presented as 'Poliomyelitis' at the Los Angeles County General Hospital in 1934. Patients presented with flu-like symptoms and fatigue (Gilliam, 1938). Despite many of the initial epidemics mirroring poliomyelitis; epidemics of physical origin, interspersed within these legitimised illness outbreaks, was evidence of doubt within the literature (eg. Lancet, 1954; Wallis, 1955; Parish, 1970). So from its inception, it appears that ME has been suffused with scepticism. The next well documented epidemic occurred in 1952 at the Middlesex Hospital Nurses Home, London. Similarly to previous epidemics, this epidemic was linked to a form of 'Encephalomyelitis' associated with Poliomyelitis (Acheson, 1954), and in 1955, during one of the most widely known epidemics in the history of ME at the Royal Free Hospital, London, there were over 200 cases of 'Royal Free Disease' predominantly affecting doctors and nurses, whereby encephalomyelitis simulated poliomyelitis (Ramsay, 1957).

As there was still some disagreement surrounding the epidemics, which was reflected by an undercurrent of scepticism within the literature, Acheson conducted a major review titled '*The clinical syndrome variously called Benign Myalgic Encephalomyelitis, Iceland Disease and Epidemic Neuromyasthenia*' in 1959. Having reviewed 14 outbreaks, Acheson (1959) concluded that of the 14 epidemics, 12 shared enough epidemiologic and clinical features sufficient to illuminate the reality of a

case for causative agent(s). A variety of names were proposed for the new clinical entity and disagreement and contention soon unravelled further amongst the medical community. Although Acheson (1959) believed the epidemics were most probably caused by an infection, some remained unconvinced, and as such began to consider the potential role of 'hysteria' (e.g. Gilliam, 1938; Sigurdsson et al. 1950; Ramsay, 1957; Galpine and Brady, 1957). In 1970, McEvedy and Beard conducted a notes review on the Royal Free Hospital patients. Due to the complexity of symptomatology, the absence of definitive evidence, and the fact that most of the patients were women, McEvedy and Beard (1970) echoed previous sceptics (e.g. Gilliam, 1934; Sigurdsson et al. 1950; Ramsay, 1957; Galpine and Brady, 1957) by suggesting the Royal Free epidemic had in fact been a psycho-social phenomena underpinned by mass hysteria.

The absence of definitive evidence as detailed above is a claim underpinned by the biomedical model of illness and disease. Engel (1977) argued that the biomedical model offered only a narrow framework within which to consider illness and disease as the biomedical model was dependent upon evidence; biomarkers. Although the invention of the biopsychosocial model (Engel, 1977) was intended to interrelate the biological, psychological, and social aspects of illness and disease, the biomedical model remains dominant and burdening within diagnoses and constructions of CFS/ME (Richman & Jason, 2001). Lupton (2012, p. viii) asserts:

Western societies in the early 21st century are characterized by peoples increasing disillusionment with scientific medicine.

Lupton (2012) also suggests that there is a type of mythology surrounding physicians which positions them as godly. In parallel with such godly status is the potential for power, dominance and oppression, which is reiterated by Moore (2010) who asserts that medicine continues to operate upon an oppressive patriarchal foundation.

The history of hysteria

Of the 14 epidemics to be reviewed by Acheson (1959), and subsequently McEvedy and Beard (1970), seven of them were hospital based epidemics which predominantly affected the nursing staff; women. These epidemics illustrated the propensity of women to suffer the illness, and the dispiriting history of 'women's illnesses' demonstrates the tendency of patriarchal medicine to label women 'mad' not 'ill' (Ussher, 2013). Hysteria permeates the history of 'women's illnesses'. According to Kohon (1984, p.73) "*A woman always at heart remains a hysteric*". The history of hysteria attends to weak women who are vulnerable to psychological dysfunction with femininity being alleged to predispose women to fragile minds which have a tendency for internal instability; hysteria (Swartz, 2013). When women are positioned as hysterics, the authenticity of their illness experience is challenged (e.g. Kohon, 1984; Showalter, 1997; Wright and Owen, 2001; Ussher, 2013). Therefore, in the absence of biomarkers; proof, a woman's experience of suffering is not legitimised but framed as 'all in the mind'. According to Richman and Jason (2001), MS was once known as a 'woman's disease'. The lack of biomarkers caused MS to become an illegitimate and contested illness,

something which was compounded by the fact that MS was vulnerable to the propensity of medicine to rely upon psychiatry for diagnoses of conditions which were considered challenging (Skegg, Corwin, and Skegg, 1988). It would appear the history of MS mirrors the history of ME as from its initial inception a lack of biomarkers and the alleged propensity of women to suffer ME has caused much confusion and contention. There is a body of research which provides evidence for the psychological component of chronic illness (e.g. Garrett and Weisman, 2001; Livneh and Parker, 2005; de Ridder et al. 2008; Hahn et al. 2010; Karnilowicz, 2011; Morris, Moore, and Morris, 2011; Weingarten, 2013; Simpson, Lekwuwa, and Crawford, 2013). However, the aforementioned research explores the psychological component of chronic illnesses which feature in both male and female populations and thus the psychological component is considered to be part of the illness experience as opposed to the cause of illness.

Despite the alleged relationship between ME and hysteria, in 1962, Myalgic Encephalomyelitis (ME) was included in the standard textbook of neurology and since 1969, ME has been classified by the World Health Organization (WHO, 1969) as a neurological disorder in the International Classification of Diseases (ICD). It is not unreasonable to assume that a neurological classification would encourage biomedical research, as for example in the case of MS, there has been much biomedical research as discussed at www.mssociety.org.uk. However, due to the contested nature of the illness, biomedical research into ME has failed to sufficiently materialise.

The construction of Chronic Fatigue Syndrome (CFS)

Moving forward a few years, 'Osler's Web – Inside the Labyrinth of the Chronic Fatigue Syndrome' is the work of journalist Hilary Johnson (1996) who over a period of nine years (1986-1995) interviewed clinicians, scientists, patients and their families about their CFS experiences. I will draw upon this work to provide an overview of the epidemic in the US which has proven most controversial in the history of ME and the construction of CFS. In 1984/1985 a mystery illness defined by flu-like symptoms and debilitating fatigue hit Incline Village, Lake Tahoe. The Epstein Barr Virus (EBV) appeared causative; however the Centres for Disease Control (CDC) appeared sceptical of the alleged epidemic suggesting "*two doctors isolated in a mountainous area had worked themselves into a frenzy*" (Johnson, 1996, p.52). Such scepticism was mirrored by other Incline Village doctors, with one, Gerald Cochran, suggesting that the patients presenting with the illness were "*hypochondriacs, neurotics and depressives*" (Johnson, 1996, p.39). Due to the broad spectrum of symptoms the CDC felt it necessary to narrow down the patient profile. All patients who presented with other medical conditions, such as "*congestive heart failure, thyroid disease, persistent bacterial infections, unspecified colitis, pneumococcal pneumonia, chronic low back pain, hypertension, and other fatiguing illnesses*" were excluded (Johnson, 1996, p.53). From over 150 cases, only 15 made the final cut; 13 women and two men.

Chronic Fatigue Syndrome (CFS): a case definition

Despite the scepticism of the CDC, Holmes et al. (1988) formulated a case definition for CFS to enable scientific research and in so doing all but erased the history of ME by excluding the fundamental features of ME which had spanned decades (Johnson, 1996). The definition also ignored the fact that ME had been classified by the World Health Organization (WHO) as a neurological disorder in the International Classification of Diseases (ICD) since 1969 and that 10 years earlier in the UK, the Royal Society of Medicine had accepted ME as being distinct and organic (Marshall, Williams, and Hooper, 2001). Perhaps the Holmes et al. (1988) definition was also not immune to the burden of scepticism shrouding the history of the illness, as according to Johnson (1996), Stephen Straus, who worked for the US government declared that the governments' view was that the Incline Village epidemic was not evidence of a new illness, but of history repeating itself; neurasthenia, a form of psychoneurosis most attributable to women.

It would appear, since ME first presented in 1934 (Gilliam, 1934), ME has been rendered a contentious illness due to an undercurrent of scepticism. The alleged propensity of women to suffer ME forged an inadvertent alliance with an age-old psychoneurotic illness; neurasthenia, and the history of hysteria, which served to reaffirm the scepticism surrounding ME and the ME sufferer. The inception of CFS; a psychosomatic syndrome, is inextricably bound with injustice as CFS has, in effect, overwhelmed the genuine case of ME as diagnoses of CFS remain prevalent despite the neurological classification of ME and the evolution of a variety of case definitions and diagnostic criteria pertaining to both CFS and ME.

A review of the evolving case definitions and diagnostic criteria

Despite the Holmes et al. (1988) case definition having been formulated for the purpose of research, due to a wealth of possible symptoms underpinning a Holmes et al. (1988) diagnosis of CFS, it is alleged that research findings have been contradictory due to contrasting interpretations and inconsistent diagnoses (Jason et al. 2012). It has also been criticised for its apparent allegiance with a psychiatric classification as neuropsychiatric symptoms such as depression, irritability, and confusion do not prevent a diagnosis of CFS when using the Holmes et al. (1988) criteria (Katon and Russo, 1992).

Jason et al. (2001) compared the Holmes et al. (1988) and Fukuda et al. (1994) criteria for CFS and found however that participants who met the Holmes et al. (1988) criteria appeared to be more incapacitated by CFS than participants who met the Fukuda et al. (1994) criteria. The Fukuda et al. (1994) criteria requires only four out of a possible eight symptoms for a diagnosis of CFS, which allows less severely affected patients to be diagnosed with CFS. Symptoms such as post-exertional malaise, which are specific to ME, are therefore not essential symptoms in diagnosis which creates further distance between CFS and ME whilst also blurring the boundaries between CFS and other fatiguing illnesses, including those which have roots in psychiatry (Brown et al. 2013).

At the same time of the Fukuda et al. (1994) criteria, Dowsett et al. (1994) developed the London Criteria for the purpose of research into ME. Lenient criteria including psychological disturbances and a lack of exclusions, once again took precedence. Similarly to the Holmes et al. (1988) criteria being criticised for leniency, the leniency of the Dowsett et al. (1994) criteria, despite its alleged allegiance with ME would also arguably be open to interpretation in diagnosis. Although the London Criteria (Dowsett et al. 1994) was developed for the purpose of research into ME, in reality it appears the London Criteria has the potential to contribute towards the lack of distinction between CFS and ME whilst it also would not necessarily prevent a psychiatric construction of ME from overwhelming the neurological classification of ME due to the inclusion of psychological disturbances in diagnosis.

According to Jason et al. (2004), there is less to critique with the Canadian Consensus Criteria for ME (Carruthers et al. 2003) as diagnosis is dependent upon specific ME symptoms, such as post-exertional malaise. Jason et al. (2004) compared patients meeting the Canadian Consensus Criteria (Carruthers et al. 2003) with patients meeting the Fukuda et al. (1994) criteria, and patients presenting with psychiatric chronic fatigue and found that the Canadian Consensus Criteria (Carruthers et al. 2003) was in fact able to differentiate between those with psychiatric chronic fatigue and those with ME who were physically more incapacitated than those meeting the Fukuda et al. (1994) criteria for CFS.

Brown et al. (2013), suggest the International Consensus Criteria for ME (ICC) (Carruthers et al. 2011), similarly to the Canadian Consensus Criteria for ME (Carruthers et al. 2003), successfully distinguishes the neurological ME which was prevalent until the 1980's from the psychosomatic CFS which has been prevalent since the demise and reconstruction of ME in the 1980's. Brown et al. (2013) compared the Fukuda et al. (1994) criteria for CFS with the ICC criteria for ME (Carruthers et al. 2011). According to Brown et al. (2013), those who receive a diagnosis of CFS using the Fukuda et al. (1994) criteria, may not be symptomatic of ME according to the ICC criteria for ME (Carruthers et al. 2011), a finding which, if invested in, has the potential to differentiate CFS from ME and perhaps the syndrome from the disease.

Despite the apparent value of both the CCC (Carruthers et al. 2003) and the ICC (Carruthers et al. 2011), according to Brown et al. (2013) it is the Fukuda et al. (1994) criteria for CFS, which remains prevalent in diagnosis.

CFS versus ME

The evolving case definitions and diagnostic criteria illustrate the contrasting constructions of ME and CFS and the *"convenient dumping ground for non-specific illnesses characterised by fluctuating aches, and pains, fatigue and depression"* as predicted by Acheson (1959, p. 33) as CFS/ME has been reliably branded a 'waste bucket diagnosis' in the media. The apparent discontent amongst researchers as evidenced in the seemingly ever evolving case definitions for CFS and ME is a discontent which naturally filters into the lived experience of the illness when there is so much disagreement surrounding diagnoses. One could assume difficulty in defining an illness would stem

from a lack of physiological evidence which would inhibit a definitive definition. However, there is a wealth of literature which provides physiological evidence for the case of ME. For example, autonomic dysfunction has been confirmed by Van Houdenhove, Eede, and Luyten, (2009); Newton et al. (2009); Myhill, Booth, and McLaren-Howard (2009); Maloney et al. (2009); and, Maes et al. (2011). Immune dysregulation has been confirmed by Raison, Lin, and Reeves, (2009); Hokama et al. (2009); Fremont et al. (2009); Wolbeek et al. (2008); and, Brenu et al. (2011), and neuroendocrine abnormalities have been confirmed by Miwa and Fujita (2009); Van Den Eede et al. (2008); Nater et al. (2008); and, Fuite, Vernon, and Broderick, (2008).

Despite ME having been reconstructed as CFS in the US with the Fukuda et al. (1994) definition of CFS being the most widely used and accepted definition universally (Brown et al. 2013), it might also be assumed that the aforementioned physiological evidence for the case of ME has sustained the WHO (ICD-10) classification of ME in Chapter VI 'Diseases of the Nervous System' under G93.3 'Other Disorders of the Brain' alongside 'Post Viral Fatigue Syndrome' (PVFS). Chronic Fatigue Syndrome (CFS), in contrast, is classified by the WHO (ICD-10) in Chapter V 'Mental and Behavioural Disorders' under F48.0 'Other Neurotic Disorders' alongside 'Neurasthenia'. Evidence has enabled and sustained a neurological classification of ME, but not one which has superseded the psychiatric classification of CFS which continues to take precedence in diagnosis.

The amalgamation

The precedence of CFS diagnoses is further complicated by the recommendation of the Working Group for CFS/ME (2002) that CFS and ME, as the name of the Working Group would suggest, should be amalgamated into the acronym CFS/ME. The acronym was introduced to negate the dissatisfaction embodied by the ME community who were unhappy with the name 'Chronic Fatigue Syndrome' asserting that it undermined their experience of chronic illness and furthermore, many diagnosed with CFS strongly believed they had ME, a distinct entity distinguishable from CFS (e.g. Brown et al. 2012; Maes et al. 2012; Twisk, 2014). Despite the amalgamation which could have enabled CFS and ME to transcend one another in diagnosis in the UK, Wojcik, Armstrong, and Kanaan (2011) found 84% of British neurologists' surveyed did not believe CFS was neurological, thus exemplifying the boundary between CFS and ME. Evidence would suggest the CFS/ME acronym was at best ill conceived as the amalgamation of a neurological disease with a mental and behavioural syndrome served only to further complicate diagnosis and treatment whilst diffusing the neurological classification of ME. 'CFS/ME' features heavily in the literature, but it would appear that CFS is central to many studies, not ME (or CFS/ME).

In early 2015 an Institute of Medicine (IOM) report outlined the need to redefine CFS/ME:

IOM Diagnostic Criteria for 'Systemic Exertion Intolerance Disease' (SEID) (IOM, 2015, p. 3)

Diagnosis requires that the patient have the following 3 symptoms:

- 1) *A substantial reduction or impairment in the ability to engage in pre-illness levels of occupational, educational, social, or personal activities that persists for more than 6 months and is accompanied by fatigue, which is often profound, is of new or definite onset (not life-long), is not the result of ongoing excessive exertion, and is not substantially alleviated by rest AND*
- 2) *Post-exertional malaise AND*
- 3) *Unrefreshing sleep*

At least 1 of the 2 following manifestations is also required:

- 1) *Cognitive impairment OR*
- 2) *Orthostatic intolerance*

According to an anonymous editorial in the Lancet (2015) titled '*What's in a name? Systemic Exertion Intolerance Disease*', the redefinition was a reaction against the stigmatisation experienced by those diagnosed with CFS/ME. The redefinition endeavours to change attitudes and alter perception for the good of the CFS/ME community. As such, the name SEID is alleged to reflect the literature surrounding CFS/ME. For example, inherent in 'systemic' is the multiple bodily systems affected by CFS/ME; 'exertion intolerance' is intended to reflect the fundamental feature of CFS/ME; and 'disease' attempts to convey the pathological mechanism and disease process underpinning CFS/ME which has yet to fully emerge. The redefinition equates to a planted seed and as such it has yet to interact with the lived experience of CFS/ME. Only time will tell as to whether SEID can overpower CFS/ME and the history of the illness, but perhaps in SEID there may be the potential for a cleaner slate.

Implications of CFS for sufferers; management and treatment

The contrasting case definitions have contributed towards the scepticism surrounding CFS/ME, scepticism which has fuelled psychosomatic research which negates the need for biomedical research. For example, there has been much interest in links between CFS and depression (e.g. Wessely et al. 1997; Roy-Byrne et al. 2002; Axe et al. 2004; Dancey and Friend, 2008; Van Houdenhove, Kempke, and Luyten, 2010), and personality disorder (e.g. Johnson, DeLuca, and Natelson, 1996; Ciccone et al. 2003; Deary and Chalder, 2010; Valero et al. (2013) and, the alleged neuropsychiatric and neuropsychological features of CFS have recently been reviewed (Christley et al. 2013). The investment into research which seeks to support the psychiatric classification and psychosomatic construction of CFS as opposed to biomedical research into ME encompasses the injustice surrounding CFS/ME. Conversely, there have been recent advancements in the field of somatisation whereby the biological underpinnings of somatisation such as biomarkers and immune-inflammatory pathways provide evidence for the organic 'physio-somatic' symptoms of depression,

somatisation and CFS/ME (Anderson, Berk, and Maes, 2014). However, treatments for CFS continue to be bound by its construction and classification as a psychoneurotic disorder. Treatments moreover have a psychiatric and psychological foundation such as medications and Cognitive Behavioural Therapy (CBT) (White et al. 2011). Although research provides evidence to support the role of psychosocial interventions in physical illness (e.g. Tsang, Cheung, and Lak, 2002; Martire and Shultz, 2007; Artherholt and Fann, 2012), psychosocial interventions are not invested in 'cure'.

For example, the PACE trial (2011) was the first large-scale trial to test and compare the four main treatments which are currently available in the UK for patients with CFS:

- Standardised Specialist Medical Care (SSMC) is the most common treatment for CFS whereby specialist doctors are trained to explain the illness to patients whilst offering advice on how to manage the illness which includes prescribing medications such as anti-depressants.
- Adaptive Pacing Therapy (APT) endeavours to coordinate the activity levels with energy levels of patients with CFS in view to improving quality of life and enabling a natural recovery.
- CBT explores how the thoughts, behaviour and symptoms interact in sustaining illnesses such as CFS. CBT endeavours to enable new coping mechanisms which will negate the propensity of patients to be symptomatic of CFS.
- Graded Exercise Therapy (GET) is designed to gradually increase levels of physical activity to improve fitness and negotiate the CFS patients' aversion to activity which is considered indicative of CFS.

According to White et al. (2011) results of the PACE trial indicate that CBT and GET can moderately improve outcomes for patients with CFS when combined with SSMC, whilst APT was an ineffective addition. The ME Association (2011) conducted a survey of patient opinion on management options with over 4000 responses at the same time as the PACE trial and results are at variance with White et al. (2011). Not only did APT which was alleged to be an ineffective addition by White et al. (2011) help 71% of participants, but GET made 57% of participants worse. Conversely, according to Twisk and Maes (2009) the reason GET is a dangerous intervention for people with CFS/ME relates to the pathophysiology of ME. Twisk and Maes (2009 p.284) suggest exertion (GET) induces symptoms such as *"post-exertional malaise with a decreased physical performance/aerobic capacity, increased musculoskeletal pain, neurocognitive impairment, fatigue, and weakness, and a long lasting recovery time. As, findings suggest exertion may amplify inflammation, immune dysfunction, oxidative and nitrosative stress, channelopathy, defective stress response mechanisms and a hypoactive hypothalamic-pituitary-adrenal axis"* which collectively equate to the pathophysiology of ME (Twisk and Maes, 2009).

Despite the results of the ME Association's (2011) survey providing evidence to contradict the results of the PACE trial whilst additionally supporting the neurological classification of ME, Sharpe (2011) asserts the results of the PACE trial may provide evidence to support the psychosomatic construction of CFS by questioning whether CBT and GET would be effective treatments for CFS if CFS was in

fact neurological. The literature provides much supporting evidence that there is a psychological component to chronic illness (e.g. Garrett and Weisman, 2001; Livneh and Parker, 2005; de Ridder et al. 2008; Hahn et al. 2010; Karnilowicz, 2011; Morris, Moore and Morris, 2011; Weingarten, 2013; Simpson, Lekwuwa and Crawford, 2013). However, according to Twisk and Maes (2009), the bio-psychosocial explanation for CFS is underpinned by the belief that psychogenic, cognitive and behavioural factors are fundamental in the aetiology and maintenance of CFS. Therefore, predisposing factors such as personality; triggers such as infection; and, maintaining factors such as illness beliefs allegedly equate to the trichotomy of CFS. The bio-psychosocial model informs the bio-psychosocial treatment plan for CFS which moreover involves the aforementioned CBT and GET. It is alleged the dysfunctional illness beliefs of the patient are negotiated by CBT whilst the de-conditioned body of the patient is negotiated by graded exercise. However, the ME community are strongly opposed to CBT as CBT reinforces the controversial belief that ME is 'all in the mind' and GET is feared by the ME community as to reiterate Twisk and Maes (2009) and The ME Association (2011), GET can often make ME worse.

There is much contention surrounding the management of CFS/ME. Despite NICE guidelines recommending early treatment and tailored care packages for patients with CFS/ME (including SSMA, APT, CBT and GET), this is rarely realised in primary care (Hannon et al. 2012). Perhaps this relates to the fact that CFS/ME is not incentivised as part of the Quality and Outcomes Framework (QOF). The QOF is a pay-for-performance incentive scheme which motivates GP practices to meet certain clinical and organisational targets. Granted, the illnesses included in the QOF such as asthma, coronary heart disease, heart failure, chronic kidney disease, and diabetes mellitus have higher prevalence rates than CFS/ME, but the management of such illnesses is not as problematic as CFS/ME and therefore if CFS/ME was to become part of the QOF, perhaps the diagnosis of CFS/ME would become less problematic. Hannon et al. (2012) suggest it is the complex nature of CFS combined with a lack of incentives that affects diagnosis and treatment; 65% of Action for ME members claimed to have never received any treatment. According to McDermott, Lynch, and Leydon (2011), a diagnosis enables patients presenting with CFS/ME to make sense of their symptomatology so as to allow them to better manage their illness and articulate their difficulties to others whilst a diagnosis was also believed to restore self-respect. In the absence of definitive or visible disease, society at large struggles to grant those with CFS/ME permission to be ill (Nettleton, 2006) and as such casts doubt on their experience of alleged illness. On being diagnosed, hopes for support to counter feelings of isolation are prevalent (McDermott, Lynch and Leydon, 2011), which is arguably problematic when CFS/ME remains on the periphery of legitimate diagnoses and treatment (Hannon et al. 2012). De Carvalho Leite et al. (2011) found that those with CFS/ME expressed a lack of equity in their health and social care typified by barriers to diagnosis and treatment, namely medical scepticism.

Wading through the undercurrent of medical scepticism

Chew-Graham et al. (2010) highlighted how the negative views and scepticism of doctors concerning the reconstruction of ME into CFS, the alleged undesirable traits of patients and contentious origin of

disease equates to a conflict between doctor and patient which signifies a barrier to diagnosis and treatment. It is reasonable to suggest the history of ME and the construction of CFS is perhaps indicative of the scepticism surrounding CFS/ME on the contrasting illness beliefs inherent in CFS/ME and the all encompassing dichotomy of mind and body often overwhelming the primary care consultation. As discussed, when two distinct entities such as ME and CFS (Brown et al. 2013; Twisk, 2014) are amalgamated despite ME and CFS having contrasting WHO ICD-10 classifications; neurological versus mental and behavioural, it is unsurprising that CFS/ME has become a source of contention for all involved within primary care. What is beyond reason, however, is the 'scapegoating' of patients (Murray, 2004).

I previously made reference to the body of literature exploring the alleged relationship between CFS and depression, personality disorders, and, the alleged neuropsychiatric and neuropsychological features (p.26) which inform and reaffirm the psychiatric classification and psychosomatic construction of CFS. Due to a focus on internal psychological factors, the individual with CFS can be held responsible for their diagnosis through the assertion that they are predisposed to develop CFS for a variety of reasons pertaining to personality (Deary and Chalder, 2010). Despite evolving theories concerning the 'CFS prone personality' there is much variance in findings. According to van Geelan et al. (2007), methodological issues are central to the said variance in findings. For example, contrasting control groups and patient populations compromise generalisability. Overlapping DSM-IV criterion are also problematic particularly with regards to the alleged relationship between CFS and depression as to be diagnosed with CFS, a patient could as easily be diagnosed with depression which arguably undermines both diagnoses (Buchwald, 1996). However, having reviewed the variety of case definitions, it is not without reason to suggest it is the conflict in definition that poses the greatest problem for CFS/ME research.

As noted earlier, the CDC Fukuda et al. (1994) definition is the most widely used definition universally; despite many people diagnosed with CFS believing they have ME not CFS (e.g. Brown et al. 2012; Maes et al. 2012; Twisk, 2014). However, not all studies use this definition and therefore the wealth of studies exploring the complexity of 'CFS/ME' have the potential to draw upon definitions pertaining to CFS or ME. Maes, Frank and Johnson (2012) echo the contention surrounding the amalgamation of CFS/ME in their quantitative study which concluded ME, CFS and chronic fatigue (CF) are three separate entities. Furthermore, a fundamental distinction was made between ME and CFS using the Fukuda et al. (1994) definition. According to Maes, Frank and Johnson (2012), although the Fukuda criteria adequately distinguish CFS/ME from CF there is a need for patients with post-exertional malaise (ME) and patients without post exertional malaise (CFS) to be differentiated, something which was echoed by Twisk (2014). The blurring of boundaries between CFS and ME has served to reinforce the psychosomatic construction of CFS/ME which has blindsided ME. The lack of distinction between CFS and ME, within research, has enabled pervasive investigations into the psychiatric classification and psychosomatic construction of CFS. I will now attempt to reveal what perhaps underpins the seemingly effortless reconstruction of ME which has enabled the psychiatric

classification and psychosomatic construction of CFS to traverse decades of physiological evidence for the case of ME.

The dominance of patriarchal medicine

Although I did not begin with a feminist reading, what emerged on engaging with the literature caused me to turn to the history of hysteria in an attempt to make sense of the history of CFS/ME. The biomedical model continues to burden diagnoses and constructions of CFS/ME as patriarchal medicine continues to rely upon the biomedical model (Richman & Jason, 2001). As such, evidence would suggest that the patriarchal scepticism, as illustrated by the history of hysteria and women's illnesses, peppers the history of CFS/ME. Within the literature, links between the US and the UK are tenuous. It would therefore appear that the US and the UK have dealt with ME and CFS independently. Around the same time of the Holmes et al. (1988) definition in the US, a psychiatrist in England, Simon Wessely was rising to prominence (Marshall, Williams and Hooper, 2001). In his paper 'Old Wine in New Bottles; Neurasthenia and 'ME' (Wessely, 1990), Wessely argued ME was in fact 'neurasthenia', and so endeavoured to illustrate the similarities between ME and neurasthenia and in so doing reposition ME and its sufferers within the boundaries of psychiatry. Wessely (1990) observed the work of 19th century American neurologist, George Beard (Marshall, Williams and Hooper, 2001). Beard first introduced 'neurasthenia; an organic disease' in an essay in 1869. Neurasthenia was prevalent in the 19th century, until, according to Wessely (1990) the diagnosis shifted from the organic to the psychiatric. Wessely therefore questioned the neurological classification of ME, writing in the Lancet, Wessely (1993, p.1247) states that:

The inclusion in the tenth revision of the International Classification of Diseases (ICD-10) of benign myalgic encephalomyelitis as a synonym for post-viral fatigue syndrome under Diseases of the Nervous System seems to represent an important moral victory for self-help groups in the UK. Neurasthenia remains in the Mental and Behavioural Disorders chapter under Other Neurotic Disorders. Neurasthenia would readily suffice for ME. Applying more stringent criteria for CFS in the hope of revealing a more neurological sub-group succeeds only in strengthening the association with psychiatric disorders. We believe this latest attempt to classify chronic fatigue syndromes will prevent many people from seeing the world as it actually is.

Wessely's beliefs demonstrate the aura of ME being one defined by 'faith versus fact'. Wessely has written many papers pertaining to his controversial beliefs about CFS/ME (Marshall, Williams and Hooper, 2001). However, one of his most controversial moves came in a contribution to the WHO Guide to Mental Health in Primary Care (November, 2000) in which Wessely, without WHO approval, re-classified ME as psychiatric. The reclassification ignited international disapproval and was subsequently revoked by the WHO. It would be wrong to suggest Wessely alone is responsible for the contentious nature of CFS/ME in the UK, but having written a wealth of papers detailing his controversial beliefs about CFS/ME it would appear his dominant patriarchal discourse has been pervasive.

The reality of disbelief for patients

Horton et al. (2010) suggest some areas of professional practice continue to deny CFS/ME exists which is a serious problem for patients, and according to Jason et al. (2004) many patients diagnosed with CFS frequently report negative experiences within primary care. Bayliss et al. (2014) explored the barriers to diagnosis and management of CFS/ME in primary care, and found for over twenty years medical professionals have admitted to a limited understanding of the illness. Despite the invention of the biopsychosocial model (Engel, 1977), the dominant biomedical model causes many GP's to be sceptical of CFS/ME which acts as a fundamental barrier to diagnosis and treatment. Therefore, some GP's favour a diagnosis of depression over a diagnosis of CFS/ME with patients being held accountable for somatisation and as such many patients continue to experience disbelief and doubt within primary care (Bayliss et al. 2014). According to Horton et al. (2010), many GP's alleged to have low confidence in diagnosing and managing CFS/ME with some refusing to refer CFS/ME patients to specialist services on the grounds of disbelief (Horton et al. 2010). A survey of GP's attitudes to and knowledge of CFS revealed 48% were not happy to make a diagnosis of CFS and 41% lacked confidence in treating CFS (Bowen et al. 2005, p.389).

Horton-Salway (2007) explored the discourse of morality surrounding ME as a contested illness and found the medical scepticism and controversy which is central to ME engendered derogatory labels such as the 'bandwagon' which serves to invalidate the genuine case of ME. Doctors and patients hold views about CFS/ME which are defined by variance, which equates to a battle of will within primary care. GP's construct negative psychosocial identities for patients for whom a psychosomatic diagnosis is considered appropriate (Horton-Salway, 2007) and patients work hard to construct their experience of illness as physical to counter the potential for a psychosomatic diagnosis and in so doing avoid the stigma of mental illness (Tucker, 2004).

According to Anderson, Maes and Berk (2012), the education of primary care workers which aligns with the psychosomatic construction of CFS reinforces the stigma of CFS/ME which acts as barrier to diagnosis and treatment. Horton-Salway (2002) analysed interview transcripts discussing ME (CFS) which illustrated how GP's draw upon bio-psycho-social reasoning to construct patient identities and define their illness as either physical or mental. Such strategic identity construction served to justify a psychosomatic diagnosis which negated blame for what could have equated to uncertainty or a 'medical failure'. CFS is a condition which is medically unexplained (Erikson et al. 2013), and therefore CFS could be seen as a medical failure if psychosomatic diagnoses did not take precedence. Medically unexplained symptoms (MUS) are challenging for doctors which causes some to harbour negative beliefs about patients presenting with MUS (Shattock et al. 2013). Shattock et al. (2013) interviewed four medical trainees about MUS and associated negative attitudes towards patients with MUS. The analysis revealed that participants had received no formal training in MUS and as such knowledge of MUS was achieved through clinical observations. Bowen et al. (2005) found GP's who had more positive attitudes towards CFS had personal experience of CFS, knew someone male with CFS and saw more patients with CFS, which appeared to compensate for inadequate training. It would appear the overarching phenomena of MUS that encompasses CFS

within the medical domain also echoes a paucity of investment, which does little to serve either those working in primary care or those who are reliant on the expertise of those working in primary care.

Chapter summary

The current and detailed introduction to CFS/ME reflects an attempt to provide a depth of insight into the millennia of meaning surrounding the current construction and lived experience of the illness that is not fractured but representative of the 'CFS/ME story'. It was necessary to present as much of this story as was possible within the constraints of a single chapter as the literature illuminated to me the need for the CFS/ME story when much of what I read equated to mere parts of the CFS/ME story which lacked both context and depth. If the CFS/ME sufferer is to be understood, it is essential that the illness is understood, in terms of the history and scepticism surrounding the illness, but also how the history and the scepticism continue to infiltrate the lived experience of the illness.

The history of ME and the construction of CFS inform today's construction of CFS/ME and the CFS/ME sufferer which has far reaching ramifications for sufferers. The inception of CFS has rendered ME an abandoned illness. Patriarchal values associated with the medical model of health appear to underpin the psychiatric classification of CFS, which has stigmatised sufferers and negated biomedical research into CFS/ME; cure. The contentious nature of CFS/ME compounds the experience of illness for sufferers as the realm in which they now reside, being primary care, fails to provide necessary support or salvation. The scepticism of doctors which is arguably underpinned by the history of ME and the construction of CFS as a psychosomatic woman's disease or 'yuppie flu' relegates the CFS/ME sufferer to stigmatised grounds which are guarded from empathy and understanding; coping. On moving forward, it would be useful if the CFS/ME story could be positioned alongside the following chapters as they unravel.

CHAPTER TWO (C2)

Conceptual chapter

The previous chapter provided a detailed introduction to CFS/ME which illuminated how the history of the illness interacts with the lived experience of CFS/ME today. I will begin here with an introductory rationale for the re-conceptualisation of Wenger's (1998) 'Communities of Practice' theory (CoP). I will subsequently draw upon three specific chronic illnesses and chronic illness in general so as to provide an opportunity to illuminate the potential for CoP to make sense of the existing chronic illness literature. I have done this in some detail because this, as far as I am aware, is the first time that CoP has been applied to chronic illness and as such it was imperative that a minutiae of detail was presented to make transparent the concepts of CoP. In so doing, my argument, which is driven by a need to understand the overall identity of those who are chronically ill by exploring their whole process of being in chronic illness, will also be transparent. CoP theory is used widely in transition and as such provides a novel opportunity here to understand the personal story of chronic illness by foregrounding the shifts in identity which are aligned with the unavoidable shifts in participation. Although I recognise that there are a number of other theories that could have been drawn upon such as identity theory (Mead, 1934) and social identity theory (Tajfel and Turner, 1979) this thesis is about the re-conceptualisation and use of CoP in understanding the lived experience of chronic illness and as such will be framed as both a new resource to consider and new contribution to the literature.

Illness intrusiveness as rationale for the re-conceptualisation of CoP

There is a substantial body of health literature surrounding chronic illness that gives consideration to quality of life (QoL) (e.g. Yousef and Wong, 2002; Heckman, 2003; Murdaugh et al. 2006; Devins, 2010; Kristofferzon, Lindqvist, and Nilsson, 2011; Balderson et al. 2013; Kurpas et al. 2013; Lopez-Larrosa, 2013; Eaton, Bradley, and Morissey, 2014). A variety of quantitative measures such as the Satisfaction with Life Scale (SWLS) (Diener et al. 1985); World Health Organization Quality of Life Instrument Short Form (WHOQOL-BREF) (WHO, 1996); Chronic Illness Quality of Life Ladder (CIQOLL) (Murdaugh et al. 2006); Functional Status Questionnaire (FSQ) (Jette et al. 1986); The MOS-Social Support Scale (MOS-SSS) (Sherbourne and Stewart, 1991); The Jalowiec Coping Scale (JCS-60) (Jalowiec, 1988); The General Self-Efficacy Scale (GSE) (Schwartz and Jerusalem, 1995); and, The Quality of Life Enjoyment and Satisfaction Questionnaire – Short Form (Q-LES-Q-SF) (Endicott et al. 1993) are used in QoL research. One particular measure resonated mostly with the current research, and that was the Illness Intrusiveness Ratings Scale (IIRS) (Devins, 2010). Chronic illness demands adaption. If one is to cope with chronic illness, one must adjust to a life with chronic illness. A life with chronic illness often involves treatments and side effects, disabling symptoms, pain, incapacity, dysfunction, a loss of employment due to chronicity, financial difficulties, and a compromised social life (Devins, 2010). According to Devins (1994), indicative of such chronic illness consequences is a fundamental disruption to life: *illness intrusiveness*. Illness intrusiveness is the psychosocial impact of chronic illness which reflects compromised functioning in domains and activities which were once valued and central to one's QoL. It is the consequence of no longer being

able to function in valued domains and activities, the reality of which being a reduction in meaning and gratification that infiltrates QoL and well being in chronic illness.

The illness intrusiveness concept caused me to revolutionise my thinking around the lived experience of chronic illness. I began to look beyond the symptoms of chronic illness to the psychosocial impact of chronic illness. I needed to draw upon a theory that reflected the illness intrusiveness concept and CoP was reflective of the illness intrusiveness concept. CoP is not, however, a theory of chronic illness, but a social theory of learning and thus my application of the theory to the lived experience of chronic illness is a re-conceptualisation.

Wenger (1998) asserts that 'learning' and 'being' are enabled by engagement in social practice. Therefore learning is not boundaried by the self and the self does not evolve independently of social engagement. The underlying assumption of CoP is that social participation enables both learning and identity and according to this theory, ontologically, identity is understood as participation. With a focus on identity I began to think about the two predominant theories of identity in the social science tradition; identity theory (Mead, 1934) and social identity theory (Tajfel and Turner, 1979). Simplified, identity theory (IT) is a microsociological theory of identity which asserts we are the roles we embody. People embody a variety of roles such as mother, daughter, doctor, and patient and such role identities reside within a hierarchy of salience which is contextual (Stryker, 1968). The self in IT is a multifaceted social construct which is fluid in response to context and the appropriate role behaviours of embodied roles (Hogg, Terry, and White, 1995). In contrast, social identity theory (SIT) is a social psychological theory which asserts that we are the groups to which we belong. In SIT, social categories such as nationality, with which one has an affinity and a sense of belonging affords a self-definition which informs the self-concept (Tajfel and Turner, 1979). Not dissimilar to the various role identities asserted in IT, in SIT it is alleged people have a number of social identities which serve to differentiate in-groups from out-groups; us and them. In SIT, the self is not individualistic, but collective and therefore in order to belong, one must fit the prescription of the group (Tajfel and Turner, 1979).

Arguably, both IT and SIT could be applied to illness intrusiveness and the lived experience of identity in chronic illness by perhaps exploring the roles successfully embodied by those who are chronically ill and/or the groups with which those who live with chronic illness are able to identify with and continue to belong to. However, as in CoP, identity is understood as participation and, despite a lack of clarity in the literature that in the case of IT, in order to embody a role, one must have to 'participate' in the practices of that role and in the case of SIT, in order to belong to a group which makes transparent one's collective identity, one must have to 'participate' in the practices of that group. Appropriate role behaviours in IT and the prescription of the group in SIT are discussed in the literature (e.g. Hogg, Terry and White, 1995; Ellemers, Spears, and Doosje, 2000; Stets and Burke, 2000; Stryker and Burke, 2000; Desrochers, Andreassi, and Thompson, 2004; Stets and Carter, 2011; Morris, 2013; Carter, 2014), but the role of participation remains somewhat implicit, and therefore the underlying mechanism of role identities in IT and the collective self in SIT is at best opaque. For the purpose of the current research it was essential that the guiding theoretical

framework was explicit enough in detail as to enable the analysis to become an evolving theoretical construct. As the underlying mechanism of identity being participation is an explicit fundamental assumption in CoP, despite CoP theory being positioned as a social theory of learning, the theory will provide a concise theoretical framework within which to explore the lived experience of identity in chronic illness which reflects the illness intrusiveness concept whilst foregrounding the fundamental role of participation in identity.

CoP concepts (Wenger, 1998)

Practice

In CoP, part of being human is to engage in various pursuits and enterprises; practices. Negotiating such pursuits and enterprises involves interaction with others, interaction which enables learning and identity. Practice is therefore a social endeavour which demonstrates the relationship between the individual and the social in identity work. In order to learn and grow as people, and to sustain and develop one's identity and sense of self, one must rely on interaction with others. Such interaction serves both emerging and established identities. Chronic illness, according to such a theory would fundamentally shift identity to the extent chronic illness can often enforce a withdrawal from the practices which once contributed to one's sense of self through an inability to interact with those who once enabled one's identity. For example, Multiple Sclerosis (MS) is a chronic neurological condition which causes a variety of disabling symptoms which affect physical, psychological and social domains (Tipping, 2003; Irvine et al. 2009). According to Dennison et al. (2010, p. 478):

People with MS can experience various unpleasant, unpredictable and potentially disabling symptoms including spasticity, disturbances to strength, balance, sensation, vision, bowel, bladder, sexual dysfunction, cognitive impairment, pain and fatigue.

The disability associated with MS fundamentally shifts the life-world of sufferers (Finlay, 2003). For example, according to Toombs (1995, p.12) MS equated to:

...a changed relation with one's body, a transformation in the surrounding world, a threat to the self and a change in one's relation to others.

According to CoP, the above life altering consequences of chronic illness, such as one's body being different, one's world being transformed by the boundary of chronic illness, and a jeopardised self within the reality of chronic illness would be compounded by "a change in one's relation to others" as described by Toombs (1995, p.12). As such, CoP would suggest a shift in relationships is indicative of the challenge of identity in chronic illness as it is an inability to interact with others, with those who are familiar and enabling of practices which support one's identity that fundamentally renders one's identity vulnerable in chronic illness.

Communities of practice

Communities of practice are abounding and through community membership, we become who we are and who we are is our identity. According to Murray (2011, p.8), *"Who we are is deeply bound by our experience of participation in the communities to which we belong"*. They exist in all corners of life; they are life. We can belong to multiple communities of practice, for example communities of family, work, friendship, and hobbies. The communities of practice to which we belong are fluid and therefore our sense of self is not rigid, but fluid and evolving as we traverse various community boundaries and peripheries, as we learn and grow as people; as members. As our life evolves, so do our communities of practice (or vice versa).

The tapestry of life and self is therefore sewn into the tapestry of our communities of practice, but when one's life is struck by chronic illness, the tapestry of life and self begins to unravel (Bury, 1982). Life dictates the potential for fluidity and in the case of chronic illness, the potential to participate in communities of practice is inhibited by the reality of chronic illness which often dictates isolation and a withdrawal from life and self, sometimes even at the most basic level. To provide an insight into the relationship between communities of practice and identity in chronic illness, moving forward the existing chronic illness literature will be drawn upon to highlight the potential of CoP to make sense of the crisis of identity in chronic illness.

According to Heisters (2011), Parkinson's disease is a neurological disease which attacks the nervous system. Parkinson's disease in nature is a disease which fluctuates, thus symptoms can vary in severity and are evolving. Common symptoms include tremors, muscle rigidity and stilted movement. The impact is global inasmuch as the symptoms of Parkinson's disease can have a variety of effects such as difficulty walking, talking and swallowing. Patients may also experience sleep disorders, fatigue, depression, anxiety, and memory problems, all of which contribute to the lived experience of Parkinson's disease, the reality of which is compromised functioning. The difficulties surrounding functioning and an inability to successfully negotiate basic tasks, such as washing, dressing, and eating independently etc., can cause people with Parkinson's disease to feel frustrated and isolated (Heisters, 2011).

CoP does not necessarily account for 'ways of being' and fundamental identities such as those of the chronically ill, however as we all bring ways of being to the communities of practice to which we belong, that it is necessary to move the theory forward here so as to provide a theoretical foundation upon which to consider how ways of being pervade our participation. Thus, being a competent being, an anxious being, a healthy being, a chronically ill being, being a woman or being a man are all ways of being that in part may dictate how, and the degree to which one may participate in various communities. For example, Wenger (1998) would assert that an inability to participate in the basic practices of life such as walking, talking, and eating independently etc. as in the case of Parkinson's disease, resonate with the nature of an unfamiliar self in chronic illness through an inability to be the person one once was as a result of no longer being able to participate as one once did. Although Wenger (1998) does not frame broad ways of being and fundamental identities associated with a 'life

with health' or a 'life with illness' as communities of practice, a life with health and/or a life with illness do in fact represent communities of practice through commonality; the lived experience of those who are either privileged with health or burdened by chronic illness. As such, struggling with the enormity of a fundamental dependence on others for basic self care needs such as in Parkinson's disease would jeopardise the very core of a once independent and healthy identity, an identity once defined by participation in the community of practice that was a 'life with health'. The reality of a new self as defined by the chronicity associated with Parkinson's disease would necessitate a shift in self-perception and identity. A distinct lack of familiar communities within which to participate, and through which to attempt to rehearse the facets of one's previous healthy identity, would also compound the reality of a newly acquired community of practice that is a life with chronic illness; a life with Parkinson's disease. The role of such a community would also reinforce the reality of an unfamiliar identity; a Parkinson's disease identity.

Also looking at the lived experience of Parkinson's disease, Behari, Srivastava, and Pandey (2005) found female participants with Parkinson's disease discussed their role within the family as being very important and when their role was jeopardised and they were no longer able to be the mother, or the wife they once were and instead had to be looked after by their husbands and children, they found this to be a very upsetting aspect of life with Parkinson's disease. According to CoP, the community of practice that is family is a powerful source of identity as family is a breeding ground for life roles such as Mum, Dad, brother, and daughter etc. On participating in the practices of such roles, we become who we are within the community of practice that is family. The passage of time naturally often brings with it a role reversal; the children become the parents and the parents become the children, however, when such a shift in life and self is premature, it is a difficult shift to accept when such life roles within the community of practice that is family were previously enabling of a strong sense of self and identity. As the life role of 'Mum' contributed heavily to participants' identities, it is not difficult to appreciate the distressing nature of not being able to perform as one once did alongside dealing with the symptoms associated with a life with chronic illness. Not being able to perform as one once did and the burden of symptoms and a life with chronic illness collectively compounded the lived experience of life and self in Parkinson's disease for participants (Behari, Srivastava and Pandey, 2005).

Sutton and Treloar (2007) explored the lived experience of Hepatitis C. Hepatitis C is a virus that attacks liver cells. The virus is transmitted via the blood and can be progressive inasmuch as Hepatitis C can lead to further complications such as cirrhosis and liver cancer (Dore 2001b). The most common symptoms associated with Hepatitis C are chronic fatigue, headaches, and muscle and joint pain (Dore, 2001a). Sutton and Treloar (2007) found some participants considered their Hepatitis C to be a life altering event which was now their 'way of life', a way of life which was hard to bear. The reality of a life with Hepatitis C impacted participant's ability to function within various domains such as employment, hobbies and social life. For example:

We used to have dinner together... there used to be 12 [friends]... but to cook now it's too much now. (Maureen: Sutton and Treloar, 2007, p.334).

Many found the burden of hepatitis C to be a heavy one in terms of physical, psychological and social effects, for example:

I lost all my physical attributes, my strength, my energy. (Keith: Sutton and Treloar, 2007, p.334)

I could not smile. I was absolutely introverted. I was an absolute wreck. (Mona: Sutton and Treloar, 2007, p.334).

A life with Hepatitis C and all that that life entailed did not reflect the potential of participants' old lives and selves, which engendered feelings of grief, and according to participants, Hepatitis C is a stigmatised chronic illness (Sutton and Treloar, 2007, p.334):

Some described feeling dirty and 'contaminated' (Mona) and being treated like a 'leper', particularly, in some cases, by the medical system (Sandra).

Fear of social exclusion and isolation transcended the boundaries of medicine, to the family as one participant explained:

I cannot tell my own family. My daughter would immediately break with me (Mona: Sutton and Treloar, 2007, p.334).

So, in the case of Hepatitis C, it is not only an inability to participate in communities which were once central to identity such as employment, hobbies and social life that jeopardises identity as a result of symptomatology, but also the stigma of Hepatitis C. The stigma of Hepatitis C has the potential to compound the lived experience of chronic illness by exacerbating the problematic nature of participation in chronic illness by adding a dimension of anticipated prejudice and discrimination.

Community membership

It is through the practice of participating in a community that identity emerges, through participation and reification. According to Wenger (1998, p.4), participation as defined in CoP theory is:

...an encompassing process of being active participants in the practices of social communities and constructing identities in relation to these communities.

Participation is a dynamic process as Wenger (1998, p.56) asserts:

It is a complex process that combines doing, talking, thinking, feeling, and belonging. It involves our whole person, including our bodies, minds, emotions, and social relations.

Who we are is reflected by our identity of participation and according to Edmonds et al. (2007), people with Multiple Sclerosis (MS) experience grief and distress at the loss of life; independence, employment and mobility. People with MS often discuss the far reaching impact of the disease as MS was found to compromise life roles, identity, relationships and social life (Edmonds et al. 2007; Irvine et al. 2009; Mohr, Dick, and Russo, 1999). The far reaching impact of the disease reflects the 'ways of

being' and fundamental identities, as discussed earlier, which interact with participation. For example, to be fit and well, one has independence, one 'is' independent as one participates in independence, but when chronic illness strikes, so too does a dependence on others and a shift in one's previous privilege and ability to participate in all the things that reinforced one's independence. From being employed, having a career, having purpose and a future mapped out, to being unemployed with an unrecognisable life, delivers a huge blow to identity, which is exacerbated by reduced interaction with those who previously, through the practice of participation, contributed to a valued pre MS identity.

Olsson, Lexell and Soderberg (2008) assert a life with MS was a life defined by a captured body and boundaries. Daily life which was once a taken for granted was now problematic and engendered feelings of a lost self. An inability to continue working resulted in isolation and loneliness, which was exacerbated by diminishing contact with others who at times seemed to avoid participants. They knew that with MS, they were different, but being treated differently was difficult for participants as inside they were who they always had been. Olsson, Lexell and Soderberg (2008) found people with MS often expressed the struggle of living with disabling symptoms, but in an unrecognisable body at battle with their mind. The battle typifies the resilience of the inner self, the pre MS self which can no longer be expressed through the body in terms of participation in communities, life roles, activities, and relationships etc. Of course the self in chronic illness often remains, but according to Wenger's (1998) CoP theory, it is an inability to 'be' oneself, an inability to participate in one's previous life, with the people who were once central to one's life and all that was familiar in life that jeopardises identity in chronic illness. Family however sometimes enabled women with MS to struggle daily; they did not want to abandon their loved ones and as such family was a source of empowerment for participants:

The children have been my reason to struggle... If I had not had them, I would have just stayed in bed... I would not have to get up... I would not have to see to it that they got to school... so in a way they have been my rescue. (Olsson, Lexell and Soderberg, 2008, p.423)

An inability to participate in life and self is problematic for identity in chronic illness and therefore not being able to work and having reduced contact with friends and family contributes to the struggle of identity in chronic illness. However, when there is some capacity to sustain a life role, such as the life role of a 'Mum', it evidently can be hugely beneficial for identity in chronic illness which supports the fundamental assumption of Wenger's (1998) CoP theory; identity is participation.

Practice as community

CoP asserts participation is dependent upon 'practice as community' which involves mutual engagement, a joint enterprise and a shared repertoire. The concept of mutual engagement in CoP refers to both positive and negative forms of mutual engagement which reflect diversity such as power and dependence, expertise and helplessness, success and failure etc. The mutual engagement in CoP theory echoes the complex dynamic of communities of practice whilst also illustrating the relational quality of communities of practice and the importance of a connection to others whilst in the pursuit of particular practices; a joint enterprise. A joint enterprise is a multifaceted enterprise as a

joint enterprise is not one dimensional. Any joint enterprise involves a variety of meanings, and therefore within a given community of practice, members work together, but in such collaboration diversity ripples. Members negotiate various meanings which are central to 'their' pursuit of the joint enterprise. Such pursuits are enabled by a shared repertoire which is central to the community of practice. A shared repertoire involves all the things, such as "*routines, words, tools, ways of doing things, stories, gestures, symbols, genres, actions, or concepts which have been produced or adopted by the community*" (Wenger, 1998, p.83) which have become central to the practice of a community.

According to Ohman, Soderberg, and Lundman (2003) a chronic illness diagnosis is life altering, not only the reality of symptomatology but also the disruption to life's hopes and dreams. A life with chronic illness is moreover defined by military management and transitional adaption, which is necessary to coping (Weinert, Cudney, and Winters, 2005). During the early phases of a chronic illness diagnosis it is common for people to feel isolated in various domains as they begin their journey of adaption to a new life defined by chronic illness. Although the community of practice that is family can be empowering in chronic illness, the community of practice that is family can also be compromised by chronic illness when the mutual engagement, joint enterprise and shared repertoire of family become additional casualties of chronic illness. For example, Behari, Srivastava and Pandey (2005), discussed that when female participants with Parkinson's disease were no longer able to sustain their role(s) within the family, their identities were vulnerable which was problematic for participants. When one can no longer be who one once was; there is a shift in mutual engagement and a shift in the power dynamics of the community of practice that is family. Therefore, the joint enterprise of family life and perhaps also the shared repertoire of family must now also negotiate the chronic illness of one of its members which would inadvertently cause multiple shifts in the practices of that familial community. Such shifts also represent further how problematic ways of being can be in identity as although Wenger (1998) does not account for ways of being and fundamental identities in identity, ways of being and fundamental identities interact with participation and therefore identity, and in chronic illness, this interaction is particularly problematic. Through chronic illness, Behari, Srivastava and Pandey's (2005) participants could no longer 'be' who they used to be as they could no longer 'do' what they used to do which is indicative of a fundamental shift in participants' way of being as reflective of compromised participation.

According to Marcille, Cudney, and Weinert (2012) it is not always the chronic illness per se that jeopardises the potential for sustained familial participation as participants expressed compromised relationships with their family members which exacerbated feelings of loneliness in chronic illness:

I think my disease frustrates my husband and so when I am not well he tends to stay away.
(Marcille, Cudney, and Weinert, 2012, p.248)

One participant tried to discuss her illness with her husband but her husband:

...just grumbled and walked away. (Marcille, Cudney, and Weinert, 2012, p.248)

Even within the familiar community of practice that is family, through chronic illness and the difficulty experienced by family members in terms of coping, feelings of loneliness and a lost self can be exacerbated. Even the closest familial relationships may be difficult to practice and participate in when one's family members struggle to cope and therefore withdraw from their family member with chronic illness. A reduced capacity to participate within the community of practice that is family, would further jeopardise the potential to sustain facets of one's previous life and self in chronic illness. As the community of practice that is family offers a fundamental source of identity by enabling participation in distinctive life roles it is therefore a community within which a family member with chronic illness would benefit from the potential to continue participating within if their pre illness identity was to be nurtured as opposed to marginalised.

It would appear, within the community of practice that is family for example, chronic illness can necessitate an inability to participate in that community and the reality of an inability to participate in CoP is conceptualised as non-participation and peripherality. Within the realm of participation, non-participation and peripherality are as much a source of identity as participation. We know who we are through reflections of familiarity and who we are not on observing the blur of unfamiliarity. Identities evolve in the process of engaging in practice, but also in the process of not engaging in practice. In the case of chronic illness, the active process of participating in the practices of communities becomes historical and the reliable reflection of familiarity and self becomes a blur of unfamiliarity as an inability to engage in the practices of familiar communities undermines and jeopardises identity. Participation is replaced by non-participation and inadvertently, peripherality. For example, according to Whittemore and Dixon (2008), a diagnosis of chronic illness equates to a changed life defined by profound loss. Shifts in employment and hobbies for example, amplify the struggle of the self in chronic illness. An altered body, a loss of physical function, and a compromised ability to experience life was difficult for participants:

I'm not able to do a lot of things I used to be able to do. I can't do a lot of walking. I can't do a lot of lifting. So, I have to be cautious of everything I do now. (012: Whittemore and Dixon, 2008, p.181)

The difficulty, I will tell you what the most difficult thing is. I was diagnosed at the age of 18. I remember life without it. I remember travelling. I rode horses. All these things I would do (crying). (002: Whittemore and Dixon, 2008, p.181)

I realised that I am not in the driver's seat of my life anymore and that the diseases are and they control me. You know, I don't control my life. You lose control and that is the biggest issue that I find. (027: Whittemore and Dixon, 2008, p.181)

The above quotes demonstrate the relationship between a lack of participation in the practices of familiar communities, such as employment, hobbies, and the overarching community of practice that is life and a jeopardised identity. The reality of participants no longer being who they once were is also transparent, which is arguably central to a jeopardised identity and feelings of peripherality as

people with chronic illness who cannot be who they used to be can often reside on the periphery of mainstream and the periphery of their former life and self due to an inability to participate in the practices and communities which were once central to their life and self. Such non-participation and peripherality would be an additional blow to identity in chronic illness as one struggles to make sense of a new life and self with chronic illness.

Therefore, it is through the practice of participating in a community that identity emerges, through participation and reification and in CoP, making sense of is also interlocked with both participation and reification. Reification constitutes the process whereby understanding is given form, form which is drawn upon by people in their negotiation of meaning, however reification is not restricted to objects such as forms and tools, but also processes. As such, reification can involve processes such as *“making, designing, representing, naming, encoding, and describing, whilst also including perceiving, interpreting, using, reusing, de-coding and recasting”* (Wenger, 1998, p.59). According to Wenger (1998), reification shapes our experience through the ways in which it enables meaningful practices; participation. Participation and reification are a duality. You cannot have one without the other. Reification informs participation and vice versa. A reified object or process is without meaning if the members of a given community do not engage with the reification in the form of participation and thus practice.

Meaning

The concept of meaning in CoP does not refer to a definition or an understanding, but instead relates to experience, meaningful experience. Active engagement in the world is dependent upon an ability to engage and experience the world as meaningful, and the ‘negotiation of meaning’ involves the interaction of participation and reification. A life defined by health has much meaning and purpose in terms of employment, hobbies, life roles, and social life etc., but a life defined by chronic illness, in contrast may be a life overwhelmed by a lack of meaning and purpose through an inability to participate in the variety of life domains and communities which once gave meaning to both life and self. What naturally occurs in chronic illness is a shift in communities of practice; a shift towards communities of chronic illness, the meaning of which would need to be negotiated through participation and reification. On becoming ill life can involve doctor’s appointments and hospital appointments which can evolve in a community of practice that is primary care within which one is a patient and as such within which one acquires a patient identity. The practice of being a patient gives meaning to the situation sometimes through interaction with professionals in primary care and sometimes through diagnosis and treatment including the information given to those who are newly diagnosed with a chronic illness, which collectively contribute to a shift in identity. However participation and reification within a community of practice defined by chronic illness can be resisted by some people. Dennison et al. (2010, p. 483) suggest social support was central to coping with and adaption to early stage MS. Emotional adjustment to early stage MS demanded current health to be acceptable and future health to be deemed as positive. The predominant threats to emotional adjustment were the reality of a potential future within which walking, driving, employment and independence were endangered. Using a wheelchair, relying on the care of others and no longer

being able to work were severe stressors in early stage MS. Participants spoke of avoiding facing the potential reality of MS by avoiding others with MS:

It's almost like a different world. You know, which, you kind of know that you'll probably have to join sometime, but you're just kind of thinking, well not yet please. (P5, SPMS, 3 years, 3 months: Dennison et al. 2010, p.483).

I've not really seen anybody in a wheelchair that's got MS, because I choose not to go down that route. I just don't think I could stand to sit in a room with people that have got MS on the understanding that I could end up like that. (P2, RRMS, 8 years: Dennison et al. 2010, p.483).

The distancing of participants from the world of MS also transcended into the difficulty of dealing with the information given to people with MS, information on mobility aids, for example:

It worried me. It frightened me. And again it brought up the spectre of what would happen if it all went, if it all progressed and I ended up having to use this or having to do that. What would life be like? (P6, SPMS, 2 years, 9 months: Dennison et al. 2010, p.483).

Health permitting, most participants discussed how they dealt with MS by resisting the potential to immerse themselves in the difficulties of a life with MS which enabled the maintenance of 'normality'. Normality was central to sustaining identity here, as it was through a sustained normality; roles, relationships, employment, social life, and hobbies; participation, that people with MS were able to hold on to a life and self less constrained by chronic illness. For those who are able, it would appear the assault of chronic illness on identity has the potential to be negotiated by sustained participation in communities which serve to reinforce a life and self defined by a surviving participative identity that has yet to render itself vulnerable to chronic illness.

Similar to Dennison et al. (2010), Sutton and Treloar (2007) found some participants reacted badly to a diagnosis of Hepatitis C and as such "*morals [went] out the door*" (Bugsy: Sutton and Treloar, 2007, p.334) which encapsulated a careless attitude towards life and self almost as if the diagnosis had rendered life and self insignificant in Hepatitis C. However, on considering Wenger's (1998) CoP theory, perhaps it was not a case of Hepatitis C rendering life and self insignificant inasmuch as it was a form of resistance to the reality of life and self with Hepatitis C. By not participating in the safe practices of Hepatitis C and by disengaging from the reification of Hepatitis C, such as rules and regulations in terms of behaviour, necessary lifestyle changes and information regarding the management of Hepatitis C, which included information on medications etc., participants diagnosis of Hepatitis C was not sufficiently reified by their non-participation in their diagnosis of Hepatitis C which resulted in a lack of meaning. Perhaps a lack of meaning such as this may, in some way, have prolonged the survival of their pre Hepatitis C identity. With the passage of time however, one would hope, acceptance prevailed as acceptance is key to coping in chronic illness (eg. Hunt, Nikopoulou-Smyrni and Reynolds, 2014). Only on accepting their diagnosis of Hepatitis C and engaging with both the participation and reification as defined by Hepatitis C would participants' experience of the illness have the potential to become meaningful.

The negotiation of meaning is considered a productive process in CoP. The world does not impose meaning upon us, but likewise meanings are not independent of the world in their negotiation. The meaningful experience of engaging in the world, in various domains, including chronic illness is a continuous process of renewed negotiation aligned with participation and reification. According to Wenger (1998, p.151):

It is in this cascading interplay of participation and reification that our experience of life becomes one of identity, and indeed of human existence and consciousness.

Practice as meaning

Practice as meaning emerges through the negotiation of meaning, participation and reification. By engaging in the practice of a given community of practice, one learns 'who one is'. Wenger (1998) asserts identity and practice; participation and reification, are parallels of one another. Engaging in practice enables a way of being in the world. Everything we do is everything we are. In CoP an identity in practice is not comparable to a self image. Wenger (1998) makes the distinction by asserting that although people put into words what defines them, therefore constructing a self image, a self image does not capture the lived experience of engaging in practice. Self images, narratives of the self, personality traits, roles and categories which contribute to self images are not necessarily criticised by Wenger (1998) but such reifications are not sufficient in CoP to establish an identity in practice because who we are is deeply bound by our experience of participation and reification which collectively informs the negotiation of meaning which in turn contributes to the lived experience of identity (Murray, 2011). When chronic illness strikes, the world is no longer meaningful in the way it once was. All that made the world your world, your being, your belonging, your communities and your participation, all those facets of identity pepper the unfamiliar territory that is life now defined by chronic illness, which is a difficult place to be.

According to Hunt, Nikopoulou-Smyrni and Reynolds (2014), coping with MS involves acceptance and adaption which can include negotiating ways to fill the voids created by MS. Early retirement accompanied grief for familiar identities and participants articulated that their lifeworlds had been compressed, which was problematic for identity. Similarly to familial life roles, employment is a strong identity source, and when one can no longer work, the robust identity of employment leaves a void in one's sense of self and identity which is compounded by the reliably constrained life in chronic illness, a constrained life in which much is unfamiliar. Reynolds and Prior (2003) discuss how some people with MS who had to take early retirement reinvested in MS friendly hobbies, interests and social roles which were enjoyed prior to their diagnosis, whilst some negotiated various interests that had been on the 'back burner' during their years of employment (Reynolds and Prior, 2003). According to Hunt, Nikopoulou-Smyrni and Reynolds (2014), it would appear their findings echoed the work of Reynolds and Prior (2003):

Because of the MS I had to stop that [work] and it was like a new door opened. It [art] is something I had done since I was a child. (Liam: Reynolds and Prior, 2003, p.11):

According to CoP, finding a new way to be in the world is indicative of the relationship between identity and participation in chronic illness. There is a fundamental need to participate in life in some way, a new or familiar way, if one is to be able to renegotiate one's identity through participation as a diagnosis of chronic illness can be devastating. For example, participants expressed extreme stress as a symptom of a new life with MS (Reynolds and Prior, 2003):

I had a huge fear six months ago, I had a huge fear when I was first diagnosed how I would put my time in, that I would sink into depression because I was looking at the four walls.
(Diane: Reynolds and Prior, 2003, p.11).

All participants discussed the impact of MS on all that was familiar; work, activities and life roles. For example:

My world has totally shrunk... (Diane: Reynolds and Prior, 2003, p.10).

According to Hunt, Nikopoulou-Smyrni and Reynolds (2014), a life defined by voids had to be negotiated so as to enable a meaningful life with MS which nurtured identity and relationships with others in the social world. CoP would suggest when one can no longer work, take part in familiar activities, and retain life roles etc. life can be defined by multiple voids and a lack of meaning and purpose. Participants appeared to acknowledge this in their pursuit to negotiate such voids, a negotiation which involved participation with others in the social world which was beneficial for their new identity in chronic illness.

However, in chronic illness, an inability to participate in the variety of life domains often means who we once were, we no longer are and on facing a life without meaning in chronic illness, it is difficult to negotiate meaningfulness and identity. According to Wenger (1998) the negotiation of identity is dependent upon community membership, participation, and reification which does not always reflect the lived experience of chronic illness. Therefore, the lived experience of identity can be seen as an emergent social construct which is problematic in chronic illness as an identity in practice according to Wenger (1998) is reified by social discourses and categories whilst emerging as a lived experience of participation and learning within a community.

Practice as learning

Practice as learning encapsulates development and change. Although CoP theory has been constructed as a social theory of learning, learning is about change and being diagnosed with a chronic illness is about dealing with and managing change in your life which aligns with the potential for CoP to be reconceptualised as a 'theory of being'. Communities of practice rest on a foundation of continuity and discontinuity, and according to Wenger (1998) 'practice' should be viewed as a learning process and communities of practice, as emerging structures. Practice as learning therefore enables new members to join the community which can sustain the current practices of the community whilst also providing an opportunity for development and change. Communities of practice, through learning, may evolve within a richness of old and new.

For the purpose of the current research it is necessary to move CoP forward on discussing practice as learning as, to reiterate, dealing with a diagnosis of chronic illness is about dealing with and managing change, change on an expansive scale regarding life and self. As opposed to a focus on communities and how practice as learning enables communities to evolve, here practice as learning is centred within the individual in their challenge to cope and adapt to a life and self with chronic illness.

Chronic illness disrupts everyday life and in so doing involves a shift in the familiar; participation and practices which were valued such as employment, social life and relationships with family and friends which can become additional causalities of chronic illness and as such people with chronic illness have to renegotiate their 'new normal' (Williams, 1984; Lawton, 2003; Rogers, Lee, and Kennedy, 2007). Acceptance is key to coping and coping is necessary to successful adaption in chronic illness, which can equate to letting go of one's past life and self in the pursuit of a new life and self with chronic illness. However, learning to live well with chronic illness often requires the passage of time as it is not easy to let go of one's previous life and self (Arroll and Howard, 2013), but through practice as learning, those with chronic illness are enabled to find a new way of being in the world which equates to different forms of participation, different practices and different communities. Hunt, Nikopoulou-Smyrni and Reynolds (2014) explored the role of art making in coping and well-being in MS and articulated how, over time, participants were able to move on from a diagnosis of MS:

People [with MS] have to get used to the idea that they have a disability first, but as soon as they learn to live with it [MS] then they can start focusing on something else. (Ella: Hunt, Nikopoulou-Smyrni and Reynolds, 2014, p. 10).

Being diagnosed with a chronic illness such as MS can cause one's perspective on life to be reviewed, which was found to be beneficial to coping in chronic illness:

...a concept that I thought I'd never be able to do, never, but it... opened up a whole new world to me... MS in itself doesn't mean the end of the world. For some people it's the start of a whole new life. (Ella: Hunt, Nikopoulou-Smyrni and Reynolds, 2014, p. 11).

Art provided a way to distract the mind which could be overpowered by the void created by an inability to work and the reality of a life with MS:

When you're working you were thinking about work a lot of the time and when you've no work, you've kind of an empty space to think about [MS]?, whereas if you're doing art it gives you something to think about and something that reflects your life. (Matthew: Hunt, Nikopoulou-Smyrni and Reynolds, 2014, p. 12).

I think it [card-making] keeps your mind active... I think when I'm going to sleep, if I have an order coming in... I'm thinking what will I do about that now, where could I go with that one [next card] (Rachel: Hunt, Nikopoulou-Smyrni and Reynolds, 2014, p. 16).

Well, one thing I'd say I got from it [painting] is it involves all my time and gives me a new reason to live really. (Matthew: Hunt, Nikopoulou-Smyrni and Reynolds, 2014, p. 15).

The quotes above demonstrate the potential for the negotiation of a new and positive life and self in chronic illness through a renewed purpose in life. It is necessary to move CoP on further still here as although Wenger (1998) asserts the fundamental role of 'social' participation in identity, in the case of chronic illness, it is not only participation with others in the social world, but also participation in various practices, even if such practices are independent in nature that enable a sense of purpose in life which is beneficial for identity in chronic illness. The participants of Hunt, Nikopoulou-Smyrni and Reynolds's (2014) study demonstrate the powerful role of art making in coping with MS. Participants worked independently at home, but the purpose their art gave them proved to be hugely rewarding for a self in crisis in chronic illness. From no longer being able to work and being faced with the void created by an inability to work, a void which could have been engulfed by thoughts and fears about a future with MS was instead a void negotiated by art. Through participating in art, participants were enabled to live meaningfully; it gave them pleasure, purpose and a way to express the self:

I think my painting gave me satisfaction with my life, my life could easily have been empty otherwise... I think painting has brought a very satisfying aspect to my life. (Matthew: Hunt, Nikopoulou-Smyrni and Reynolds, 2014, p. 20)

I think I'm expressing myself, my feelings toward the world. (Matthew: Hunt, Nikopoulou-Smyrni and Reynolds, 2014, p. 22).

Although I have attempted to move the theory forward here by highlighting the potential for participation in practices to nurture identity in chronic illness, even if such practices are independent in nature, it is necessary to acknowledge that the participants of Hunt, Nikopoulou-Smyrni and Reynolds (2014) study did attend regular art classes which became a place to share a mutual interest and to socialise. Rachel developed a number of friendships through her art class:

It's not all about cards, it's about what's going on in their lives and what's going on with their children. (Rachel: Hunt, Nikopoulou-Smyrni and Reynolds, 2014, p. 18).

According to Hunt, Nikopoulou-Smyrni and Reynolds (2014), the women in Rachel's art class shared equipment and card making tips, but also personal information regarding daily lives. Rachel's art class enabled community membership through a mutual engagement in the community of practice that was the card making class, the joint enterprise of card making and a shared repertoire regarding the ways in which Rachel and her friends were able to discuss their card making. To play devil's advocate, Wenger (1998) may suggest the positive impact art had on participants' lives and selves was connected to the art classes which enabled a sense of community and participation.

Having considered various CoP concepts which are relevant to the existing chronic illness literature, it became apparent that a number of these concepts may allow further insight into the relationship between patriarchal medicine and the lived experience of CFS/ME as discussed in C1 which, in essence, defined by the problematic nature of the illness for both doctors and patients alike.

Therefore, what is to follow is an elaborated insight into the said concepts in an attempt to apply CoP

to the workings of patriarchal medicine before the chapter will continue to introduce additional CoP concepts which are central to the re-conceptualisation.

Practice as meaning – What it means to be a doctor

Engaging in the practice of medicine is a practice embedded in the history and culture of patriarchal medicine, which arguably is a generative mechanism. Participating in the community of practice that is patriarchal medicine involves various forms of reification. For example, medical training allows doctors to learn the skills necessary to participate in the practice of medicine successfully and competently. Competence is central to successful participation and, models, such as the biomedical model are central to competence, as discussed in C1, and despite the invention of the biopsychosocial model (Engel, 1977), it would appear that the biomedical model continues to underpin patriarchal values within medicine as biomarkers enable definitive diagnoses. The biomedical model is therefore problematic for those who suffer an illness which fails to have a transparent aetiology. Doctors work with proof, and to be a doctor one must diagnose, treat, and if possible, cure. A lack of definitive biomarkers, as in the case of ME, renders ME a problematic illness for doctors and patients. Doctors cannot rely on diagnostic testing to prove the case of ME as there are no diagnostic tests which definitively diagnose ME and patients cannot prove they are ill which undermines their experience of illness (Hannon et al. 2012).

As doctors engage in the practice of medicine they are faced with the enigma that is CFS/ME. Is it neurological (ME)? Is it mental and behavioural (CFS)? In fact, CFS/ME is of course both as CFS/ME is an amalgamation of a mental and behavioural 'syndrome' (CFS) and a neurological 'disease' (ME). CFS/ME is unquestionably a complex illness for doctors to negotiate which may in part explain why, with regards to treatment, the bio-psychosocial model of CFS/ME has taken precedence and trials such as the PACE trial (White et al. 2011), which reinforce the psychosomatic nature of CFS/ME (The ME Association, 2011) have received financial investment. Furthermore, as CFS/ME falls into the MUS category, the MUS nature of CFS/ME adds an additional problematic element for doctors which is reflected in the prevalence of psychosomatic diagnoses which serve to alleviate the potential for engendered feelings of uncertainty or failure (Horton-Salway, 2002).

What it means to be a doctor, to participate in the community of practice that is medicine and to experience this as meaningful involves reification such as training, models and theories which enable doctors to make sense of their practice and to participate successfully within the parameters of their community of practice. In the case of CFS/ME, training is alleged to be lacking and the governing model being the biomedical model in parallel with the bio-psychosocial model of CFS/ME, the generative mechanism that is patriarchal medicine and theories such as the history of hysteria, contribute to the lived experience of CFS/ME as defined by scepticism, abandonment and isolation (Horton-Salway, 2002; Jason et al. 2004; Horton-Salway, 2007; Horton et al. 2010; Anderson, Maes and Berk, 2012; Bayliss et al. 2014).

Practice as community – Medicine

Within the societal structure of medicine, doctors engage together as doctors. Some are established doctors, some are newly qualified, but together they are doctors and doctors practice 'medicine' which involves the adherence to practices, rules and procedures which inform and sustain participation and reification. The interpretation of symptoms for example, is not an innovative enterprise, but one which draws upon the history of medicine (for example, embedded practices, rules and procedures) to guide and govern. It is the history of ME and the construction of CFS that has informed how doctors today engage with CFS/ME, or not, as the case may be (Horton-Salway, 2002; Jason, et al. 2004; Horton-Salway, 2007; Horton et al. 2010; Acheson et al. 2012; Bayliss et al. 2014). The joint enterprise of doctors is 'to be doctors', and what it is to be a doctor, what it means to be a doctor and how to be a doctor similarly cannot be detached from the history of medicine which has informed what medicine is today and in so doing what it is to be a doctor, what it means to be a doctor and how to be a doctor. The shared repertoire and shared resources of doctors is an immense category designed in nature to guide and govern. Shared repertoires could be seen to enable doctors to participate successfully in their community of practice that is medicine. The practices, rules, procedures, discourses etc. contribute to successful participation which would be experienced as competence within medicine. However, when doctors are faced with the said enigma and MUS that is CFS/ME, they must draw upon the shared repertoire which moreover promulgates the psychosomatic construction of CFS/ME which serves to perpetuate the stigma and scepticism surrounding the illness.

Practice as learning – Training and development

The community of practice that is medicine is in some ways a pulsing community which benefits from 'new blood'. However, in CoP theory whereas new blood is seen to have the potential to invigorate and further the practices of communities, medicine, aside from biomedical research which endeavours to illuminate the aetiology of 'some' complex illnesses and to demonstrate the potential for cure, is a community of practice which in many ways is rigid. The history of patriarchal medicine, being a generative mechanism, is woven into the culture of each new generation of medics who become competent within the community of practice that is modern medicine. Learning enables development and change, but within the realm of medicine, development and change is governed by the strong arm of patriarchy, fore fathers and tradition.

The literature would suggest that medicine moreover is not privileged with the emergent quality of other communities of practice and is therefore harnessed by the history of patriarchal medicine. Due to inadequate training and development, when faced with a complex illness such as CFS/ME, medicine continues to rely upon psychiatry, particularly when the population in question is female which reflects the history of MS. The reliance on psychiatry to alleviate the 'uncertainty and failure' of MUS has rendered complex illnesses such as CFS/ME psychosomatic. The beliefs of prominent figures such as psychiatrist Wessely (1990; 1993; 1999; 2000) who assert ME should not be classified as neurological but somatic alongside, for example, irritable bowel syndrome, and that CFS//ME is a modern day presentation of a form of psychoneurosis most attributable to women;

neurasthenia, have filtered into the current construction and lived experience of the illness (Marshall, Williams and Hooper, 2001). As such, the history of hysteria, stemming from the 19th century, the dominance of the biomedical model, the propensity of medicine to rely upon psychiatry, and, the mind-body dichotomy has collectively permeated CFS/ME in the 21st century. CFS/ME appears to be trapped within illegitimate borders and considering the dominant generative mechanism that is patriarchal medicine, it appears the way out is obscured by tradition. New doctors have the potential to be enabling gatekeepers, but are limited in their potential to develop this community of practice as their education and contribution to its practices are governed by tradition.

In conclusion here, Wenger's (1998) CoP theory provides a secondary layer of insight into the challenging nature of CFS/ME for doctors (and therefore patients) whilst doctors are, through their commitment to medicine, travelling a certain path, a trajectory (Wenger, 1998) within a community of practice that is steeped in tradition and as such is inflexible in its approach to complex illnesses such as CFS/ME.

Trajectories

Identity work in CoP is ongoing and therefore identity is not considered to be innate or rigid which reflects the nature of the renegotiated identity, and through membership and participation in multiple communities, identities develop trajectories. Trajectories in CoP combine the past, present and future which represent the fluidity of identity and the reality of identity being understood as a function of the past coming together with the present. There are a variety of trajectories outlined by Wenger (1998):

- Peripheral trajectories through choice or happenstance never allow full participation, however may still present an opportunity to access the practice of a community which, if significant, has the potential to influence identity.
- Inbound trajectories reflect 'new blood'. New members join the community and in so doing invest their identities in their future participation by embracing their current peripheral trajectory. Inbound trajectories reflect the promise of full participation.
- Insider trajectories reflect the furthering of a communities practices which in turn reflects the renegotiation of members' identities.
- Boundary trajectories involve the traversing of community boundaries and peripheries which can be problematic for identity as to traverse boundaries and peripheries one's identity can become fragile.
- Outbound trajectories rest upon a foundation of learning as to leave a community of practice requires an ability to learn a new way of being in a new community of practice. Such learning casts a different light on one's sense of self and identity.

The spectrum of trajectories typifies the journey of life and self which interweaves the past, the present, and the future into the lived experience of identity and as such supports the role of longitudinal data in identity research as data which is not longitudinal, is arguably narrow. Therefore, as identity is fluid, as identities shift and change over time and are constructed and experienced

differently in different spaces, data which is not longitudinal does not allow the complexity of identity to be realised, particularly the complexity of an identity in chronic illness which, as discussed, is problematic. Of the chronic illness literature cited here, only a minority used a research methodology that allowed for longitudinal data (e.g. Townsend, Wyke, and Hunt, 2006).

In chronic illness, the trajectories which once defined the journey of life and self are disrupted. The initial impact of chronic illness has been described by Bury (1982) as 'biographical disruption' which articulates the compromised structure and meaning in life as a result of a chronic illness diagnosis. All that was taken for granted regarding the future, a future mapped out by the privilege of health is no longer going to be realised which disrupts both life and self. To return to the chronic illness literature, Sutton and Treloar (2007) assert symptoms of Hepatitis C such as a loss of independence, and compromised functioning; both in life and self can disrupt the overall quality of life and well being in Hepatitis C which has been found to impact upon symptom management (Devins, 2010; Mullins et al. 2000). Sutton and Treloar's (2007) participants discussed the disruption caused by Hepatitis C to their aspirations and expectations for life. For example, some considered the potential of a life spent alone without the husband or wife they once assumed they would have; those who had expected to have children were forced to accept they no longer would. For some participants such concerns were foregrounded in their lived experience of chronic illness. According to CoP, participants' life trajectories had been halted by chronic illness. The future they anticipated evaporated on diagnosis, which is challenging not only for coping, but also for identity as the life and self they expected in the future was now compromised by the reality of a life with chronic illness.

According to Townsend, Wyke and Hunt (2006), chronic illness research that focuses on the lived experience of chronic illness exposes a common concern regarding the impact of chronic illness on 'normality' (Charmaz, 1991). The biographical disruption associated with chronic illness is typified by the inability of people with chronic illness to be who they once were and do what they used to do prior to diagnosis; an inability to sustain their normality, which undermines the self and identity in chronic illness (Bury, 1982; Charmaz, 1983).

Townsend, Wyke and Hunt (2006) discuss how some people with chronic illness, work hard to sustain normality. For example:

People... they say that I work too much... but it's not like that at all, it's completely different from that. If I did not have that [work] what, what would I be, just sitting here and that's it.
(Martha: Townsend, Wyke and Hunt, 2006, p.190).

'To work is to be' for many people and so the threat of no longer being able to work is something some people with chronic illness do almost anything to overcome as to retain a sense of purpose in life through employment; participation, contributes to the maintenance of identity which is arguably beneficial for life and self in chronic illness.

It is not only employment however that can enable a sense of normality in a life and self with chronic illness:

My doctor tells me not to struggle on but I still do try and struggle on because I feel that I'm independent and I don't want to lose that independence. Although I can feel absolutely rotten, I'm not going to wait on someone giving me a cup of tea. I'll get up and grab onto the walls using my stick and make a cup of tea for myself, and feeling absolutely ghastly... trying to make life as normal as possible... It's like a Mum thing, a mother thing, a woman thing... (Betty: Townsend, Wyke and Hunt, 2006, p.191).

Betty fights to sustain some independence through the maintenance of her familial role of 'Mum' in the context of her illness which contributes to her valued sense of self, identity and normality. Thus, a need to retain normality was evident in participants' stories. The battle with biographical disruption involved a fight to retain a continuity of life and self by being and doing whatever was possible as indicative of life and self prior to diagnosis through participation in familiar practices and communities. Some participants, such as Martha were able to remain in employment which was alleged to be fundamental for identity, whilst a need to function, to take part in life and all that was familiar in terms of employment, roles within the family and social networks empowered some participants to triumph over adversity:

...This morning I went upstairs and the next thing I knew I lay down on the bed for about between 10 and 15 minutes because I felt tired, because of the hassle of getting up, getting ready... I just had to lie down...And then you kind of force yourself, otherwise, I think I would be tempted to, you know, just take codeine and go to bed. It's that sort of fine line, I'll have a wee lie down for 5 to 10 minutes and then I'll get up and go, no matter what... I'm just kind of a law abiding person and I obey the rules. And I know you're supposed to go to work, and it's unfair if you don't go to work, so I just do it... (Peter: Townsend, Wyke and Hunt, 2006, p.190).

Peter knew who he was. He knew who he wanted to be and therefore he knew what he had to do to continue to be who he was if he was to retain some normality in chronic illness. It would appear employment for Peter, and a strong work ethic was central to his identity and therefore however difficult and challenging, Peter was going to continue to work as Peter's sense of self and identity appear strongly aligned with a conscious awareness of a mapped out trajectory that his lived experience of chronic illness was not going to interrupt. However, not everyone in chronic illness is able to triumph over adversity. For example, Ohman, Soderberg and Lundman (2003) suggest one of the challenges of chronic illness is living within a body that is no longer able to function as it once did. Participants articulated the problematic nature of a restricted life and self in chronic illness:

One feels like a half-whole or whole half. One wants to do so much and then it is not possible to do anything. (Ohman, Soderberg and Lundman, 2003, p.532).

The disruption caused by chronic illness was life altering and threatened autonomy which was problematic for some participants as they struggled to manage daily life without the help of others:

You are dependent on him [husband] all the time, to have a shower and get dressed... to clean the flat, you have to sit there and tell him what to do, because he doesn't want a home

help. Then... I said to him. You have to do it, because I can't. I can't wring out a floor cloth.
(Ohman, Soderberg and Lundman, 2003, p.533)

Sometimes participants felt as though they were no longer involved in decision making which was experienced as a painful loss of independence:

You become slight and insignificant, when all the others are against you. I tried in all possible ways... and then they took away my driving license. It was... it was hell to put it plainly.
(Ohman, Soderberg and Lundman, 2003, p.533)

The life trajectory assumed in health is often no longer viable in chronic illness; something which is reinforced by an inability to participate in life. Therefore a future which was once considered transparent becomes opaque and skewed in chronic illness on facing a trajectory of chronic illness which is often a trajectory that rests on uncertainty, unfamiliarity and a sense of peripherality (Dennison et al. 2010).

Participation and non-participation; peripherality and marginality

Having previously discussed in brief the concepts of non-participation and peripherality in CoP, I will now elaborate further to give a greater insight into the relationship between chronic illness, non-participation, peripherality and marginality which is beneficial for considering the many facets of the identity in crisis in chronic illness. Similar to communities of practice engendering feelings of what is familiar and what is unfamiliar and therefore who one is and who one is not, membership and non-membership, the traversing of boundaries and peripheries involves both participation and non-participation which according to Wenger (1998) is central to identity. A coherent identity which is woven into the tapestry of boundaries and peripheries is naturally a combination of being an insider and being an outsider. Experiences of participation and non-participation are therefore an unavoidable part of life; however non-participation can take on different forms. Peripherality can be a positive form of non-participation as peripherality can be a necessary form of non-participation which presents the potential for full participation through a peripheral trajectory which is usually aligned with a trajectory of participation. However, in chronic illness, peripherality can often be a reality as experienced through a shift in both life and self which inadvertently positions those who are chronically ill on the periphery of their old life and self. Similarly, marginality can lead to non-membership or a marginal position within a community of practice. Marginality is a form of non-participation that does not allow for full participation and is aligned with a restricting trajectory that may become so embedded in the practice of a community that an alternative trajectory may never be realised. As such, non-participation can either be enabling or disabling as can a diagnosis of chronic illness. As I have rehearsed throughout, chronic illness is life altering and as such the community of practice that is a life with chronic illness is naturally a form of marginality. The community of practice that is chronic illness is a marginalised community of practice within the overarching community of practice that is 'a life with health' which contains an unimaginable number of communities of practice which were once central to life and identity. On becoming marginalised through chronic illness, one's

previous experience of belonging within the various communities which once defined life and self, becomes historical as one must negotiate a new way to belong within an unfamiliar life and self in chronic illness.

Belonging

Not only through engaging in practice and participation can people experience a feeling of belonging. According to Wenger (1998, p.174) through “*the ongoing and mutual negotiation of meaning, the formation of trajectories and the unfolding of histories of practice*” engagement enables both belonging and identity. The work of engagement is central to the formation of communities of practice and rests upon a foundation of mutuality. Only in the mutuality of interaction can communities become communities. Through such mutuality of engagement, the duality of participation and reification once again provide a special opportunity for both learning and identity (Wenger, 1998). When access to participation and/or reification is compromised, as in the case of chronic illness through inadvertent marginality and/or peripherality, so too is the potential to belong and therefore a lack of membership through an inability to engage in participation, reification and mutuality, undermines the opportunity to belong and to ‘be’, which represents an additional hurdle for those who live with chronic illness.

Identification

According to Wenger (1998), identification refers to the process whereby belonging to a community enables distinctive identities. Identification involves both participation and reification. For example, ‘identifying as’ and being ‘identified as’ is a form of reification whereas ‘identifying with’ is a participatory process. I would identify as a doctoral student and I may be identified as a doctoral student whereas identifying with my fellow doctoral students requires participation in the community of practice that is academia. As such, identification is not only something we do to ourselves but also something we do with others. We assert who we are and we assert who others are through the process of identification. In chronic illness being ‘identified as’ can be problematic as a number of chronic illnesses, such as Hepatitis C, can be stigmatising which serves to exacerbate the lived experience of chronic illness by adding an additional layer of prejudice, discrimination, and isolation. With a greater focus on mutuality as opposed to asserting who others are through the process of identification, according to Wenger (1998), engaging in practice is a key component of identification as people not only invest in what they do, but also in the mutuality of relationships with others which is as integral to identity as the practice of a community. As a community of practice emerges, members not only negotiate relationships with others but also negotiate the expansive landscape of communities which enables a lived experience of self and identity. On engaging in practice we learn how we ‘fit in the world’ and we can only find ‘our fit’ by actively engaging in practice and with others. Aside from the potential for stigma and discrimination in chronic illness, the challenge associated with finding a way to ‘fit in the world’ with chronic illness through the process of identification is problematic according to CoP. Those with chronic illness no longer ‘fit in the world’ as they once did as one’s life and self is often unrecognisable and their capacity to find a new way to fit in the world is compromised by their compromised ability to engage in practice with others.

I have discussed the primary concepts of CoP in an attempt to illuminate its relevance to the lived experience of identity in chronic illness. I have drawn upon Multiple Sclerosis (MS), Parkinson's disease, Hepatitis C and chronic illness in general so as to consider identity in chronic illness. I have only briefly discussed the symptomatology associated with MS, Parkinson's disease, and Hepatitis C, as the literature cited did not foreground the role of symptoms in the context of identity but instead made transparent the link between a loss of identity in chronic illness and a loss of employment, life roles, hobbies, and social lives etc. As such, inherent in the chronic illness literature used to reconceptualise CoP was illness intrusiveness. Understanding the psychology of identity in chronic illness is the overarching aim here; however on arguing that identity is participation it became increasingly evident that to have quality of life (QoL) and well-being in chronic illness, one must be able to participate. Therefore, although QoL and well-being will not necessarily be foregrounded, I anticipate that on exploring the relationship between participation and identity in chronic illness, the relationship between participation, identity, QoL and well-being may emerge.

Context of chronic illnesses

Having considered the context of identity in chronic illness, moving forward it is necessary to acknowledge the role of context further, not just the context of identity in chronic illness, but the context of chronic illnesses. C1 foregrounded the history and in so doing the context of CFS/ME as to illuminate the millennia of meaning underpinning the lived experience of the illness. This chapter has drawn upon a variety of chronic illnesses which are contextually different. Parkinson's disease is a legitimate chronic illness as it is a diagnosable neurological disease affecting the nervous system (Heisters, 2011). Due to its status as a legitimate chronic illness, it is likely that people would be sympathetic to the lived experience of Parkinson's disease as they would be privileged with an understanding of what Parkinson's disease is; real, and how it affects sufferers as the literature would suggest there is little confusion surrounding the illness. As discussed in C1, MS has a turbulent history as MS was once known as a 'woman's disease' and as women were alleged to be the 'nervous sex' due to, for example their 'wandering womb', the alleged madness of women was found to permeate the history of women's illnesses, such as MS (Showalter, 1997; Ussher, 2013). It was a lack of biomarkers; proof and the fact that MS predominantly affected women that rendered MS an illegitimate and contested illness (Skegg, Corwin, and Skegg, 1988). There has however been a shift in the lived experience of MS as indicative organic biomarkers for MS have emerged and thus there is now proof that MS is 'real' and not just a reflection of women's propensity for madness (Richman and Jason, 2001). Similarly to Parkinson's disease, one would assume people would be sympathetic to those with MS as they would have no reason to question the validity of MS and/or how MS affects sufferers. In contrast, if we return to Hepatitis C, a virus that is transmitted via the blood, there is a stigma attached to Hepatitis C due to its infectious nature and its association, rightly or wrongly, with drug use and HIV (Sutton and Treloar, 2007). Despite the stigma surrounding the illness, Hepatitis C is a legitimate chronic illness, people do not question its legitimacy, conversely something which is evidenced by the stigma experienced by sufferers as people are often fearful of those with Hepatitis C and the risk of contamination which causes some with Hepatitis C to keep their diagnosis a secret

(Sutton and Treloar, 2007). Therefore, the literature would suggest that although people are not necessarily sympathetic to Hepatitis C, they do not question its legitimacy as a chronic illness.

Why CFS/ME?

One of the fundamental reasons why the current research is focussed on Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) is the context of CFS/ME, which, as discussed in C1, is bound by suspicion and contention due to a lack of biomarkers; proof (Richman and Jason, 2001). Richman and Jason (2001) use the example of the history of MS to highlight the challenges faced by those with CFS/ME as similarly to MS; CFS/ME predominantly affects women and as a result follows in the footsteps of MS as a woman's disease which has an implicit relationship with the history of hysteria due to an elusive aetiology. By exploring the millennia of meaning underpinning the lived experience of CFS/ME within a CoP framework, the current research endeavours to enable a transparent understanding of the context of CFS/ME and the context of the identity and participation structure in CFS/ME.

Chapter summary

The current chapter has argued, aligned with CoP that identity is participation; *“who we are is deeply bound by our experience of participation in the communities to which we belong”* (Murray, 2011, p.8). I have drawn upon the chronic illness literature so as to compound the relevant application of CoP; a re-conceptualisation, to the lived experience of chronic illness whilst also acknowledging the role of context in lived experience. I have demonstrated that when those with chronic illness can no longer participate in life and self that their identities, through a lack of participation, are jeopardised. Having attempted to provisionally unpick the nature of the fragile self and identity in chronic illness, it was also an endeavour to use the re-conceptualisation of CoP to illuminate the potential for the renegotiation of self and identity in chronic illness as the chronic illness literature cited illustrated that through negotiated participation in life and self, new identities in chronic illness can emerge and such identities can be positive. On giving further consideration to the nature of a positive identity in chronic illness it became apparent that through participation, it is not only identity that is enabled as under the surface of participation; identity in chronic illness were experiences of QoL and well-being. Therefore, although QoL and well-being are not central to the current research, moving forward, the relationship between identity; participation, QoL and well-being will be reflected upon in an attempt to establish the multifaceted nature of identity in chronic illness from both negative and positive perspectives.

CHAPTER THREE (C3)

Literature Review

The introduction to CFS/ME chapter looked beyond the role of participation in identity to the millennia of meaning which underpins the lived experience of CFS/ME to explore the context of CFS/ME as defined by illegitimacy and the relationship this has with the lived experience of the illness. The conceptual chapter introduced CoP and in so doing provided an in depth insight into the concepts of CoP so as to establish it as a new resource to consider in chronic illness. As such the conceptual chapter served to illuminate that who we are is deeply bound by participation in the communities to which we belong and that in chronic illness such participation is often compromised meaning so too is identity (Murray, 2011). The current chapter provides further insight into the lived experience of CFS/ME by reviewing the CFS/ME literature which focussed upon 'issues of identity' as I am claiming that issues of identity are central to the lived experience of chronic illness: CFS/ME. As discussed in chapters one and two, the lived experience of chronic illness is a complex phenomena to understand due to the history and context of the illness and as such whilst the contribution of the current CFS/ME and identity literature is acknowledged here, the fundamental weakness of the literature being a lack of integrated theory and longitudinal data will be foregrounded.

Issues of identity

There is some argument to suggest that issues of identity are central to the experience of chronic illness (eg. Whitehead, 2006). Such issues of identity in chronic illness are compounded when the chronic illness is contentious, as in the case of CFS/ME (Larun and Malterud, 2007). CFS/ME is not privileged with legitimacy and therefore CFS/ME sufferers are not privileged with a legitimate sick identity (Clark and James, 2003). The featured CFS/ME and identity literature here provides an insight into the lived experience of CFS/ME which enables an understanding of the complexity of CFS/ME as a chronic illness and the complexity of the CFS/ME assault on life and self. Throughout each summary I will interweave CoP in an attempt to demonstrate that although the literature under review provides an insight into the lived experience of identity in CFS/ME, the insight is inhibited by a lack of theory. I do not intend my positioning of Wenger (1998) to be a re-analysis, more a critical framework within which to review such analyses, which are presented in chronological order.

Ware (1999) explored the illness narratives of those with CFS in order to establish the nature of the social course of their chronic illness. Ware's (1999) study was longitudinal. Each year for three years participants (n: 80) took part in a face to face interview, completed a set of questionnaires, took part in a telephone interview and repeated the questionnaires. Ware (1999) suggests the experience of chronic illness can be seen as socio-cultural. In the case of CFS, distressing factors associated with the illness interact with culturally specific expectations regarding social life and personal performance to generate experiences of micro-social marginalization and grief:

So I kind of feel like my life is over. Sort of like the river passing by and you're watching it. Once in a while you stick your foot in the river and remember what the water was like but you're not really swimming in the stream. (Ware, 1999, p.313)

Participants could no longer sustain established roles such as family member or colleague which were once relied upon to scaffold their sense of self and identity, and according to Ware (1999) participants' experience of illness was not legitimised due to the contentious nature of CFS and an elusive aetiology, which is reflective of dominant patriarchal values within medicine, as discussed in C1 and C2, which continues to burden the lived experience of CFS/ME:

When I first got this ten years ago I just tried to keep going 100%. I kept working full-time. I kept trying to do everything, just as if nothing was wrong. Because the doctors kept telling me nothing was wrong! So I figured I just had to keep going! (Ware, 1999, p.313)

Cancer would be better. I shouldn't say that, because I don't think it would be better. But it would be easier to share with somebody. I can't tell people about this, because first of all, I don't know what to call it. I don't know how to describe it. (Ware, 1999, p.316)

In some ways you're treated as though you have AIDS. A lot of people back away because they know you have a chronic illness and they have a hard time dealing with that. But then a lot of people back away because they hear you have a chronic illness that is not understood. I probably don't see the majority of my friends that I had before I got sick. So many of them have just kind of backed off. (Ware, 1999, p.316)

An inability to work equated to unemployment which further exacerbated participants' experience of marginalisation. The isolation born out of a contested chronic illness extended to the social world which compounded the illness experience for participants:

It was my birthday and the only thing I got in the mail was my Medicare handbook. No one remembered my birthday. It just compounds the isolation. It kind of says to you when nobody remembers, 'Well, maybe I'm not really here! (Ware, 1999, p.313)

Ware (1999, p.318-319) discusses how participants were found to adopt ways of resistance such as, 'preserving worlds of wellness' whereby individuals with CFS may cut corners in order to sustain their place in the social world; 'Passing' whereby health is simulated to avoid further rejection from within the social world; 'Payback' which was avoided by some to limit the consequences of activity associated with CFS, whilst accepted as a price worth paying by others for valued social interaction; and, finally 'Re-making the life-world' whereby one's old life is negotiated so as to create a new and enabling life within the parameters of chronic illness. Prioritising was a required skill for the negotiation of a new life which for some participants turned their illness experience into a positive one as their new lives symbolised new and stronger selves expressed by feelings of personal growth:

A lot of things you can't do as well as you would like to do, or used to do, but you can do them well enough. I've lowered my standards. 'Good enough' has become a way of being for me. (Ware, 1999, p.320)

I've found out a lot about myself. It's been a positive experience. This illness is like drinking a can of Jolt. It puts you on notice that you don't have control over everything. It reinforces your human frailties. But it also forced me to go back into the world for another bucket more times than I thought I could. And because of that, I know I can face anything. Anything at all. (Ware, 1999, p.320)

As considered in C2, sometimes those with chronic illness will do almost anything to sustain their place in the world and the themes highlighted above such as 'preserving worlds of wellness' and 'passing' would appear to reflect a need to sustain one's sense of self and identity.

Ware's (1999) findings contribute to the chronic illness literature as using a longitudinal framework, Ware (1999) has provided an insight into a variety of issues pertaining to the crisis of identity in chronic illness: CFS/ME. Ware has discussed the impact of CFS within the parameters of marginalisation through an inability to sustain roles such as family member or colleague which once scaffolded participants' sense of self and identity. Ware (1999) has also acknowledged the problematic relationship between unemployment, a withdrawal from the social world and the crisis of identity in CFS whilst also providing an insight into the nature of identity survival in CFS. However, Ware (1999) has not theorised participants' experiences and in so doing has not unearthed the mechanism underpinning the crisis of identity in CFS. Ware (1999) does assert the experience of CFS is not limited to symptoms as the experience of CFS transcends symptoms to experiences of isolation, particularly within the social world, and illegitimacy within primary care. However, if such findings are to be substantiated, a theoretical framework which can enable a more comprehensive understanding would arguably be preferable in future work. Without transparency the concepts of CoP have been presented by Ware (1999) in an attempt to provide an insight into the socio-cultural facet of identity in CFS, which reaffirmed to me the importance of CoP: a re-conceptualisation, not only within the current research, but also future chronic illness research.

Asbring (2001) conducted semi-structured interviews with 25 women who had either CFS or Fibromyalgia to explore the disruption caused by chronic illness and subsequent identity transformation using a grounded theory approach. Asbring (2001) found that biographical disruption peppered the analysis with the challenge of adjusting from an active life to a passive life being transparent:

Of course I felt that something was wrong with my body, as I normally work full-time at the Health Care Centre as well as having two extra jobs and working nights as well. I dare say I was very active and [had] a very active social life. I met friends and am used to keeping on the go, but then suddenly it wasn't me! There was something up with me. I felt in my whole body that it wasn't the old me. (CFS-15) (Asbring, 2001, p.315)

Participants expressed feelings of longing and grief for the life once lived and the roles which defined that life such as wife, colleague, and friend. The new self was, for some of the women, detached from their normal self which equated to a new self that had not yet been integrated into the old self which was isolating for participants as they expressed feeling isolated in a sense of self and identity with which they could not be intimate:

This having lived a little over 2 years with a 'me' that is no longer the 'real me', because it is a completely new person. As time passes I can find certain things that I recognize from before but the rest is actually new and it's not me and I don't recognize myself. And still, I must socialize with this person. (CFS-9) (Asbring, 2001, p.315)

When participants were no longer able to work they expressed feelings of marginalisation as they now resided on the periphery of everyday life which did little to support their previous identities and self-esteem. According to Asbring (2001), experiences such as adjusting from an active life to a passive life, longing and grieving for the life once lived which was indicative of life roles, feelings of isolation in a life and self that are unfamiliar, and a lack of employment reflect the biographical disruption caused by chronic illness.

Asbring (2001) discussed that although many roles were compromised and/or lost, a minority of women worked hard to maintain certain activities which were integral to their sense of self and identity. These women negotiated their job, role within the family and social life as to reduce the biographical disruption and maintain more of their 'previous self':

From having been a very sociable person and having socialized a lot with people, having been active in various clubs and everything, I have just had to cut down on all that sort of thing. So work is the only thing I have, which is some sort of porthole to the normal world. (CFS-1) (Asbring, 2001, p.316)

Similarly to Ware (1999) and the chronic illness literature cited in C2, it would appear that Asbring's (2001) participants believed that if they were to nurture their 'previous self', they had to participate in their 'previous life'.

The social life of Asbring's (2001) participants was often an additional casualty. The incapacity and unpredictability of CFS and fibromyalgia was a barrier to the social world as participants were either too ill to participate or unable to plan to participate due to unpredictability of symptom severity. Aside from incapacity and unpredictability, sometimes participants withdrew from their social worlds as they could no longer be who they once were within a social sphere within which a connection to others had been severed:

Our lives have become like that of a pensioner. You just can't cope with having guests at the house, at least very rarely. And you can't plan for it as you may feel so awful that you can't face seeing anyone. (CFS-12) (Asbring, 2001, p.316)

Asbring's (2001) participants negotiated new identities through a process of acceptance and re-evaluation of life and self. Understanding the limits of their new bodies and exploring new activities and a pace of life which were achievable enabled a new sense of self and identity within the parameters of chronic illness. Some participants tried to return to old lives and selves but moreover were disappointed as such pursuits were unsuccessful. Participants sometimes prioritised subjective gain over loss and as such re-entered their social world despite the consequence being subsequent days spent in bed recovering. 50% of participants expressed an insight into illness gains such as increased self-respect, which perhaps relates to prioritising the self within a life with illness. For some a new perspective on life enabled materialistic matters to become insignificant and for others the experience of chronic illness had been humbling and as such a greater appreciation for life was realised:

[I have got insights about] what is worth doing in life and not. I am surely seen as very boring and bothersome by some of those around me when I tell them; not to work too much, to live, have more leisure-time and go in for oneself. (CFS-1) (Asbring, 2001, p.317)

Asbring (2001) asserts however, that irrespective of an insight into illness gains, rarely were such illness gains superior to feelings of loss and grief for the life and self lost.

Similarly to Ware (1999), Asbring (2001) has presented participants' experiences without theorising them. Experiences such as adjusting from an active life to a passive life, longing and grieving for the life once lived which was indicative of life roles, feelings of isolation in a life and self that were unfamiliar, a lack of employment and the negotiation of life and self in CFS do contribute to an understanding of the biographical disruption caused by chronic illness, however, the findings of Asbring (2001) would have been elevated by the integration of theory and enhanced by a longitudinal framework. Had participants' experiences been positioned within a theoretical framework, the negotiation of life and self in CFS would become more transparent and as such the application of such findings would be better enabled. Despite providing only a snapshot, Asbring (2001) has provided an insight into the lived experience of identity in chronic illness, but had Asbring (2001) drawn upon a theoretical framework, such findings would better serve those who are newly diagnosed with chronic illness. A more transparent foundation of theory and enhanced insight into the mechanism underpinning the renegotiation of life and self in chronic illness would be beneficial for those who are, through the onset of chronic illness, having to adjust to a new life and self. Therefore, a re-analysis using CoP: a re-conceptualisation would provide a transparent insight into the mechanism underpinning the renegotiation of life and self in chronic illness as presented by Asbring (2001) which would benefit those with CFS/ME and future chronic illness research.

Clarke and James (2003) conducted open-ended yet focused telephone interviews with 59 participants with CFS to explore the impact on the self of the contested nature of CFS using a case comparison analysis. According to Clarke and James (2003), the sudden onset of CFS was experienced as a huge shock as participants went from busy, active people to people who were incapacitated, house bound and bed-bound. Feelings of profound loss encapsulated lost jobs, friends, self-worth and identities:

It's getting better, but it was like, I was at a low ebb last year when I left work, I lost my self-esteem, my identity, you feel like just a blot on the face of the earth, that you have no self-worth. (Carol: Clarke and James, 2003, p.1390)

It was the worst thing that I've ever had to do in my life. It was like giving up my whole identity. It was my whole life, because for me, I'm single, work was my life, the people at work were like my family and it was ... it was an ideal situation for me and it was the hardest thing I've ever done, giving it up. (Susan: Clarke and James, 2003, p.1390)

They were separated from the roles which once defined them yet were unable to adopt the legitimized 'sick role'. The contested nature of CFS compounded the experience of loss for participants who lived with a disputed illness which was constructed in the media as 'residing in the mind of sufferers' which reflects the history of the illness:

You know, you feel like you've lost yourself, your identity and everything. And also just the reaction of other people, that you don't get any compassion. (Jaclyn: Clarke and James, 2003, p.1390)

I think for a while my self-esteem took a real blow because of people constantly questioning whether I was sick. (Vera: Clarke and James, 2003, p.1390)

There have been times when I've said to myself, maybe I wish I had M.S. or cancer, then people will say, well, Rick has cancer and so he definitely is ill. (Rick: Clarke and James, 2003, p.1391)

I don't understand the closed-mindedness of it. But on the other hand, I can understand that there isn't a blood test that says this is what this is. And so... I know where they're coming from but I just think that there's very little empathy out there. (Tara: Clarke and James, 2003, p.1391)

The lives of participants no longer had meaning, structure, purpose or legitimacy. Clarke and James' (2003) analysis reveals the complex nature of identity in CFS. On acknowledging participants shift from busy active people to incapacitated people who grieved for lost jobs, friends, self worth and identities, Clarke and James (2003) provide an insight into the complexity of identity in CFS/ME.

The history of the illness interacts with the lived experience of the illness for participants as Clarke and James (2003) discuss how the contested nature of the illness compounds the lived experience of the illness through an inability to adopt a legitimised sick role which exacerbates the lived experience of CFS for participants. Doctors often trivialised participants' experience of chronic illness and were reluctant to provide a diagnosis whilst friends struggled to accept the chronicity articulated by participants in light of the contentious nature of CFS. As disbelief and rejection ensued participants expressed a withdrawal from their social worlds:

I've lost so many friends that... the girl I thought I would marry deserted me. There's a distrust of getting involved with anything, relationships, for example. (Jason: Clarke and James, 2003, p.1391)

Yes, all my relationships with family and everything are different... As far as other relationships with friends and that; they have pretty well all ended. (Carol: Clarke and James, 2003, p.1391)

According to Clarke and James (2003), in order to accept a life with CFS, participants had to accept their new sense of self and identity:

Right, I would totally sum it up as it has changed every single fibre of me as far as internal changes, lifestyle changes, relationship changes, career changes, body changes, mind changes, everything possible it's really big. (Janet: Clarke and James, 2003, p.1392)

As opposed to returning to their previous selves, participants created new and 'better' selves and in so doing rejected their old selves. A new perspective on life and self was central to personal growth. Clarke and James (2003, p.1393) suggest the '*radicalised self*' responds to the illegitimate illness experience that encapsulates the CFS experience. The medical profession does not legitimise the CFS experience for sufferers and as such those with CFS cannot draw upon legitimate discourses which justify their illness and disability so have to create a new way of being in the world independently of legitimacy. Similarly to Ware (1999) and Asbring (2001), Clarke and James (2003) discuss the renegotiation of life and self in CFS through an acceptance that allows personal growth. Participants reflected upon what was important in life and in so doing reflected upon the shifts that underpinned their renegotiation of life and self such as a shift from employment to the priority of familial relationships and roles.

On considering the impact on the self of the contested nature of CFS, Clarke and James (2003) reflected upon the crisis of identity in CFS which was exacerbated by an inability to sustain previous life roles, the shift from an active life to a life without meaning, structure, purpose or legitimacy, and a withdrawal from the social world. Clarke and James (2003) also discussed the renegotiation of life and self in CFS, however, such discussions were not harnessed by theory. Clarke and James (2003) undoubtedly contribute to the chronic illness literature by providing an insight into the workings of the CFS identity in crisis, but had their findings rested on a foundation of theory, the application of such

findings would have greater scope for those working in the area of chronic illness and likewise those living with chronic illness: CFS/ME. Had Clarke and James (2003) had the foresight to draw upon CoP, for example on acknowledging participants shift from busy active people to incapacitated people who grieved for lost jobs, friends, self worth and identities, Clarke and James (2003) would have provided an insight into the relationship between participation and identity and in so doing the mechanism underpinning identity for those who through chronic illness have been forced to reevaluate life and self.

Whitehead (2006) conducted in-depth interviews with 17 people with CFS/ME to explore identity reconstruction and CFS/ME using a thematic narrative analysis. According to Whitehead (2006) the initial acute phase of CFS/ME was one defined by loss and grief for life and self lost. Participants were isolated in a world and self that were unfamiliar and no longer rooted in the meaning, structure and purpose of their old lives and selves:

A few years back I could still use my catering skills, I've done a few weddings for family, but now I can't even ice a cake... (Alan: Whitehead, 2006, p.1028)

Whitehead (2006) discusses that during the 'medium term' of illness, participants attempted to 'move on' typified by a return to work and previous life roles. Such attempts were often unsuccessful. However, negotiating the pace and structure of life and activities, resisting marginalisation through the pursuit of chosen activities and exploring new activities was significant for participants:

They were very good and arranged a room with a bed in for me... so I used to nap between lectures, that was the only way that I could get through the day. (Helen: Whitehead, 2006, p.1027)

I was lucky really because the girls there knew that I wasn't so good and I used to go in and I used to have to sleep before I could open the branch. (Linda: Whitehead, 2006, p.1027)

Through CFS/ME Whitehead's (2006) participants were forced to renegotiate life and self as there had been a fundamental shift in life and self due to the onset of chronic illness. They often tried to return to their previous life roles, which was not however always successful and as a result participants were found to pursue a new way to be in the world.

According to Whitehead (2006), diagnosis was central to identity reconstruction. The burden of uncertainty epitomised a life with illness; a life without legitimacy, which is indicative of the burdening biomedical tradition of patriarchal medicine. Participants only approached their GP's when they had collected enough evidence to support their symptomatology claims and a proposed diagnosis of CFS/ME. Once diagnosed, participants were able to begin managing their illness as the fight for diagnosis had been won. It would appear, according to Whitehead (2006) that the context of CFS/ME as discussed previously denies a rite of passage to diagnosis and as such diagnosis is a battle that needs to be won if participants can reinvest their energies into coping with the reality of a life with

CFS/ME. Whitehead (2006) suggests the third phase of identity reconstruction evolved as a new sense of self and identity was realised:

It makes you evaluate life and decide what's really important. (Richard: Whitehead, 2006, p.1028)

I think I'm a different person for having come through it, I think it's made me a lot stronger than I was, made me face up to things. (Angela: Whitehead, 2006, p.1028)

Participants did not strive to return to their former selves, instead embracing a new and positive self which was for the majority preferable to their old self. Acceptance was key to identity reconstruction in the third phase. Not all participants (n: 2) were able to accept their new life and self and as such continued to grieve and yearn for the life and self lost. Whitehead (2006) has explored the renegotiation of life and self in CFS/ME and in so doing has provided an insight into coping.

Whitehead (2006) discussed how participants felt isolated and on the periphery of life as they once knew it and how they attempted to renegotiate their lives and selves that were casualties of chronic illness: CFS/ME. However, similar to the previous literature reviewed, a longitudinal framework that would have allowed for greater depth was not favoured, and as participants' experiences were discussed outside of the parameter of theory, comprehension and the potential for wider application was also inhibited. I do acknowledge the useful contribution of such experiences to the understanding of the lived experience of identity in CFS/ME, but as such experiences are not guided by a theoretical foundation, I would assert they are rendered more opaque than they would have had they been harnessed by a solid foundation of explicit theory such as CoP: a reconceptualisation, which has the potential to guide future work and coping in chronic illness: CFS/ME.

Dickson, Knussen, and Flowers (2007) used in-depth interviews and IPA to explore identity crisis, loss and adjustment in CFS (n: 14). The 'life' before CFS was one defined by activities and roles which were no longer part of a 'life with CFS'. Biographical disruption permeated the analysis which illustrated the relationship between a loss of roles and responsibilities and an ongoing crisis of identity and personal loss in CFS:

When it comes to the bit you think, well, if you actually summed up your life, it's in absolute shreds, you've eh, you know, you're in your thirties and your thirties are supposed to be a really good time of your life, a very productive time at work, productive time socially and relationship wise and everything, and you're going along . . . eh . . . and it's in tatters. You can't really do anything you want. (Stuart: Dickson, Knussen, and Flowers, 2007, p.465)

CFS evolved as an alleged dictator who relinquished participants of personal control and agency whilst engendering feelings of failure, worthlessness and insignificance:

CFS is a dictator. It dictates my everyday life. It determines what I can and cannot do. It controls my body and my mind and every part of my being. (Anne: Dickson, Knussen, and Flowers, 2007, p.463)

I mean sometimes just a feeling that em. . . I had no purpose. I was an empty shell. I am a fragment of the man I used to be. I can do nothing now. I'm useless to everyone. I'm useless to myself. My self-esteem is rock bottom. (Bartholomew: Dickson, Knussen, and Flowers, 2007, p.464)

When participants were unable to exert control and agency over their lives due to an inability to function physically and/or mentally, they sometimes experienced a loss of self which transcended into experiences of disembodiment. They were no longer able to inhabit either body or mind, and when access to body and mind was moreover denied, participants found themselves overwhelmed by profound loss which reflects the crisis of identity in chronic illness:

I felt numb. I was empty. There was this huge part of me that was missing. People talk about a part of them being missing when their spouse dies after many years of marriage and that's how I felt. I felt like part of me had died. I'd have given anything to have it back again. I just wanted to be me. The old me before I got ill. (Sophia: Dickson, Knussen, and Flowers, 2007, p.464)

I didn't want to go out because I didn't know how to behave. I didn't know who I was anymore and I was always conscious of other people judging me. I had to put on a face and pretend to be well and things because otherwise, the eyes would roll if I talked about how I was really feeling. (Angie: Dickson, Knussen, and Flowers, 2007, p.466)

The scepticism surrounding CFS, which questions its very existence, was found to heighten the grief for a lost self. Dickson, Knussen and Flowers (2007) assert a need to consider CFS within a socio-cultural context suggesting when those with CFS are faced with the uncertainty of a contested illness, scepticism may be internalised which can exacerbate the crisis of identity in the shadow of the questioned authenticity of CFS:

Well, people thought you were a malingerer That you were 'at it' and there was this idea that you were just lazy, or whatever, or you didn't want to work or anything and that you were using it as an excuse. (Kelly: Dickson, Knussen, and Flowers, 2007, p.465)

The scepticism surrounding CFS also exacerbated the isolation of participants:

I think with CFS you become very isolated and even though you might be surrounded by a lot of people, you still feel very isolated and I think that's to do with people not taking it seriously. And then realistically, you don't want to talk to them because if your CFS is part of your life, part of your everyday life, it's obviously going to come into your conversation but they hint that

they're not interested and they don't believe or accept that it is very much part of your life. So up theirs. (Thomas: Dickson, Knussen, and Flowers, 2007, p.466)

Well, to be honest . . . I would probably have been like that myself.

You know, if I'm totally honest with you. Even if I knew that a person had CFS, unless I had actually seen what they were going through 24/7, I would probably have said 'Oh, they're needing to pull themselves together' or you know, 'they just need a right good kick up the backside' or something like that. But now that I've actually experienced it for myself, my whole attitude has changed. You absolutely cannot understand CFS until you have experienced it for yourself. You must have it to appreciate what it's like. (Emily: Dickson, Knussen, and Flowers, 2007, p.467)

Moreover, the identity crisis was a crisis of the past for participants. Acceptance was considered necessary if CFS was to be integrated into the lives and selves of those with CFS and in so doing enabled a new sense of self and identity. Such acceptance was alleged to involve a period of re-embodiment whereby the fractured mind was re-embodied which engendered trust and enabled personal growth in CFS/ME. Dickson, Knussen and Flowers (2007) acknowledge the problematic context of CFS for CFS identities and the role of acceptance in coping:

It's all about accepting the illness and learning to deal with it. Accepting it stops you from feeling down in the dumps and it helps you to just take each day as it comes. That helps a lot. You know that you're going to have good days and bad days and that people don't understand what you have but you've just got to get through it. There's no point in moping around, you just have to accept it and move on. And that attitude helps you to recover. So yeah, just accept that you have it, adapt your life and move on. That's the key because once you've accepted something, it's much easier to deal with. (Rosemary: Dickson, Knussen, and Flowers, 2007, p.467)

Well, you're forced to re-evaluate your life. Somewhere in the process of being ill and having to give up everything that you once enjoyed, everything that made you who you were, you have to re-assess your life, your priorities, what's important in your life. For me, I learned that being a sportsperson was important to me, and yes, maybe it did make me who I was for a while, but now I think I was just lucky to have that for as long as I did. Some people will never have that. But that was my old life, it's almost like a past-life now. I don't think of myself as being like that anymore. Now my priorities just lie in being healthy and happy. If you're healthy and you're happy, then you're damn lucky. It's more than a lot of people have. They are my priorities now, not sport or competitions. (Angie: Dickson, Knussen, and Flowers, 2007, p.468)

It's about taking baby steps and making goals em. . . but they have to be realistic so maybe try to cook dinner or do the food shop or something small and you feel great when you do it. You really get a boost from achieving something and you feel you have value because you cooked your wee boy's tea or your husband comes home to a well-stocked fridge so it makes you feel better when you do something a wife should do or a Mum should do..so..yes.

(Pamela: Dickson, Knussen, and Flowers, 2007, p.468)

Similar to Ware (1999), Asbring (2001), Clarke and James (2003), and Whitehead (2006), Dickson, Knussen and Flowers (2007) make a valuable contribution to the chronic illness literature by providing a powerful insight into the reality of the relationship between the lived experience of chronic illness and the crisis of identity in CFS/ME but a theoretical framework would have allowed participants (and others living with chronic illness: CFS/ME) a more transparent insight into their identity crisis and ways in which to negotiate their identity crisis if they were to live well with chronic illness. On considering the negotiation of living well with chronic illness as discussed by Dickson, Knussen and Flowers (2007), it once again struck me that the re-conceptualisation of CoP would provide the transparent insight necessary to negotiate identity, and quality of life and well being in chronic illness by foregrounding the mechanism underpinning identity; participation for those whose participation in life and self has been profoundly compromised.

Travers and Lawler (2007) drew narratives from semi-structured interviews with 19 participants so as to explore the experiences of CFS in relation to a 'climate of contention' using grounded theory. The analysis revealed a narrative of the '*struggling self seeking renewal*' (Travers and Lawler, 2007, p.318). The self was threatened either by disruption or invalidation. Disruption related to chronicity, incapacity, unpredictability, invisible disability, loss of independence and loss of 'life'. Invalidation related to the social construction of CFS as a contentious illness shrouded in scepticism. Invalidation was an additional burden for sufferers as invalidation belittled the chronic illness experience which negated empathy and an appreciation of suffering:

Suddenly everyone started to get the symptoms of it at work. They all thought they had it as well and that was really annoying it was like making a mockery of it. They were just thinking it was a little bit of tiredness. (Female, 34 years, recovered after 6 year illness, full-time secretary: Travers and Lawler, 2007, p.318)

Disruption and invalidation caused a 'violation of self'. When those with CFS failed to recover, they too began to question their experience of illness on the grounds of reality, legitimacy and responsibility which mirrored the scepticism of others pertaining to the alleged hypochondria and/or malingering of the CFS sufferer:

There's also a constant feeling of maybe there is something I can do myself to make it better. Maybe the headaches are my fault 'cause I'm feeling tense, or I'm not taking the right vitamins. Maybe there's something I can do. And then you try it and no, that wasn't it.

(Female, 58 years, previously adult education officer, retired due to CFS: Travers and Lawler, 2007, p.319)

Such self-doubt was often paired with self-blame and self perceptions of inadequacy and inferiority; the self was altered and the self was now inadequate and inferior:

I feel like I'm the ugly twin that has nothing to offer... I think probably the foremost thing would be that I just feel like I'm so different. (Female, 39 years, full-time government officer: Travers and Lawler, 2007, p.319)

People who knew me before-I met one recently and she was gob-smacked that I was a housewife because that's not what I'd planned, it's not what I'd envisaged, and it's probably not what I would have done. (Female, 47 years, previously a health worker, retired due to CFS: Travers and Lawler, 2007, p.319)

Biographical disruption was evident in participants' stories:

We are so often described as what we do rather than who we are, so that it becomes when we lose that, like when somebody retires, you lose that identity. But you've attained an age so that it's your right to do this, whereas I hadn't attained any of the things to make it my right to not be at work. (Female, 46 years, previously a health worker, retired due to CFS: Travers and Lawler, 2007, p.319)

It would appear the context of CFS/ME was a catalyst for Travers and Lawler's (2007) participants. The loss of life through CFS/ME was exacerbated by the illegitimacy of CFS/ME and therefore the scepticism surrounding the illness which negated the potential for empathy and support:

I feel disliked. I feel nobody sees me clearly because I'm basically never seen I'm a nonperson. (Female, 71 years, retired instructor: Travers and Lawler, 2007, p.320)

[When] you meet with any scepticism, your focus then becomes to prove that you're not malingering. (Female, 45 years, previously a resource officer, retired due to CFS: Travers and Lawler, 2007, p.321)

According to Travers and Lawler (2007), identity was also compromised by an inability to sustain identity roles such as family member, friend or colleague which was compounded by an inability to participate in the social world with the contested nature of CFS and the disbelief of others exacerbating feelings of isolation and abandonment. The stigma of an illegitimate illness coupled with the guilt and shame of not being able to function in the world; private, professional or social, engendered feelings of failure and a loss of self-worth:

You become very internalised and that can help out to a certain degree to cope, but you can keep on going inwardly becoming diminishing, the spiral downward. (Male, 41 years, previously a photographer, retired due to CFS: Travers and Lawler, 2007, p.321)

The hardest lesson I think was to give up that [former] life it was like a death. You had to grieve for that it was a long time before I allowed that it took a number of years to readjust my [perceptions of] successes and failures. (Female, 46 years, previously a health worker, retired due to CFS: Travers and Lawler, 2007, p.321)

The 'Guardian Response' protected participants through a necessary focus on the 'needs of the self' such as living within the boundaries of CFS which protected participants from over exertion and the potential for amplified symptoms and suffering. The guardian response enabled participants to salvage and recover valued aspects of the self which was a rite of passage to the 'Reconstructing Response' (Travers and Lawler, p.320). The reconstructing response involved a 'review of the self' which negotiated the reality of a 'new self' within the parameters of chronic illness, but parameters which allowed for improved quality of life:

I don't expect myself to conquer the world anymore. I don't place undue pressure on me anymore. (Female, 39 years, full-time government officer: Travers and Lawler, 2007, p.322)

Finding new sources of fulfilment were evident in participants' stories:

By doing a thing like this [working with a youth support group]... I'm developing another circle of friends through CFS... it's budding, it's opening up again. (Male, 38 years, part-time student: Travers and Lawler, 2007, p.322)

Things that I can do, I do, and that impresses me. And when I achieve, it doesn't matter whether it's doing the chores or washing the dog, I've achieved, and that's how you have to try and keep up your self-esteem... in the past I wouldn't even consider those worth noting, so you have to completely re-prioritise everything. It's not easy but if you get to that point, then you can be really pleased. (Female, 46 years, previously a health worker, retired due to CFS: Travers and Lawler, 2007, p.333).

Travers and Lawler (2007) illuminated the reality of the contentious nature of CFS/ME for participants and participants' need to renew the self in chronic illness. Travers and Lawler (2007) of course contribute to the literature by considering the multifaceted impact of CFS/ME as defined by incapacity, illegitimacy, isolation, abandonment, and participants' compromised identities (a consequence of their inability to function), and coping in CFS/ME through acceptance and the renegotiation of life and self. However, without a theoretical foundation, such findings are limited in their application. On considering an emancipatory framework, on absorbing how Travers and Lawler's (2007) participants salvaged and recovered valued aspects of the self I could not ignore my knowledge of CoP. Had the

findings of Travers and Lawler (2007) been harnessed by a re-conceptualisation of CoP, the application of such findings would have given a greater insight into how to negotiate both life and self in CFS/ME for those who are overwhelmed by grief for a life and self lost to chronic illness.

Larun and Malterud (2007) utilised a meta-ethnography strategy to synthesise 20 qualitative studies to explore identity and coping experiences in CFS, a synthesis that illuminated the dominance and reality of patriarchal medicine within primary care interactions. For example, the contrasting illness beliefs of patients and doctors was evident with patients adhering to physical explanations (Clements et al. 1997; Lovell, 1999; Horton-Salway, 2001;) and doctors navigating towards psychosomatic explanations when biomedical evidence was lacking (Horton-Salway, 2002; Asbring and Narvanen, 2004) and in so doing asserting the relevance of personality (Horton-Salway, 2002; Raine et al. 2004). Receiving a diagnosis was of great significance to patients (Denz-Penhey and Murdoch, 1993; Woodward, Broom, and Legg, 1995; Clarke, 1999; Asbring and Narvanen, 2002) and a diagnosis could help wage the war over 'psychosomania' when a diagnosis of ME was made as ME was believed to infer a 'disease' as opposed to the chronic fatigue 'syndrome' that is CFS (Horton-Salway, 2004). According to Larun and Malterud (2007, p.25):

- *CFS patients' symptom experiences shape their illness beliefs;*
- *Doctors' beliefs, shaped by biomedical presumptions, are very different;*
- *Tensions emerge in the doctor-patient interaction when these beliefs are conflicting;*
- *The antagonism has an impact on CFS patients' identity and coping.*

Patients felt discredited by doctors when CFS was suggested as being 'all in their mind' (Horton-Salway, 2002) which cast doubt on their morality and credibility as people (Denz-Penhey and Murdoch, 1993):

It (the illness) hit me at a time of life when I couldn't have been more fulfilled. So at no time must anyone dare tell me that it is all in the mind. [Lovell, 1999] (p.24)

I think a lot of the depression side of ME in sufferers comes from the fact that we become depressed trying to convince the doctors, the medical profession that there is something wrong with us! [Horton-Salway, 2004] (p.25)

I am not that stupid that I don't get it, when it is like implied that it is probably due to nerves in some way. [Asbring and Narvanen, 2002] (p.25)

...I've got something which no one believes in. Even the doctor who gave me the diagnosis told me he had always thought it was hysteria. [Asbring and Narvanen, 2002] (p.25)

The questioned legitimacy of participants' illness experience by family, friends, and colleagues heightened the burden of chronic illness for participants as feelings of blame, untrustworthiness and shame engulfed their fragile CFS self (Woodward, Broom, and Legge, 1995; Horton-Salway, 2001;

Asbring and Narvanen, 2002; Taylor, 2005). Larun and Malterud (2007) illustrate the relevance of the context of CFS/ME to CFS/ME identities. The tug of war between ME 'the disease' and CFS the 'syndrome' typifies the battle and ramifications of diagnosis for sufferers in terms of their identities. The problematic diagnosis also transcended primary care to the private worlds of participants within which friends, family and colleagues also, through scepticism, contributed to their fragile CFS/ME identities. As discussed previously, the media is the primary source of information on health issues and the media is stigmatising of CFS/ME which could explain the lack of sympathy surrounding the illness.

The chronic and disabling character of CFS resulted in experiences of social marginalisation. Isolation from the social world further jeopardised the sense of self and identity of patients with CFS. The biographical disruption which is central to the CFS experience accompanied a fractured and evaporating self (Asbring, 2001; Gray, 2003). However, coping evolved as knowledge enabled power (Clements et al. 1997; Gray and Fossey, 2003; Asbring, 2001). Learning how to manage CFS was central to coping (Ware, 1998; Asbring, 2001; Horton-Salway, 2001; Gray and Fossey, 2003) and negotiating how to live with CFS made room for a re-established quality of life and self (Ware, 1998; Gray and Fossey, 2003). However a desire to return to a less restricted life came at a cost for some participants:

I don't like giving in to it. . . But then I'm always sorry because I can spend all day tomorrow in bed for fighting it today. [Clements et al. 1997] (p.26)

In their synthesis, Larun and Malterud (2007) explore the lived experience of CFS/ME from a broad perspective. However, Larun and Malterud (2007) report the experiences of participants from a perspective not governed by theory. On synthesising such a wealth of CFS/ME studies which had the potential to give a complex insight into the lived experience of CFS/ME as defined by breadth and depth, a re-analysis drawing upon a transparent and explicit theoretical framework such as CoP: a re-conceptualisation would better serve a more comprehensive understanding of participants' experiences which would allow for a more robust application of findings and insight into coping in chronic illness: CFS/ME.

Edwards, Thompson, and Blair (2007) conducted semi-structured interviews with 8 women with CFS/ME. An Interpretive Phenomenological Analysis (IPA) was used to explore coping in CFS/ME. The analysis revealed two predominant phases. Participants were initially overwhelmed by CFS/ME as they were virtually unable to sustain even a fragment of their previous lives and selves. Multiple losses induced feelings of grief and despair as an attempt to negotiate a new life and self was compromised by chronicity:

... all the things that I like to do that were me, and that ... made me feel OK... those things you have lost... but I've not got anything that I can find ... to put it back together in a different

thing which is OK. So I'm just like this blob. (Belinda: Edwards, Thompson, and Blair, 2007, p.207)

The contentious nature of CFS/ME compounded participants suffering. Initially feeling abandoned within primary care to the reality of a medical diagnosis which was for many medical practitioners, repelling. Limited advice on how to manage CFS/ME exacerbated the distress of participants in the early stages of their illness:

... because I didn't understand what was happening to me I'd try to carry on with my normal everyday life, which really was a bad thing to do. (Claire: Edwards, Thompson, and Blair, 2007, p.207)

A number of participants tried to 'fight it', by 'not giving up' and 'keeping going' before reality hit that this was not a battle that would ever be won:

I clung on to the mother thing, and then when I couldn't do that I was so distressed. I mean really distressed cos it was like the very important thing that I was hanging on to. (Belinda: Edwards, Thompson, and Blair, 2007, p.206)

Phase two involved a process whereby participants learnt how to live with CFS/ME. Due to negative experiences within primary care and feelings of abandonment and hopelessness many participants engaged with 'self help' as to explore various treatments, therapies and remedies. Such pursuits symbolised the first step to taking control. Learning to live within limits enabled participants to function and to engage in activities which were of value to life and self. Life was still defined by limits and consequences but a positive attitude was beneficial and necessary to coping and recovery:

All the time that I've had the illness I've been trying to do something to improve the situation. (Greta: Edwards, Thompson, and Blair, 2007, p.207)

Your body needs rest, but you need a regime and you need to be working towards something and pacing yourself, and nobody tells you how to pace yourself. (Hanna: Edwards, Thompson, and Blair, 2007, p.208)

... even though I'm aware of all the things and how one should pace and how one should stop and all that . . . but if something very interesting comes up, I can kind of re-energize myself even if I know that I'm going to suffer for it. (Elizabeth: Edwards, Thompson, and Blair, 2007, p.208)

Support and understanding were found to be fundamental mediating factors, both positive and negative. The burden of scepticism and disbelief weighed heavy. Some medical professionals endeavoured to help but with little knowledge or understanding of CFS/ME were unable to support participants, whilst others stigmatised participants which left them feeling rejected and hopeless.

Aside from a lack of support from within the realm of primary care, participants also spoke of feeling isolated and abandoned within their social worlds. Family and friends were not always supportive or understanding which was extremely difficult for participants who felt completely alone:

I felt like I was on a desert island, no way of getting anywhere or reaching anyone else.

(Debra: Edwards, Thompson, and Blair, 2007, p.209)

I didn't know what to do, what are you meant to do if you don't have anybody to help? (Alice: Edwards, Thompson, and Blair, 2007, p.209)

I think if I had some help with like, even with the housework, it might give me a bit more energy to do something to keep my spirits up. (Belinda: Edwards, Thompson, and Blair, 2007, p.209)

When participants did have the support of others, coping with CFS/ME was better enabled. Acceptance was key to long term coping but was a slow process. Only after battling with CFS/ME and enduring the consequences of battle could participants accept the new limits of life and self which equated to a better quality of life:

It's been a very hard slog mentally to accept what I've got. (Claire: Edwards, Thompson, and Blair, 2007, p.209)

I don't feel frightened now, you come to realize that you are ill after a while. It took a long time to accept that you'll be ill for a long time. (Alice: Edwards, Thompson, and Blair, 2007, p.209)

A new perspective on life was coupled with a new perspective on self which was positive for some participants:

I suppose as well you change your outlook on life cos, I am a motivated person but I'm not as motivated by things that I used to be, like career and money, they're not my priorities now.

(Hanna: Edwards, Thompson, and Blair, 2007, p.210).

Edwards, Thompson and Blair (2007) suggest however that despite acceptance being key to coping, that total acceptance was not as beneficial to life and self as partial acceptance. Thus, continuing to fight CFS/ME was interpreted as empowering for participants.

Edwards, Thompson and Blair (2007) explored coping in CFS/ME and in so doing discussed a variety of issues such as participants' inability to function, multiple losses, the contentious nature of the illness, patriarchal values which underpinned primary care interactions, the fight to not give up and to keep going, and how participants coped with CFS/ME as reflected by their attempts and ability to negotiate a new way to be in the world. However, if such experiences had been harnessed by theory,

findings would have become more explicit and enabling of understanding for those who are perhaps struggling to negotiate CFS/ME, a chronic illness that often decimates life and in so doing, self. Coping is an essential construct in chronic illness and as such had Edwards, Thompson and Blair (2007) been able to theorise participants' experiences of coping by integrating an explicit theory such as a re-conceptualisation of CoP, a more thorough understanding of the mechanism underpinning a renegotiated identity would have been better enabled which would have served both future chronic illness work and the CFS/ME community.

Arroll and Howard (2013) used semi-structured interviews and IPA to explore the potential for post traumatic growth (PTG) in CFS/ME. Participants compared their old self to their new self as defined by an inability to be who they once were. Their compromised physical ability, inability to maintain previous roles and previous behaviours which were once central to their sense of 'self' and identity led to a shift in identity which was assumed permanent for the majority of participants:

It's erm . . . given me a lot of losses. I lost erm (pause) my job, my work colleague relationships, my health (pause) friends (pause) and freedom. (Dave, illness duration 6 years: Arroll and Howard, 2013, p.309)

Cos I remember like sitting in the pub and realising that I had been ill for like a year, all these people talking about normal lives, like jobs and aspirations (pause) and all that kind of stuff, you kind of (pause) my cousin said (pause) cos he's like an architect, and he was, it shapes, if you find a career that you like, it shapes who you are kind of thing. (Gary, illness duration 3 years: Arroll and Howard, 2013, p.309)

I mean you don't lose it (your previous life), you still live it, there are still enjoyable things (pause) but, you are just not the person you were, and you want to be the person you were, because that was a more involved functioning person. (Amy, illness duration 7 years: Arroll and Howard, 2013, p.309)

It's in my nature, to open a door for somebody (pause) but if I walked to the bank and my arms are hurting, I would stand back and let somebody else open the door for me. But therefore you can't be yourself, the self that you would choose to be. You have to be somebody else, and you have to learn to live with that. (Sharon, illness duration 13 years: Arroll and Howard, 2013, p.309)

The above quotes provide an insight into the identity losses associated with CFS/ME by foregrounding the dichotomy of life as defined by health and illness and an inability to sustain roles, the reality of which meant participants could no longer be who they once were.

The additional acknowledgment by 'others' that participants were now 'different' compounded their experience of identity change as defined by a new and limited self. An inability to maintain social interactions was found to also compound their experience of isolation in a new world which was for them detached from the comfort of the real world:

... they all thought that I wasn't bothered with them, and there was all sorts of other stuff going on (pause) and I didn't have other friends, it was just really horrible, and very isolating. I found that really hard (pause) really, really hard. (Sally, illness duration 7 years: Arroll and Howard, 2013, p.310)

So yeah, that was difficult, cos I wasn't going out, you know. I can only remember only very occasional things, like a couple of things a year. A few things like weddings. But I'd be really clumsy, and do things like spill drinks (pause) which made the thought of going out in the future much harder. So not a lot of going out. (May, illness duration 8 years: Arroll and Howard, 2013, p.310)

I mean I don't know a lot of people, but no, I mean nobody calls round. So I think with a long-term illness people get sort of fed up don't they. Sort of erm (pause) well they just don't want to know really. I mean I'd probably be the same, if I didn't understand it. (Sharon, illness duration 13 years: Arroll and Howard, 2013, p.310)

Biographical disruption was expressed by participants:

It's totally altered my path of life if you like, I mean I'm sort of at the point now where I am sort of thinking, well (pause) where do I go from here? You know, I'm 32 now, I know that I am never going to get better in time enough to have kids (pause) and that's a big problem for me, luckily it isn't for him, and we've talked it through and everything. So something like that really affects you, sort of makes you very emotional and stuff. (Leslie, illness duration 6 years: Arroll and Howard, 2013, p.311)

The negative reactions of others to the 'new' and 'different' and an uncertain future was particularly hard for participants who found themselves reflecting and grieving for the person they once were but could no longer be. In order for participants to renegotiate a new positive sense of self and identity (PTG), they had to let go of their old selves. The letting go of previous selves was instrumental to the renegotiation of a new 'true' self with CFS/ME:

... when you're that bad (pause) when you're suicidal (pause) there's nothing of you inside (pause) you know you can tune into your higher self, there's a you inside this physical self (pause) well, there's nothing (pause) you cease to exist, which is why you can actually go to the extent of getting rid of the physical body, because the rest does not exist (pause) and what that did (pause) I don't recommend it to anybody, but what it did was give me the most marvellous opportunity to rebuild myself (pause) because I completely stripped myself down.

(pause) OK I did it the wrong way (pause) it's not exactly the healthiest way. (Paul, illness duration 10 years: Arroll and Howard, 2013, p.312)

Cos when I went to India I had another sense of being stripped mentally. It was a psychological cleansing I went through when I stayed on an Ashram (pause) very powerful. But very subtle, and very safe. But if you are in tune it just happens, and I just remember the letting go, and then the building up, and the, I could see myself going through that again. And so yeah (pause) then I started the gradual process of rebuilding. (Paul, illness duration 10 years, p.312)

Arroll and Howard (2013) have focused on loss and growth in CFS/ME. On acknowledging the shift in participants' identities through illness, the reality of an unfamiliar self and inability to sustain social lives, the ramifications of biographical disruption, and the negative reactions of others Arroll and Howard (2013) subsequently considered how participants were able to renegotiate a new and positive sense of self and identity in CFS/ME by letting go of their previous self and identity as to allow a 'true' self to emerge. On making transparent the need to let go of previous selves in CFS/ME if one is to be able to negotiate a new self, Arroll and Howard (2013) have provided an insight for those with CFS/ME who are struggling to cope with the dichotomy of life pre and post chronic illness. However, had Arroll and Howard (2013) integrated a theory such as CoP: a re-conceptualisation, that the insight given to those with CFS/ME would have been more explicit in terms of the mechanism underpinning identity which could have allowed for an easier journey to a new life and self in CFS/ME.

Moving forward

Having reviewed the CFS/ME and identity literature, having considered both strengths and weaknesses, I will now discuss further the ways in which my research will be markedly different. In the cited CFS/ME and identity literature, I have made reference to a fundamental weakness being that the research has not been guided by theory and as such findings are useful and insightful, but limited in their application due to the lack of a clear and concise guiding light; theoretical foundation. For example, the word 'identity' is used, but what 'identity' is remains implicit, which is problematic. If the central concept of research is actually not conceptualised, I question the scope of such research. CoP argues identity is something very specific; identity is participation and therefore using CoP: a re-conceptualisation, in the current research will allow identity to be conceptualised and in so doing, identity in chronic illness (CFS/ME) to be theorised. Despite the fact that '*Communities of practice - Learning, meaning, and identity*' (Wenger, 1998) does provide a theoretical foundation upon which to consider identity, CoP is predominantly constructed as a social theory of learning. Therefore, despite my critique of the CFS/ME and identity research reviewed here, I am aware that CoP would not necessarily fall under the radar of researchers who work within the realm of chronic illness. However, as discussed in C2, CoP provides an opportunity to revolutionise our thinking around identity in

chronic illness and the current literature review served to reaffirm the value of CoP: a re-conceptualisation in the current research, and future chronic illness research.

The potential for emancipation

Something that resonated whilst reviewing the CFS/ME and identity literature, and something which I touched upon briefly in review, was the potentially constrained relationship the reviewed research has with the CFS/ME community. Participants' experiences were described, but as such experiences were not framed by theory, the potential for an emancipatory framework was overlooked. As CoP provides a framework within which to understand the renegotiation of identity in chronic illness (CFS/ME), by making explicit the workings of an identity in practice through participation, those who live with chronic illness, those who are newly diagnosed or those who have been ill for many years can see in CoP that identity is participation and as such if an identity is to be enabled in chronic illness, participation is key. Therefore my research methodology will adhere to an emancipatory framework as it is an endeavour to enable those with chronic illness (CFS/ME) to overcome their jeopardised identities by learning how to renegotiate an identity in chronic illness through participation. I intend to make an invaluable and unique contribution to the chronic illness literature, but as I also hold dear to me those who live with chronic illness: CFS/ME, I would like to show the CFS/ME community that a life and self in chronic illness is possible, even if that chronic illness happens to be contentious, as in the case of CFS/ME.

Longitudinal data

Aside from Ware (1999) who conducted longitudinal research, none of the other studies used a research methodology that allowed for longitudinal data. Whilst interviews can provide interesting data as evidenced in the cited CFS/ME and identity literature, a single interview, by definition, provides only a snapshot of the lived experience of participants. As discussed in C2, the trajectory concept in CoP represents the 'journey of life and self' as defined by the interaction of the past, the present, and the future in identity. Therefore CoP suggests that identity shifts over time and context and as such it is in longitudinal data that an understanding of the complexity of the CFS/ME identity will be able to emerge. For example, identities are complex constructs, particularly identities in chronic illness and specifically CFS/ME identities. In CFS/ME, every day can be different in terms of symptomatology and incapacity. Therefore, on one day certain aspects of life with CFS/ME may be foregrounded whilst on another day a competing aspect may be foregrounded which would interact with the experience and story of identity in CFS/ME. The concept of identity in chronic illness (CFS/ME) data that is not longitudinal is rendered narrow which confirmed to me that longitudinal data had to be central to my research methodology and is something that will be elaborated upon in C4.

Chapter summary

The history of ME and the construction of CFS inform today's construction of CFS/ME and the CFS/ME sufferer which has far reaching ramifications for sufferers. The inception of CFS has

rendered ME an abandoned illness. The psychiatric classification of CFS which is dominated by the patriarchal approach to medicine and diagnosis has stigmatised sufferers and negated biomedical research into CFS/ME; cure. The contentious nature of CFS/ME compounds the experience of illness for sufferers as the realm in which they now reside, being one of patriarchy, tradition, and fore fathers, fails to provide necessary support or salvation. The scepticism of doctors which is arguably underpinned by the history of ME and the construction of CFS as a psychosomatic woman's disease or 'yuppie flu' relegates the CFS/ME sufferer to stigmatised grounds which are guarded from empathy and understanding. The media perpetuate the negative construction of CFS/ME and the CFS/ME sufferer which negates the potential for family, friends, colleagues and sometimes doctors, to 'be there' for sufferers. When those with CFS/ME are isolated, abandoned and stigmatised by medicine, family, friends and colleagues they find themselves completely alone and unfamiliar. The identity and CFS/ME literature presents a number of transcending themes. When CFS/ME strikes, the assault is global. Body, mind, life and self are affected by chronic illness which leaves those with CFS/ME lost and alone in an unfamiliar life with an unfamiliar self. They are no longer able to be who they once were as their capacity to function is profoundly compromised. The roles which once defined their life such as family member, friend and colleague are neither viable nor sustainable. A life with CFS/ME is a life without meaning and purpose which equates to a life and self lost. The contentious nature of CFS/ME compounds the vulnerability of the sense of self and identity of those with CFS/ME as those with CFS/ME are often stigmatised. Furthermore, the legitimising medical discourse is unavailable to them as is the legitimising 'sick role'. As such there appears to be no rightful place in society for those with CFS/ME. They can no longer be who they once were, but they are not privileged with an alternative legitimate way of being in the world. Only with the passage of time and through a process of acceptance and reconciliation can those with CFS/ME begin to carve a new sense of self and identity for themselves which involves a reintegration into life and a renegotiation of self.

The CFS/ME and identity literature has contributed to my understanding of the lived experience of identity in CFS/ME. However, a lack of theory left such analyses vulnerable in their inability to enable wider application. Therefore I have attempted to foreground the value of CoP; a re-conceptualisation, as to provide a theoretical framework within which the lived experience of identity can be fully explored and theorised within a longitudinal and emancipatory framework.

CHAPTER FOUR (C4)

Epistemology

In C2 I presented my ontology as defined by CoP: *who we are is deeply bound by our experience of participation; identity is participation* (Murray, 2011, p.8). In C3 I argued for longitudinal data which was moreover not evident in the reviewed CFS/ME and identity literature. My ontology is aligned with longitudinality as I believe that to understand people, their lives, their experiences, and their meanings there is a need for a lot of contact, contact over a period of time during which a consideration of many things occurs to explore people, lives, experiences, and meanings *in depth*. If a depth of data such as this was to be realised, if my ontological notions were to be answered, the CFS/ME voice needed to be enabled. I will begin by presenting my chosen methodology before providing a rationale for my methodological choices. Having introduced 'cfsid' I will subsequently discuss my ontological and epistemological framework further, paying particular attention to the emancipatory paradigm, and my position as a critical relative rationalism. I will close the chapter with consideration of an insider perspective and dual role.

Virtual Quasi Ethnography

In C3 I critiqued the CFS/ME literature that did not feature longitudinal data, having made such critiques, it was encumbering of me to address this in my methodological choices and as such I referred to the longitudinal qualitative research (LQR) literature. Hermanowicz (2013) asserts longitudinal research is traditionally quantitative however longitudinal qualitative research has emerged to prominence during the last decade (e.g. Laub and Sampson, 2003; Neale and Flowerdew, 2003; Harocopos and Dennis, 2003; Ward and Henderson, 2003; Millar, 2007; and, Hermanowicz, 2009). According to Koro-Ljungberg and Bussing (2013), although longitudinal designs are diverse in their conceptualisation, longitudinal research shares an objective which is to enable a depth of data across time. Holland (2011) asserts the longitudinality of longitudinal research is by design a framework within which to observe change and continuity. However, the observation of change and continuity as described by Holland (2011) did not reflect my notion of longitudinality. I did not expect participants' identities to shift during data collection (six months), but what I did expect was a layering of data which would allow me to observe the complexity of their identities in context.

On acknowledging data had to be layered, I contemplated longitudinal qualitative interviews (LQI) (Hermanowicz, 2013), but due to the profound incapacity of participants, interviews were not appropriate. Those with CFS/ME can often not talk for long periods (an hour is an extremely long period for many) and such experiences can be stressful due to the physical consequences of such an activity. Therefore, I did not want to expose participants to anything that would in effect make them worse, I did not want to disable anyone from participating whilst also wanting to avoid the possibility of data being compromised by exacerbated chronic fatigue. I subsequently considered online interviews, but feared they also may be too labour intensive for participants and as such I concluded if my method was going to work; it had to be participant led and it had to enable longitudinal data.

An ethnography, which happens to be the quintessential CoP method, would have served my research well as according to Hammersley and Atkinson (2007, p.3), ethnography:

...usually involves the ethnographer participating, overtly or covertly in people's daily lives for an extended period of time, watching what happens, listening to what is said, asking questions – in fact, collecting whatever data are available to throw light on the issues that are the emerging focus of inquiry. Generally speaking ethnographers draw on a range of sources of data...

However, I could not do ethnography as participants did not exist in a group in that manner. They belonged to the same population, but due to their incapacity, they did not share a 'life space'. It was therefore essential that I found an alternative way to collect data over time, which would provide an opportunity to explore a depth of meaning that would illuminate participants' lived experience of CFS/ME. I needed to create a context in which to enable participants to talk about their CFS/ME experiences which would enable a necessary depth and breadth of data, central to which would be multiple activities designed to explore participants' identities. According to Hine (2000, p.64):

The status of the internet as a way of communicating, as an object within people's lives and as a site for community-like formations is achieved and sustained in the ways in which it is used, interpreted and reinterpreted.

Drawing upon the potential of the internet to enable a sense of community which reflects the role of the internet in isolation reduction (e.g. Cummings, Sproull, and Kiesler, 2002; Bradley and Poppen, 2003), the opportunity for longitudinality, the familiarity and usability of the internet, and understanding that on using the internet to gather data participants would be able to contribute as and when they were able to do so, I created a closed Facebook group for people with CFS/ME; cfsid.

cfsid

cfsid was not a life space as discussed by Hammersley and Atkinson (1995) and therefore cfsid was not ethnographic in those exacting terms. However, cfsid gave me an insight into participants' worlds over time which gave me an insight into their life spaces. I was unsure what to call this, but believed it was a form of ethnography. I began reading around 'virtual ethnography'. Similarly to classic ethnography, Dominguez et al. (2007) suggest the methodological approach to virtual ethnography is broad and diverse. However, central to virtual ethnography is cyberspace. The internet has evolved as a culture and context for social interaction within which practices, meanings and identities interconnect, which echoes the facets of Wenger's (1998) CoP theory. Interactive media such as the internet has revolutionised classic ethnography and as such has relaxed the borders of classic ethnography to allow the inclusion of the 'virtual world' in ethnographic studies. Virtual ethnography is not dependent on immersion in the 'real world' of participants and as such Hine (2000) acknowledges that 'virtual' can suffer an alignment with negative connotations of what is and what is not 'real'. However, Hine (2000) also acknowledges that in contrast to classic ethnography whereby the real world of participants is accessed via face to face interaction, virtual ethnography does connect to the

real world of participants as virtual ethnography relies upon committed engagement and interaction which has the potential to illuminate real worlds.

cfsid was an online community, albeit a community for the purpose of research and as such cfsid was 'virtual'. I do not claim cfsid was a life space, but I am claiming a form of ethnography in light of the blurred lines surrounding the method and the richness of the layered, longitudinal cfsid data which illuminated participants' worlds. Having considered all of the above, the form of ethnography I am claiming is a 'virtual quasi ethnography'. I am claiming 'virtual' as cfsid occurred online and 'quasi' as cfsid was not a life space in exacting ethnographic terms.

The role of the mass media in the construction of CFS/ME, and majority voice in CFS/ME

Having introduced cfsid and presented the rationale for a virtual quasi ethnography, the current section will look beyond the practicality of cfsid for participants and rationale for a virtual quasi ethnography to the silence of the CFS/ME community which serves to reaffirm the value of cfsid. Initial consideration will be given to the relationship between the media and the public perception of CFS/ME. Consideration of this relationship is given here as opposed to within C1, as it is a relationship that makes transparent the reality of the majority voice in CFS/ME and in so doing the need for cfsid.

According to Culley et al., (2010), the mass media filter into daily lives and in so doing evolve as dominant sources of information and knowledge. The mass media are in a powerful position as it is through content choices that public perceptions are moulded. Content choices however, are not beholden to objective facts, but are also indicative of subjective opinion and constructions (Curren and Seaton, 2003). Like all social systems the mass media are embedded in wider societal, reified and implicit meanings which contribute to the promulgation of particular positions. Such promulgation can intersect with an inadvertently pervasive negative influence as the relationship between the mass media and the perpetuation of negatively stereotyped marginalised groups is well documented (e.g. Cottle, 2000; Van Dijk, 2000; Veno and van den Eynde, 2007; Voorehees, Vick and Perkins, 2007; Freston, 2009). According to Brodie et al. (2003) the mass media provide the principal source of public information on issues pertaining to 'health and illness' and as such the mass media are in a position to raise awareness which is beneficial for health. However, Kline (2006) asserts the mass media are in part responsible for the stigmatization of certain illnesses. According to Chew-Graham et al. (2008), and Anderson, Maes, and Berk (2012), primary care workers were found to turn to the media for an increased knowledge of CFS/ME when their training failed to fully equip them for the diagnosis, treatment and management of CFS/ME, but what are primary care workers, and the general population faced with when they turn to the media for information on CFS/ME?

CFS/ME; the media sensation

During the 1980's and 1990's ME was akin to a media sensation (Wolfe, 2009). In a paper titled '*ME: The rise and fall of a media sensation*', Wolfe (2009) reviews the media coverage of ME during the 1980's and 1990's and reflects upon the waxing and waning of media interest in ME. Whilst those with

ME asserted ME was an organic disease, the mass media moreover constructed ME as evidence of female hysteria; 'yuppie flu'; and, depression. Drawing upon Wolfe's (2009) review, I will provide a brief overview of the history of the media construction of ME involving female hysteria; 'yuppie flu'; and, depression before discussing the alleged shift in trend as discussed by Wolfe (2009).

Theories of gender have been an affliction of ME since its inception. To reiterate, McEvedy and Beard (1970) conducted a notes review on the Royal Free Hospital patients and due to the complexity of symptomatology, the absence of definitive evidence, and the fact that most of the patients were women, McEvedy and Beard (1970) echoed previous sceptics (Gilliam, 1934; Sigurdsson et al. 1950; Ramsay, 1957; and, Galpine and Brady, 1957) by suggesting the Royal Free epidemic had in fact been an epidemic case of psycho-social phenomena underpinned by mass hysteria. McEvedy's views were not restricted to medical journals as in 1988 McEvedy appeared on the Horizon programme (BBC2, 27th June, 1988) during which his beliefs about ME appeared unchanged as he likened the pathology of ME to the ME prone personality; the personality of women (Wolfe, 2009). McEvedy was not alone in his beliefs and as such did not stand alone in the media construction of ME which alleged that ME was a gendered disorder of insufferable women (e.g. Richmond, 1992; Hudgson, 1993; Ware, 1993 cited by Woodham, 1993).

According to Wolfe (2009), 'Yuppie Flu', a malady of the over ambitious city high fliers who were responsible for their own undoing featured most heavily in accounts of ME in the press during the 1980's and 1990's (e.g. Walsh, 1987; Askwith, 1989; Bryan and Melville, 1989; Wookey, 1988; and, Rowe, 1989). There was also a version of 'yuppie flu' that involved a theory of hyperventilation whereby altered breathing was asserted to reduce levels of carbon dioxide which impacted muscle and organ function as detailed in an article titled '*Yuppie flu' is all in the mind, say doctors*' by Hodgkinson (1988). The hyperventilation theory originated in the work of McEvedy and Beard (1970b).

According to Wolfe (2009) by the 1990's psychiatrists were heavily invested in ME (or their reconstruction of ME; CFS) suggesting it was for example, a form of depression masquerading as physical (e.g. Stuttford, 1993; and, Wessely, 1993). Similarly to McEvedy (1988) traversing medical journals into the mass media, so too did Wessely (1993). As discussed in C1, Wessely was an eminent psychiatrist who did not believe ME was a legitimate medical entity (Wessely, Nimnuan and Sharpe, 1999). According to Wolfe (2009), Wessely championed the role of learned helplessness in the pathology of ME (CFS) whilst also asserting the role of 'social pathology' in one of Wessely's most well-known papers '*Old wine in new bottles; neurasthenia and 'ME'*' (1990) in which Wessley outlined the alleged similarities between the 19th century form of psychoneurosis most attributable to women and ME. Wessely's neurasthenia theory is alleged to have heavily permeated the mass media (Wolfe 2009).

Silencing

According to Tobbell et al. (2010), Wenger (1998) suggests that in the construction of meaning, practices, and identity, silence can be as powerful as presence. Research has shown that there is a relationship between the strength of an opinion and the dominant majority voice (e.g. Glynn & McLeod, 1985; Salmon & Neuwrith, 1990; Ajzen, 1991; and, Neuwrith & Frederick, 2004). On theorizing about public opinion formation, Noelle-Neumann (1974, p.44) suggests “*The active role of starting a process of public opinion formation is reserved to the one who does not allow himself to be threatened with isolation*”. The dominant voice is a confident voice whose voice encourages compliance and as such creates the foundation for the majority voice. McEvedy (1988) and Wessely (1993) were confident voices who contributed to the majority voice in CFS/ME during the 1980's and 1990's as discussed by Wolfe (2009). On considering why McEvedy and Wessely did not fear isolation, perhaps they were confident that their views were in fact rooted in the history of their community of practice being patriarchal medicine. Their claims of CFS/ME women, for example, were not novel claims, but one's which had been rehearsed since the 19th century regarding women and their propensity for ‘madness’ (e.g. Ussher, 2013; Swartz, 2013). According to Seaton (2003) and Culley et al. (2010), dominant accounts of unfamiliar and uncertain topics in the media act as a reference point for alleged understanding. In a climate of uncertainty as in the case of ME in the 1980's and 1990's, confident voices such as McEvedy and Wessely became dominant voices which contributed to the public perception of ME and ultimately the majority voice in CFS/ME today.

In conflict with the majority voice is the minority voice, a voice that can be defined by silence. Research has illuminated the relationship between self-silencing, and eating disorders in women (Frank & Thomas, 2003; Piran & Cormier, 2005; Wechsler et al., 2006); decreased psychosocial adaption of women with cancer (Kayser et al., 1999); and, depression amongst both men and women (Thompson et al., 2001; Uebelacker et al., 2003; Whiffen et al., 2007; Flett et al., 2007; and, Cramer et al., 2005). As rehearsed throughout, CFS/ME is a chronic illness that is shrouded in scepticism. Such scepticism, as aligned with the dominant voices of McEvedy and Wessely, for example, can silence the CFS/ME voice; the minority voice. It would appear the minority voice and silence is indicative of the isolation experienced by those on the periphery of mainstream society, those who are marginalised and who are subordinate to the majority. Those who are silenced in mainstream society have little opportunity to become the majority voice. I have learnt that people with a contentious chronic illness such as CFS/ME can be silenced in mainstream society due to incapacity, disbelief, stigma and scepticism. A coping mechanism in CFS/ME can be ‘to keep quiet’ and therefore keep your illness to yourself if at all possible and to only talk when it feels safe to do so.

The internet; a medium of community for those who are both isolated and silenced

Epistemologically I am not interested in the silence of people with CFS/ME; I am driven by a need to allow people with CFS/ME the space to speak as freely and extensively as they can. The internet, as a form of mass media not only informs (e.g. Brodie et al. 2003; Kline, 2006; Culley et al. 2010) and stigmatises (e.g. Cottle, 2000; Van Dijk, 2000; Veno and van den Eynde, 2007; Voorehees, Vick and

Perkins, 2007; Freston, 2009), but also provides a gateway to like minded others, which can reduce feelings of isolation (e.g. Cummings, Sproull and Keisler, 2002; Bradley and Poppen, 2003). Some research suggests the internet can increase feelings of loneliness (Kraut et al. 1998; Moody, 2004), and reduce face to face contact with friends and family and ultimately one's social circle which contributes to feelings of loneliness (e.g. Kraut et al. 1998). However, those living with chronic illness (CFS/ME) do not sacrifice contact with friends and family for contact with their virtual friends and family as their contact with real-world friends and family has been compromised by the chronicity of their illness and the scepticism surrounding their illness. Therefore, perhaps for some, the internet offers the *only* way to be a part of a community again in CFS/ME, and therefore possibly the *only* way to reduce feelings of isolation and experiences of silence in CFS/ME. As such, it was imperative that I created a place for CFS/ME voices to be heard; cfsid.

The emancipatory paradigm

As briefly discussed in C3, the CFS/ME and identity research cited overlooked the potential for an emancipatory framework. According to French and Swain (1997), emancipatory research is associated with the development of the Disability Movement and social model of disability. In opposition to the medical model of disability which alleges disability is located within the disabled individual, the social model of disability argues that disability demands a layered definition which considers both the physicality of disability and the lived experience of disability. The social model of disability classifies disability as:

Impairment: lacking part of or all of a limb, or having a defective limb, organism, or mechanism of the body;

Disability: the disadvantage or restriction of activity caused by a contemporary social organisation that takes little or no account of people who have physical impairments and thus excludes them from the mainstream of activities (UPIAS, 1973, pp.3-4)

Inherent in the classification above is the belief that impairment is a medical issue whereas disability is a social issue. The overarching aim of the social model of disability is to challenge the perpetuated belief as defined by the medical model of disability that disability equates to the deficits of disabled individuals (Stevenson, 2010).

Empowerment is central to the emancipatory paradigm as emancipation is empowerment and therefore an objective of emancipatory research is to generate knowledge which can empower members of marginalised communities to emancipate themselves (Woodhams and Lupton, 2014). Although disability is central to emancipatory research, the emancipatory paradigm is also central to research exploring the inequalities associated with gender, ethnicity, and sexuality etc. and as such Woodhams and Lupton (2014) have considered the potential of intersectionality research to be emancipatory. Woodhams and Lupton (2014), on observing the work of for example, Crenshaw (1991); Nash (2008); and, Denis (2008) acknowledge that individuals may not be disadvantaged by a single identity. Multiple identities may intersect within the boundary of marginalisation meaning

intersectionality research; according to Woodhams and Lupton (2014) has the potential to be a broad framework within which to consider the emancipation of marginalised and oppressed groups who must negotiate multiple forms of marginalisation and oppression. If we look at CFS/ME, as discussed in C1, it is perhaps the intersection of a lack of biomedical evidence; proof and the gendered construction of CFS/ME that renders CFS/ME an illegitimate chronic illness and those with CFS/ME more often than not, silent. As rendering a group silent is contrary to any emancipatory endeavour, and contrary to the CFS/ME and identity research reviewed in C3, CFS/ME research would be best served by a research methodology that could negotiate both intersectionality and emancipation.

Lincoln and Denzin (1994, p.575) suggested the future of qualitative research would benefit from synthesis:

There is an elusive centre to this contradictory, tension ridden enterprise that seems to be moving further and further away from grand narratives and single, overarching ontological, epistemological, and methodological paradigms. This centre lies in the humanistic commitment of the qualitative researcher to study the world always from the perspective of the interacting individual. From this simple commitment flow the liberal and radical politics of qualitative research. Action, feminist, clinical, constructivist, ethnic, critical and cultural studies researchers are all united on this point. They all share the belief that a politics of liberation must always begin with the perspective, desires, and dreams of those individuals and groups who have been oppressed by the larger ideological, economic, and political forces of a society, or historical moment.

Here there is a transparent focus on the potential to synthesise interpretivism and critical theory, a synthesis that is central to the current research. Having given an overview of interpretivism and critical theory, I will now discuss my position in more detail so that on moving forward, my guiding ontological and epistemological framework is clear.

Critical relative rationalism

I am an interpretivist, but specifically I position myself as a 'critical relative rationalist'. My overarching research aim is to explore the identity transition of those suffering chronic illness; CFS/ME. My ontological position is relativist as I believe the issues of identity that are central to the lived experience of CFS/ME are by definition, a social construction. The experiences of those with CFS/ME, the culture within which they live and the context of the person and the chronic illness that is CFS/ME intersect which shapes the reality of the CFS/ME identity. My objective is to understand experiences in context as opposed to manipulating experiences to fit alleged universal laws and truths beholden to an 'out there' reality. I therefore acknowledge that both the research process and reality of participants are social constructions.

My epistemological position being rationalist reflects my belief in the relationship between rational thinking, reflection, knowledge, and understanding. I do not believe that you *have* to experience something through the senses in the physical world in order to understand and know about it.

Experience *is* arguably beneficial to understanding, but through exposure, understanding can emerge. I hope, therefore, that my research will enable an insight into the lived experience of CFS/ME for those who do not suffer CFS/ME, and although their interpretation of my research will be relative to their experience, culture, and context, I believe that my research will contribute to their knowledge which could be media led and therefore indicative of the contentious construction of CFS/ME which does little to serve either CFS/ME or the CFS/ME identity.

I am drawing upon a synthesis of interpretivism and critical theory regarding the history of ME and the construction of CFS/ME as discussed in C1, as the objective of critical theory is to critique the current ideology as to render the dominant oppressive societal dynamics explicit. As above, my rationalist epistemology in part rests on the objective to provide an insight into CFS/ME for those who do not live with CFS/ME. However, on drawing upon critical theory in the synthesis of interpretivism and critical theory, a research aim becomes to provide an insight into CFS/ME for those who live with CFS/ME who may be unaware of the ramifications of the social construction of CFS/ME but who may be in a position to challenge and negotiate any associated oppression and marginalisation. In C2, CoP demonstrated the role of communities of practice, community membership and participation in the renegotiation of identity in chronic illness; CFS/ME. As the CFS/ME identity intersects with the contentious history and nature of the illness, if those with CFS/ME are more informed of the injustice surrounding CFS/ME, and perhaps their CFS/ME identity, they may have the potential, through shared knowledge of CoP to emancipate themselves through the renegotiation of their identities within communities whose ideology does not oppress or marginalise those with CFS/ME; cfsid, for example.

cfsid; Insider perspective and dual role

The prologue outlined my desire to explore the lived experience of participants. However, as the current research was heavily driven by theory, despite a commitment to lived experience, a phenomenological framework was inappropriate. The term lived experience is rehearsed throughout, but as opposed to aligning with phenomenology, within the current research the term lived experience aligns with a desire to give voice to those with CFS/ME, to those whose voices have the potential to illuminate the lived experience of chronic illness: CFS/ME and in so doing, enable greater understanding. According to Richards (2008), recent health, illness, and disability literature has questioned the expertise of researchers who do not have actual lived experience of health, illness and disability. Some question as to whether such researchers can represent the experiences of others when such experiences are to them, alien (e.g. Foster, McAllister, and O'Brien, 2005; Frank, 1995, 2002; Kleinman, 1988; Marks, 1999; McDougall, 2006; Miller and Crabtree, 2005). The person who lives with illness and/or disability is the expert; the insider, not the researcher who is an 'onlooker'; outsider. Being an onlooker can reveal an insight into illness and disability, but an insight that is not bound by experience; expertise (Richards, 2008). Although such beliefs are not necessarily aligned with my critical relative rationalism regarding not having to experience something through the senses in the physical world in order to understand and know about it, such beliefs do perhaps represent the

relationship between exposure to experience and understanding as an insider perspective reflects the kind of expertise that has the potential to shape the beliefs of those who lack experience; expertise.

Richards (2008) discusses how the problematic nature of being 'othered' is inherent in disability studies. Othering involves objectification whereby those who are disabled are central to research, but do not have a voice within research. According to Sullivan (1986, p.332), a lack of voice within illness and disability research silences "*the impact of an illness on a person's life*" through deafening medicalisation. In order to counter medicalisation and the 'silence of disability', some researchers draw upon their own experience of illness and disability in autoethnographic studies. Autoethnography resonates emancipation as those who require emancipation, for example due to their lived experience of illness and disability, are in a position, through autoethnography, to represent their own realities so as to counter their realities being constructed and represented by onlookers; outsiders (Richards, 2008). However, such representations are not necessarily empowering of the majority as in an autoethnography, only one voice is heard and that voice although belonging to a population or community, would not necessarily represent the diversity of experience within the specific population or community. Positioning the voice of the researcher alongside the voice of participants has the potential to render all voices equal which negotiates the diversity problems inherent in autoethnographies (Wilkison and Kitzinger, 2013). The central role and voice of the researcher in autoethnographic studies dictates a generosity of contribution which can engender vulnerability (Richards, 2008). As discussed in the prologue, I have personal experience of CFS/ME, but this is not something I discuss freely. During the years I was most severely ill but able to function in small ways, I did not wear CFS/ME on my sleeve, if anything I tried to conceal it. My PhD was never going to be an autoethnography as I did not want it to be about 'me me me me me' (no pun intended), but I could not ignore the value of an insider perspective.

According to Eppley (2006) the last 30 years has seen advancement towards research within which the researcher is, or has been, an insider. Paechter (2012) acknowledges that there are multiple advantages to an insider perspective, such as ease of entry into the field and ease of access to the 'familiar' lived experience of participants which enables the research process in ways that an outsider perspective could not (e.g. Acker, 2000; Breen, 2007; Dwyer and Buckle, 2009; Hodgkinson, 2005; Humphrey, 2007; Keval, 2009; Labaree, 2002; Taylor, 2011; Watts, 2006). According to Taylor (2011), an insider perspective promotes a certain trust in participants which contributes to an emergent rapport. The rapport between researcher; insider, and participant; insider, often reflects the researchers comprehensive consideration of participants through a shared empathy. Taylor (2011) also acknowledges that an insider perspective is not a rite of passage to 'absolute truth' as the representation of a particular community or culture from the perspective of an insider is not immune to error.

However, it is not 'error' as such that casts a shadow over an insider perspective but the problematised 'subjectivity'. Wilkinson and Kitzinger (2013, p.251) assert:

...traditional mainstream psychology remains (more than any other social science) deeply committed to a concept of objectivity that treats insider research as contaminating the production of knowledge.

The desirability of objectivity within psychology has rendered discussions around insider perspective to, by definition, be defensive of subjectivity. According to Wilkinson and Kitzinger (2013), as researchers we are always 'inside' our research and even if there are grounds for an insider perspective in exacting terms, there are likely to be differences such as age, gender, and ethnicity etc. (Wilkinson and Kitzinger, 1996). I was an 'insider', but my experiences and my 'being' were not identical to participants' experiences and being just as participants were not necessarily a definitive blue print of CFS/ME, if there is such a thing. There was a fundamental similarity amongst us all which was our overarching experience of CFS/ME, but the experience of CFS/ME as discussed by myself and participants was aligned with a variety of personal experiences, which all were of equal value.

My personal experience of CFS/ME guided every aspect of my research from aims, to methodology, to the conversations I had with participants. By revealing myself as a CFS/ME sufferer, my research was enabled. Although my experience of CFS/ME is not something I discuss freely, I was very open with participants about my experiences and I believe the generosity of my contribution did engender the trust in participants as discussed by Taylor (2011), which enabled a richness and quality of data that superseded my expectations. On discussing my personal experience of CFS/ME with participants, the value of an insider perspective was reaffirmed:

It was a breath of fresh air for me to know that you are a sufferer too. The most sincere research is being done by either sufferers themselves or by those who have a loved one who suffers. (Dan)

I definitely think your experience helps. As a Dr who treated ME before I was ill I realise that most professionals don't understand this illness and ask the wrong questions. Your experience allowed people to be more open in their replies because they knew you would understand. Increasingly researchers are being asked to include the patients voice- being part of the community helps you hear it. (Kate)

It meant a lot that you were a sufferer as I feel that to have any idea of how to research this illness you need to understand it and it is near impossible to understand without having a firsthand experience of it. (Catriona)

Hi Rebecca, the fact that you suffer with CFS/ME yourself speaks volumes to me, I have found that no-one understands the illness more than those who experience it, so for someone to do what you are doing and sees the short falls in the support we receive rather than an outsider thinking they have done what needs doing. (Dark Knight)

Participants knew that I was 'one of them' and as such they knew I understood. A number of participants expressed gratitude, they were grateful that I was investing in them, that I wanted to hear their stories and so participated and contributed as much as they could. In no way am I claiming that my research is not representative of me, but in no way am I claiming that my research is not also representative of participants.

Chapter summary

Having introduced cfsid; a virtual quasi ethnography and in so doing discussing my rationale for methodological choices regarding a need for longitudinal data, I elaborated upon the media construction of CFS/ME before reflecting upon the dominant majority voice in CFS/ME. It was then that if my ontological notions were to be answered, the minority CFS/ME voice needed to be negotiated. I subsequently paid further attention to my ontological and epistemological framework on discussing the emancipatory paradigm, and my position as a critical relative rationalist. Consideration was then given to the role of the researcher in interpretivist research which became the foundation for reflections upon an insider perspective and dual role in research. There was discussion of the success of cfsid regarding CFS/ME voices having the opportunity to become the majority voice in parallel with the trust engendered by my insider perspective and dual role which enabled a richness of data that was not anticipated. In the following chapter, I will provide a greater insight into my research methodology to illuminate further the success of cfsid.

CHAPTER FIVE (C5)

Methodology

Research aims; what I did and why

Having outlined the research aims, the current chapter will begin with an insight into the journey which led to cfsid before outlining all cfsid activity in an attempt to illuminate the chosen method of data collection. Having provided a detailed insight into the chosen method of data collection the chapter will then move onto the chosen method of analysis. A detailed outline of the analysis will be given here with specific attention being paid to all decisions made in an attempt to provide a clear and concise rationale for all methodological choices.

Research aims:

- Explore the shifting social identity of those living with Chronic Fatigue Syndrome (CFS/ME) and the subsequent impact such shifts have on the sense of 'self' and identity of those living with CFS/ME.
- Explore the utility of Wenger's (1998) 'Communities of Practice' theory in understanding identity in chronic illness.
- Widen the knowledge about CFS/ME; and by extension contribute to the chronic illness literature in general, how it (CFS/ME) is experienced, how the person interacts with the illness and the context of the person and the illness.
- Provide an insight into CFS/ME for those who live with CFS/ME who may be unaware of the ramifications of the social construction of CFS/ME but who may be in a position to challenge and negotiate any associated oppression and marginalisation.
- Explore the mediating effect of social media support in chronic illness: CFS/ME.

How cfsid evolved

As discussed in the previous chapter, CFS/ME voices and longitudinal data are central to the current research. Considering both the incapacity of those suffering CFS/ME and the silence of the CFS/ME community, I acknowledged I needed to create a 'safe place' within which CFS/ME voices could become the majority voice as and when participants were able to participate. I introduced the closed Facebook group, cfsid; however, Facebook was not the original plan.

I initially endeavoured to create a forum through which to gather much of my data. I worked with a technician at the University of Huddersfield to create a user friendly forum which would enable interactive chat. Interactive chat was essential as I endeavoured to begin various conversations pertaining to various research aim topics that participants could engage with and then redirect if they desired. The forum was problematic from the outset with its usability being questionable. It was imperative that participants would find the forum easy to navigate and use if they were going to be able to engage with my research, however, the forum in reality was not user friendly. My participants

were people who were housebound and bed bound and as such, the way in which I gathered data had to be participant led. My methodology had to be catered to the needs of my participants in terms of how their voices could be heard. In short, the forum was shelved during my final meeting with the university technician (October 2013) on realising that aside from the forum not being user friendly, the forum did not allow interactive chat. I was now behind schedule and so needed to be pragmatic. I began to consider Facebook on the grounds of usability and familiarity. I searched for CFS/ME groups on Facebook to establish if there was a CFS/ME community on Facebook. To my relief there were many CFS/ME groups. On discussing the redirection with my main supervisor I then set about contacting various CFS/ME groups to ask permission to advertise my research and closed Facebook group; cfsid.

Why the name cfsid?

I chose the name 'cfsid' so as to combine Chronic Fatigue Syndrome (CFS) and identity. It is worth noting that until I immersed myself in the history of ME and the construction of CFS, I had intended to use the term CFS in my thesis. As discussed in the prologue, my first diagnosis was 'ME', but then years later I was told that what I had was now called 'CFS'. Although my personal experience of CFS/ME made me an 'expert', therefore giving me an insider perspective that was superior to the perspective of a non sufferer, what became apparent was that although I was an expert on the lived experience of CFS/ME, I was not necessarily an expert on the extensive body of literature surrounding CFS/ME. I had never been drawn into the name debate as in truth when the change came about I was invested only in rehabilitation and so at that particular time, a change in name to me appeared irrelevant. Arguably, as discussed in C1, the name of course did impact upon treatments and so I can now see how the change in name and construction of CFS underpinned part of my CFS/ME journey. On realising the importance of the name used in the chronic illness that is CFS/ME in terms of the lived experience of CFS/ME today, despite grievances as discussed in C1 regarding a disease and a syndrome being amalgamated which does little to serve the neurological classification of ME within a doubting world, I have chosen to use the acronym CFS/ME (Working Group, 2002). Having unveiled the injustice surrounding the history of ME and the construction of CFS, I did consider using the term ME, but realised that some of my participants would have been diagnosed with CFS and may in fact be more symptomatic of CFS and as such I did not want to alienate anyone or devalue anyone's experiences within the wide reaching realm and broad spectrum that is CFS/ME. Therefore, the acronym seemed most appropriate.

The development of cfsid

I private messaged a number of CFS/ME Facebook groups and was given permission to post about my research and cfsid in the following groups:

Chronic Fatigue Syndrome Support UK

CHRONIC FATIGUE SYNDROME/FIBROMYALGIA

MEspace

Kirklees Independent ME Support Group (KIMESG)

Sanctuary for ME/CFS/Fibro UK

FELLOW TRAVELERS, Support and chat (FMS CFS ME)

CHRONIC FATIGUE SYNDROME/FIBROMYALGIA (CFS/FM IS TREATABLE)

The lighter side of M.E.

As you can see, the Facebook groups above make reference not only to CFS/ME, but also Fibromyalgia. The focus of the current research is CFS/ME, however, Fibromyalgia will feature in the literature review (C3), as similarly to the Facebook groups within which I advertised the current research, the literature also recognises the similarity between CFS/ME and Fibromyalgia, and as such on conducting research into CFS/ME, there is often an inclusion of both patient groups. I can confirm however, that participants of the current research participated because they claimed to have a diagnosis of CFS/ME (see Appendix 2).

Also see Appendix 2 for the information I pinned to the cfsid page, including information about me and the current research project, the protocol, and participant consent form.

Issues around participant consent

Participants were asked to email me a signed copy of their consent form and send me a hard copy via my university address. However, it soon became apparent that this was not working for participants. It demanded too much of their time and energy. Some struggled to negotiate the emailed consent form and some did not have access to a printer. On observing other CFS/ME Facebook groups and their consent policy being a pinned post at the top of the group page that members had to comment with 'AGREE', regarding terms and conditions of the group, I realised cfsid consent also had to be participant led. I subsequently pinned a consent post to cfsid asking participants to type AGREE to give their formal consent to take part in my research. Approximately 48 hours later, cfsid had 60 members, 37 of which gave their consent to take part in the current research.

Preliminary activities

Having gained consent from those cfsid members who wanted to take part in the current research, I introduced the first preliminary activity which followed on from voluntary introductions some members gave on joining cfsid (n: 17). The preliminary activities were designed to enable me to 'get to know participants' whilst enabling participants to also 'get to know me' before the main data collection

began. The first preliminary activity was a timeline activity which endeavoured to explore the shifts in life and self caused by CFS/ME.

On the 9th Dec 2013 I posted the following to cfsid (I used capital letters after a participant told me that using capital letters in posts made such posts stand out and was therefore easier to navigate in their busy notification list):

“CALLING ALL PARTICIPANTS! TODAY IS THE DAY WE CAN (HOPEFULLY) START TO GET TO KNOW EACH OTHER A LITTLE BETTER.

****TIMELINE ACTIVITY****

THE TIMELINE ACTIVITY INVOLVES SHARING A FEW DETAILS ABOUT CERTAIN TIMES IN YOUR LIFE. I AM INTERESTED TO (BRIEFLY) EXPLORE:

- YOUR LIFE PRIOR TO BECOMING ILL*
- ON BECOMING ILL*
- ON BEING DIAGNOSED*
- SINCE BEING ILL*

The timeline activity will allow me to gain an insight into some of your key life events surrounding your experience of CFS/ME. You can either post your timeline directly to the cfsid group, or if you prefer you can send your timeline to me (Rebecca Murray) via private message or email me (rebecca.murray@hud.ac.uk).

If this activity is too much as a whole, you could maybe create a word document and complete the activity this week, a little at a time and then post it to the group or me. You could also break it down for example; today tell me a little about your life before becoming ill and tomorrow a little about when you became ill etc. THE MAIN THING IS THAT YOU SHARE A LITTLE ABOUT ALL THESE KEY PERIODS AS TO ENABLE YOUR STORY TO DEVELOP.”

I then went on to share my personal timeline with the group to show them what was involved and what kind of thing I was interested in. I also wanted to show participants from the outset that I was going to contribute richly to cfsid and my dual role would be defined by generosity. I wanted to be seen as ‘one of them’ so that they knew I understood and that any parallels between their stories and mine were transparent. I hoped such transparency would encourage participants to share their stories in the comfort of cfsid and in the comfort of ‘our majority voice’. The timeline activity was completed by 21 participants (See Table 1 for aims and methods used).

On the 18th Dec 2013 I posted about the second preliminary activity:

“CALLING ALL PARTICIPANTS! HERE GOES! ACTIVITY NO.2 PART 1 ☺

THE TWENTY STATEMENT TEST (TST) IS A VERY POPULAR PSYCHOLOGICAL TEST WHICH ALLOWS PEOPLE TO SHARE THINGS ABOUT THEMSELVES IN A QUICK AND EASY WAY. It is designed to enable 20 statements (or words) that capture 'you' (4 statements or words per category, as below). There are 3 parts to this particular activity which will explore your identity. The first part will explore who you are now. My 'I AM' can be found below as an example. You can either post your 'I AM' directly to cfsid, private message me on here, or email me (rebecca.murray@hud.ac.uk) as before."

The defining categories used for the TST were:

Physical characteristics

Roles

Emotions

Activities

Hopes and fears.

I again, included my 'I AM' TST to give participants further insight into my lived experience of CFS/ME and to show them what was involved.

On the 20th Dec 2013 I posted about Parts 2 and 3 of the second preliminary activity:

"CALLING ALL PARTICIPANTS! ACTIVITY NO.2 PART 2 (AND 3)... I thought I would post about the next two parts so you can complete the activity before Christmas/over Christmas (if you want to). Basically PART 2 is 'I WAS' (using the same categories: Physical characteristics, Roles, Emotions, Activities, Hopes/Fears) and PART 3 is 'I WOULD LIKE TO BE' (again using the same categories)... For those of you who haven't been to cfsid for a while; PART 1 is 'I AM' ☺"

The 'I AM' TST was designed to provide an insight into the current lives and selves of participants.

The 'I WAS' TST was designed to demonstrate the contrast in life and self as defined by the dichotomy of life and self pre and post CFS/ME.

The 'I WOULD LIKE TO BE' TST was designed to allow an insight into what participants wanted from life and self and as such to provide an interesting platform to compare their previous lives and selves with their current lives and selves and their hopes for the future. The TST activity was completed by 13 participants.

Most participants broke down the TST activity which enabled them to carry out the activity. Had I not been a CFS/ME sufferer, perhaps participants would not have been enabled in such activities as an outsider may not have contemplated the challenge of such 'quick and easy' activities for those with CFS/ME. My insider perspective allowed me to consider hurdles before they had an opportunity to emerge and in so doing reaffirmed to participants that I understood CFS/ME, and in so doing, understood them.

As participants broke down the activities, not all participants completed all parts of the activities. I therefore private messaged those participants who still had various parts to complete of either the timeline activity or the TST activity to ask if they were able/wanted to complete the activities. The majority of participants, who had completed parts of the activities, subsequently completed all parts.

Conversations

The underpinning rationale for the development of the Facebook questions emerged from the research undertaken in my undergraduate final year project (Murray, 2011). This work used CoP to explore identity transition in CFS/ME. The relationship between identity and participation was unveiled, which provided the rationale for the explicit reconceptualisation of CoP in the current work. The Facebook questions were designed to explore the lived experience of CFS/ME to establish if there was a relationship between the history of the illness and the lived experience of the illness, whilst they were also designed to explore the identities of participants; jeopardised and participative. The first conversation (conversation 1) in cfsid, which 9 participants contributed to, began on the 8th January 2014:

"HELLO ALL... HAPPY NEW YEAR! I know some of us are playing catch up re activities, but I would like to start beginning various conversations, if possible?"

I have been looking through all the data collected so far and have been contemplating a few questions.

So, today, I am interested to find out:

WHAT DO YOU DO WHEN YOU ARE STRUGGLING (more than usual)?

HOW DO YOU COPE? (both physically and psychologically)?"

These questions were designed to explore support networks (communities), coping strategies and mechanisms as to provide an insight into the lived experience of chronic illness (CFS/ME).

On the 10th January 2014 I began conversation 2, which was contributed to by 9 participants:

"SOMETHING TO PONDER:

The response to my first conversation topic was brilliant, so thanks to all who contributed.

One area to be illuminated was the scepticism which surrounds CFS/ME. I think we are safe to suggest the scepticism relates to the illegitimate nature of the illness within the medical domain.

My experiences are varied in relation to medical professionals. Some good experiences, some not so good.

(I then gave an insight into my experiences)

COULD YOU TELL ME ABOUT YOUR EXPERIENCES WITHIN THE MEDICAL DOMAIN?

AND, WHAT A DIAGNOSIS MEANT FOR YOU?"

This conversation was designed to explore the history of ME and the construction of CFS through participants' lived experience of CFS/ME.

On the 17th January 2014 I began conversation 3, which was contributed to by 9 participants:

"IT'S FRIDAY AGAIN! I have just been reading through the conversation threads to date and something that has been touched upon briefly by a few of us is the reluctance to share a diagnosis of CFS/ME. I would like to explore this further as I am interested to know 'why we do what we do'.

SO,

- DO YOU SHARE YOUR DIAGNOSIS?*
- IF SO, WITH WHO AND WHY?*
- HAS YOUR DIAGNOSIS MADE YOU FEEL DIFFERENTLY ABOUT YOURSELF?*
- HAS IT BEEN A POSITIVE OR NEGATIVE THING FOR YOU, AS A PERSON?*

Something to ponder over the weekend!"

This conversation was an extension of the last which sought to explore further participants lived experience of CFS/ME in relation to the history of ME and the construction of CFS.

On the 22nd January 2014 I posted the following (conversation 4) which 11 participants responded to:

"HELLO ALL... I HOPE TODAY IS A GOOD DAY.

ONE OF THE THINGS THAT HAS INTRIGUED ME IS THE LENGTHS AND EFFORTS PEOPLE GO TO/HAVE TO GO TO IN ORDER TO GET HELP. I may be over thinking it, and perhaps looking at the efforts through rose tinted lenses, but:

- IS THE FIGHT FOR DIAGNOSIS IN ANY WAY EMPOWERING?
- DOES IT GIVE YOU PURPOSE IN THIS UNFAMILIAR WORLD?
- DOES IT MAKE YOU FEEL BETTER ABOUT YOURSELF/ENABLE A SENSE OF CONTROL OVER YOUR LIFE THAT COULD BE DEFINED BY A LOSS OF CONTROL?"

This question was designed to explore whether there were any positives to be taken from the struggle to get a diagnosis, something which was touched upon briefly during the previous conversation.

On the 15th January 2014 I posted the following (conversation 5), which 10 participants responded to:

"HELLO ALL... HOPE TODAY IS TREATING YOU AS WELL AS POSSIBLE SO FAR. We have discussed the responses of the medical profession, but if possible, I would like to know a little about the responses of other people to your illness, friends and family for example. A few of us have touched upon this, for example Katie, who spoke of her friend (the soon to be GP) who was very cynical of a Fibromyalgia diagnosis. So, have they (your friends and family etc.) been supportive or have they made your life harder?"

This question was designed to look beyond the medical domain to the friends and family of participants as to explore the responses of others to CFS/ME.

On the 27th January 2014 I posted the following (conversation 6), which 10 participants responded to:

"HELLO EVERYONE, HERE I AM AGAIN, ASKING MORE QUESTIONS... LAST WEEK I HAD A CHAT WITH Kate ABOUT THE GREATEST VOID IN MY LIFE WHEN I FIRST BECAME ILL. IT BECAME APPARENT THAT 'VOIDS' CAN OFTEN BE INTRINSIC TO IDENTITY AND SO TODAY:

PLEASE COULD YOU TELL ME ABOUT THE GREATEST VOID IN YOUR LIFE WHEN YOU FIRST BECAME ILL? THE THING YOU MISSED THE MOST? HOW THIS MADE YOU FEEL AND HOW YOU NEGOTIATED/NEGOTIATE THIS?"

This question was designed to establish what participants missed the most about their lives and selves before CFS/ME and how they negotiated or continue to negotiate this.

On the 3rd of February 2014 I began the following (conversation 7), which 9 participants contributed to:

“HELLO ALL. I HOPE YOU ARE HAVING A GOOD DAY SO FAR? I HAVE JUST BEEN THINKING ABOUT ‘WEEKENDS’ AND WHAT THEY REPRESENT IN TERMS OF ‘TIME OUT FROM THE DEMANDS OF THE WORKING WEEK’.

I WONDERED IF YOU COULD TELL ME ABOUT YOUR WEEKEND?

WHAT YOU DID OR DID NOT/COULD NOT DO?

HOW YOUR WEEKENDS NOW DIFFER FROM YOUR WEEKENDS BEFORE YOU BECAME ILL?

WHY? I am interested to know about the contrast between your old weekends and your current weekends as the contrast enables me, in part, to explore the shifts in your life which are intrinsic to who you are/were as people and how these shifts that are often underrepresented are hugely important in understanding the global effect of CFS/ME on our lives and selves.”

As above, this question was designed to enable an insight into the global effect of CFS/ME such as the loss of ‘weekends’ and an inability to participate in the structure of life.

On the 19th February 2014 I began the following conversation (conversation 8), which 12 participants contributed to:

“I WOULD LIKE TO EXPLORE YOUR EXPERIENCE OF AN ILLEGITIMATE ILLNESS, THE FAR REACHING RAMIFICATIONS OF THIS FOR YOU AND THE LENGTHS YOU HAVE HAD TO GO TO TO MEDIATE THIS BURDEN IN RELATION TO SUPPORT SEEKING.

PLEASE COULD YOU TELL ME WHY YOU CAME TO FACEBOOK?

WHAT FACEBOOK GIVES YOU?

HOW IT HELPS?”

Having observed the CFS/ME Facebook groups and participated in cfsid, I hoped participants could articulate to me why there is such a strong CFS/ME Facebook community.

On the 11th of March 2014 I posted the following (conversation 9), which 5 participants responded to:

“HELLO EVERYONE, the next step for me is to review all the data collected here at cfsid to date. I will then be able to see any gaps in the data etc. You have been a truly amazing group of people who have given me so much. Whilst I am reviewing the data IF THERE IS ANYTHING YOU WOULD LIKE TO DISCUSS HERE, IF THERE IS ANYTHING YOU FEEL IS MISSING AROUND THE AREA OF CFS/ME AND IDENTITY, OR ANYTHING YOU

WOULD JUST LIKE TO GET OFF YOUR CHEST, PLEASE FEEL FREE TO POST ABOUT IT AS WHAT IS IMPORTANT TO YOU, IS ALSO IMPORTANT TO ME.”

This question was designed to give participants the reigns. To date, I had asked direct questions, some of course did follow on from previous conversations and points raised by participants, but I wanted to give participants the freedom to talk about whatever was important to them regarding their CFS/ME stories and their CFS/ME identity.

On the 13th March 2014 I began the following conversation (conversation 10), which 4 participants contributed to:

“HELLO AGAIN, FOLLOWING ON FROM YESTERDAYS CONVERSATION ABOUT ‘LABELS: CFS versus ME’:

PLEASE COULD YOU TELL ME HOW YOU DESCRIBE TO PEOPLE HOW YOU FEEL WITH CFS/ME?”

This question was designed to explore the lived experience of CFS/ME from a physical perspective.

On the 9th of April 2014 I posted the following (conversation 11), which 3 participants responded to:

“I WOULD NOW LIKE TO SUGGETS WE CREATE A PHOTO GALLERY AS I WOULD REALLY LIKE TO BE ABLE TO REPRESENT YOU ALL IN MY RESEARCH.

Your participation is anonymous (I will give you all pseudonyms) and as such you do not have to upload photos of yourself (although if you are happy to be ‘seen’ in my thesis then of course feel free to upload photos of yourself). Ultimately, I would like you to upload photos which represent you or what is important to you. Please tag your photo with a couple of lines to illuminate the relevance and importance.

In short I have grown fond of many of you and I would like to cement the honesty of my analysis by using your photos as an introduction to you.”

As CFS/ME is such a contentious illness which is stigmatising of sufferers, I wanted to give participants an opportunity to represent themselves here, to choose how they were to be seen through the medium of photography. However, it transpired that this particular activity was too labour intensive for participants and as such only three participants uploaded a photo to cfsid, which ultimately drew a line under this activity. I do not regret giving participants an opportunity to represent themselves, but feel sad that they were unable to and/or chose not to engage with this opportunity.

On the 21st July 2014 I posted the following (conversation 12), two posts which 9 participants responded to:

“CAN I ASK A FAVOUR?”

There are so many different definitions of CFS/ME, but I would like to include definitions as described by you?

Could you tell me what CFS/ME is? If someone was to ask you what is CFS/ME, how would you answer giving as much depth and insight as possible?

I'm thinking it could be quite powerful to include your definitions at the start of my 1st chapter to illustrate what this illness means to us, what it does to us, how we experience it etc.”

“ME AGAIN.

APOLOGIES FOR THE LAST FAVOUR REQUEST. I WILL NARROW IT DOWN A LITTLE!

PLEASE COULD YOU:

- 1) LIST/DESCRIBE YOUR SYMPTOMS?*
- 2) TELL ME WHAT YOU THINK CAUSES CFS/ME?”*

This conversation was an extension of the the conversation on the 13th March 2015 which endeavoured to explore the physical reality of CFS/ME. The two questions above were designed to allow participants to define what CFS/ME was for them, how it was experienced in terms of symptoms etc, and their beliefs about the illness as it was important to me that ‘their’ voices were heard.

On the 4th of September 2014 I posted the following (conversation 13), which 14 participants responded to:

“HELLO EVERYONE, I HOPE TODAY IS TREATING YOU WELL SO FAR.

I will be giving everyone a pseudonym as to make sure your data is anonymous within my thesis, so the burning question today is:

WHAT DO YOU WISH YOU HAD BEEN CALLED? Lol

WHAT NAME WOULD YOU LIKE ME TO USE FOR YOU IN MY THESIS?

Feel free to private message me if you want to remain as anonymous as possible within the group (some have private messaged me answers/activities etc., so not all data has been on the cfsid wall).”

Following on from the rationale behind the photo gallery, I asked participants what they would like to be called as I wanted participants to feel that they had some control, that in the research process we

worked together and that their opinions and wishes mattered. I wanted to do right by them and in asking questions such as this I hoped they would see that I wanted to do right by them. Although I had planned for pseudonyms (see Appendix 3), the majority of participants asked me to use their real name as opposed to a pseudonym, but those participants who did wish to remain anonymous, provided me with their name of choice which then became their pseudonym. It is also worth acknowledging that aside from asking participants research related questions, as to build up and sustain both a rapport and momentum I regularly kept participants up to date with what I was doing, what stage I was at in my research, conference presentations and papers etc. whilst also regularly asking how they all were, if they had any news etc. My research ethic was not underpinned purely by 'give me data'.

On the 8th January 2015 I posted the following (conversation 14), to which 11 participants responded:

*"Hope all as good with you as possible so far this year!
I'm just wondering if you could do me little favour?
In my thesis I'm arguing for the benefits of an 'insider perspective' when doing research. For example, as a CFS/ME sufferer, I believe I am in a better position to conduct research on CFS/ME than an outsider (a non-CFS/ME sufferer). But, you may think otherwise! So, when you first read the information about my project and cfsid, what did you think about the fact that I was a CFS/ME sufferer? Did this mean anything? Or not really? Hope you can help, but no worries if not."*

As I was arguing for the benefits of an insider perspective, I realised I should really ask participants what they thought about my insider perspective.

On the 24th April I posted the following (conversation 15), to which 10 participants responded:

*"Well, I had a supervision this week with my three supervisors. It was the first time two of them had read any of my work (50k words) and well, they both said "Where is the positivity? Where is the wellness? Where is the hope? Where is the health in illness?" One said "It reads like 'Shit, it's chronic all the time, but it isn't". So, I defended my position re there being very little positivity, wellness, hope, and health in illness etc. but I wondered if I had been blindsided by my own experiences? There is very little positivity in the CFS/ME literature, but what are your thoughts? How would you have responded to the suggestion of a lack of positivity in my writing about CFS/ME?
Hope you are all as OK as possible and managing to enjoy the warmer weather a little.
Rebecca"*

When my perspective had been questioned I felt it only right to consult participants. I wanted to see if I had in fact been blindsided by my own experiences or as to whether my representation of CFS/ME was aligned with their lived experience.

On the 26th March 2015 I posted the following (conversation 16), to which 13 participants responded:

“Me again :-S I'm sorry to be a pest! I just wondered if you could have a think about quality of life and well-being in CFS/ME? Do you have a quality of life? If yes, could you tell me about it? What gives you a sense of quality of life and well-being? If no, what would you need in your life with CFS/ME to enable a sense of well-being and a better quality of life? R x”

Moving on from the issue of positivity in CFS/ME I wanted to explore more explicitly participants' experiences of quality of life and well-being in chronic illness.

On the 17th September 2015 I posted the following (conversation 17), to which 11 participants responded:

*“HELLO EVERYONE, I hope today is treating you as well as possible.
Little update: I have now written approximately 70,000 words so the thesis is coming along nicely, but the end is not quite yet in sight. Oh well, I have to believe it will be soon!
Please could some of you give me a couple of lines about how we all do stuff knowing that we will pay for it? How 'pay back' becomes our way of life? I ask as I don't think this part of CFS/ME is to be underestimated.
Pretty please...”*

In consideration of positivity, quality of life and well-being in CFS/ME whilst being aware of the 'pay back' in CFS/ME I wanted to explore how participants negotiated the balance between participation and pay back. It was important to illuminate such experiences as to unearth the lengths participants went to to participate and/or the context surrounding their inability to participate in an attempt to provide an insight into coping in chronic illness: CFS/ME.

On the 24th September 2015 I posted the following (conversation 18), to which 9 participants responded:

*“ME AGAIN... Please don't despair!
So, one of the things I'm arguing is that when life and self are floored by this chronic illness, you have to find a new way to be in the world, new ways to participate in life by participating in something, in some way. I am interested to know however large or small, what did you do when you couldn't do what you used to do? How did you find purpose, meaning, and enjoyment in your life with CFS/ME? Hobbies, activities, roles etc.? We have touched upon this in a number of conversations but I need it to be a bit more concrete, if possible, so...
pretty please?
Bye for now,
R x”*

Following on from the previous conversation, I wanted to gain a greater more explicit insight into the ways in which participants negotiated their CFS/ME identities, and perhaps QoL through participation.

Following a supervision during which the lack of positives in my work was questioned, on the 1st November 2015 I posted the following (conversation 19), to which 17 participants responded:

Hello everyone,

I wondered if you could help me to explore a tension that emerged during a recent supervision. The lack of positivity in my work was questioned. Could I have been blindsided by my own experiences? Am I ignoring the positives?

Although I gathered data between December 2013 and November 2015, the main data collection occurred between December 2013 and March 2014. During this period, cfsid was at its most active due to the various activities and conversations I engaged participants with. Between March 2014 and November 2015, to reiterate I regularly posted in cfsid to keep participants up to date with my progress and to tell them about conference presentations etc. I also touched base regularly to ask how they all were, if they had any news etc. I felt it was important to sustain a rapport with participants during the months that I was 'working behind the scenes'. I didn't want them to feel that as they had shared their experiences, that I was no longer interested in them and their CFS/ME journeys. Although I intended to conduct 6-10 semi-structured interviews, due to the wealth and richness of data, it was concluded that the proposed interviews would not be able to sufficiently contribute anything new to the data. Following my request for help from participants on the 1st November 2015, I reviewed the data. I subsequently aligned the data with the research aims in an attempt to clarify that sufficient data had been collected in order to begin analysis. Despite the photo gallery proving unsuccessful, due to the generosity of participants' cfsid contributions the data proved more than sufficient to meet the research aims, and as such the data collection period drew to a close in the knowledge that, if needed, I could return to cfsid to discuss various findings/gaps with participants.

Table 1: *Research aims and methods employed*

RESEARCH AIMS	METHODS EMPLOYED
Explore the shifting social identity of those living with CFS/ME and the subsequent impact such shifts have on the sense of 'self' and identity of those living with CFS/ME.	Timeline activity; TST activity; Conversation 1 (C1), C6, C7, C8, C15, C16, C17, C18.
Explore the utility of Wenger's (1999) 'Communities of Practice' theory in understanding identity in chronic illness.	Timeline activity; TST activity; Conversation 5 (C5), C6, C7, C8, C15, C16, C17, C18.
Widen the knowledge about CFS/ME, and by extension contribute to the chronic illness literature in general, how it (CFS/ME) is experienced, how the person interacts with the illness, and the context of the person and the illness.	Timeline activity; TST activity; Conversation 1 (C1), C2, C3, C4, C5, C6, C7, C8, C10, C12, C15, C16, C17, C18.

Provide an insight into CFS/ME for those who live with CFS/ME who may be unaware of the ramifications of the social construction of CFS/ME but who may be in a position to challenge and negotiate any associated oppression and marginalisation.	Timeline activity; Conversation 2 (C2), C3, C4, C5, C6, C8, C12, C15, C16, C17, C18.
Explore the mediating effect of social media support in chronic illness: CFS/ME	Conversation 8 (C8), C16, C18.

The timeframe of the current research did not allow for a return to participants to discuss my final interpretations. However, as an objective is to share my work with participants, they will have the potential to consider and communicate their reaction(s) to my interpretations. Their reactions, whether positive or negative, would subsequently be reflected upon within the design process and execution of future work.

Analysis; rationale for all decisions made

The story:

How different things would be...if the social sciences at the time of their systematic formation in the nineteenth century had taken the arts in the same degree they took the physical science as models. (Nisbet, 1976, p. 16)

I choose to begin the analysis with a story as the literature surrounding stories reaffirmed that a story here would provide a creative introduction to participants' CFS/ME stories, and in so doing an overview of the data (e.g. Elliott, 2005; Clandinin, 2007; Owens, 2007; Hamilton, 2008; Holstein & Gubrium, 2009; and, Abrams & Harpham, 2011). According to Nisbet (1962), within the arts is a reflection of lived experience and individuality as creativity is inseparable from self expression. Story writing is inherently creative, but when stories are biographical, such creativity is dependent upon an insight into lived experience. Biography, according to Abrams & Harpham (2011, p. 15) is:

...a relatively full account of a person's life, involving the attempt to set forth character, temperament, and milieu, as well as the facts of the subject's experiences and activities.

The writing of the story flowed due to my familiarity with the data and my insider knowledge and understanding of CFS/ME. As such, the fluidity of the story writing reflects the knowing relationship I had with participants and the insight they had given me into their lived experience of CFS/ME; a life and self lost. According to Hamilton (2008), understandings of identity are enabled by biographical stories as such stories illuminate one's place in the world; we are our past, and our present is our future. However, as in the case of CFS/ME, not all futures are predictable in this way. According to Frank (1997, p. 58) "*telling an interrupted life requires a new narrative*". When a life is struck by chronic illness, it is a life interrupted. In order to understand the reality of an interrupted life, Frank (1997) asserts it is necessary to provide a new framework within which to consider such a life; a life

unexpected. As the re-conceptualisation of CoP was always central to the thesis, a theoretical thematic analysis was an obvious choice. However, as the voice of participants was also central to the thesis, having analysed the data, two important aspects emerged which provided an opportunity to present an unbroken insight into the CFS/ME trajectories of participants which reflected their interrupted lives and selves. I began reading around the role of stories in qualitative research further, and found the literature reaffirmed the worth of a story here to present a powerful introduction to the data which was not fractured but whole (e.g. Tovey & Manson, 2004). Being mindful of an overarching aim being to unpick the lived experience of CFS/ME, I believed a story could creatively and powerfully introduce the reality of participants' lived experience of CFS/ME and in so doing, a number of aspects which would be elaborated upon within the theoretical thematic analysis. Although the story is only 2000 words, approximately, the featured participants are in focus; their lives, their selves, and their losses. Thus, the power of the story aligns with an opportunity to engage the reader before their immersion into the theoretical thematic analysis as the story provides an insight into the complex chronic illness that is often pre-conceived and misunderstood. A desire for empathy underpins the story.

As above, the story fundamentally presents two important aspects of the lived experience of CFS/ME for participants that emerged during the analysis of the data, and as such, the story is analytical as the story is rooted in analysed data, but the story itself will not be analysed. Before constructing the story I considered how I was going to focus the story, and what I wanted the story to do; how could it serve both the reader, and the analysis? Within the data, CFS/ME was villainous, so I positioned CFS/ME as the protagonist, which allowed me to consider not only the physical hit of CFS/ME, but also the many outside influences that were found to pepper the data and as such underpin participants' lived experience of CFS/ME. I subsequently began to think about the participants whose data had imprinted, and their CFS/ME trajectories. I made notes about a number of participants and then began to cross-reference their individual stories so as to reaffirm the themes that, as above, had emerged during data analysis. Feeling confident that my initial findings appeared to be evident within the cross referenced notes surrounding participants' trajectories, before beginning to write the story, I returned once again to the data. I reviewed the data so as to check that my memory and interpretation of the data was an accurate representation of participants' lived experience of CFS/ME. When I was satisfied that my interpretations were accurate, drawing upon my notes, I wrote the story.

The story chapter does not present all participants as I chose to draw upon data from those participants who gave me the greatest insight into their CFS/ME trajectory. The foundation of participants' CFS/ME trajectories is the duration of their illness. As discussed in C2, Wenger (1998) has conceptualised both peripherality and marginality, and on considering the duration of participants' illness, the story chapter also had the potential to provide an insight into the nature of participants' participation within the practices of CFS/ME; peripheral versus well established, and as such the dynamic of the CFS/ME community. However, as the story chapter was never intended to be a chapter defined by fracturing analysis, the consideration and analysis of participants' participation in the practices of CFS/ME, and the dynamic of the CFS/ME community will be discussed in C10. The

acknowledgement of the CFS/ME community dynamic could reflect a hierarchy, but it was never an intention to align participants with a hierarchy as all participants' experiences were valued and as such no-one's experiences were privileged over another based upon the duration of their illness. However, within the story chapter it was necessary to illuminate the length of time participants had been living with CFS/ME so the reader was in a position to discern the similarity of their experiences regardless of the duration of their illness. The biographical data for participants who do not feature in the story chapter can be found in Appendix 3. The duration of illness as expressed by participants in the current chapter, and Appendix 3, is not from diagnosis, but from when they first became ill. In order to participate in the current research, participants were made aware that a diagnosis of CFS/ME was necessary. However, as diagnoses of CFS/ME are problematic, people are often ill for many years before they receive a diagnosis and as I wanted to explore participants' illness trajectories so as to unpick their jeopardised identities, such trajectories did not begin with diagnosis, but with participants' lived experience of chronic illness.

The story is not a light hearted read as it is an unquestionably dark story, but the darkness here reflects the darkness of CFS/ME. The literature cited in C1 and C3 does of course paint a picture of the illness, but speaking from personal experience, the story here presents a rawness of experience which communicates the suffering of participants and the impact of CFS/ME on lives and selves more powerfully. To reiterate, the story is only a short story so I do not suggest that the insight given here is defined by depth and breath, but I can confirm that I wanted the story to be succinct in the delivery of a clear, concise, and unbroken insight into the reality of this illness for participants before exposing the reader to the theoretical thematic analysis.

Why a theoretical thematic analysis?

As the re-conceptualisation of CoP was central to the thesis, it seemed imperative that the analysis was theory led and due to the necessity of clarity involved in the re-conceptualisation of a theory I believed that a thematic analysis would allow for a transparency of clarity that would serve a re-conceptualisation the most. Therefore I decided a theoretical thematic analysis would be most appropriate and on reading around thematic analyses I made the decision to align my theoretical thematic analysis with Braun and Clarke's (2006) version. The six stages of analysis as cited by Braun and Clarke (2006) were clear and concise and reaffirmed a no nonsense approach to analysis which appeased an innate need for my analysis to be one defined by clarity.

Thematic analysis (Braun and Clarke, 2006)

I will now present and discuss the six stages of Braun and Clarke's (2006) thematic analysis (Braun and Clarke, 2006, p.87).

- 1) Familiarizing yourself with your data: Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.

As my research took place online, throughout the data collection period, I copy and pasted all data as it emerged and stored it in a word document on a password protected computer. I therefore did not have to transcribe any data, which I cannot deny was a bonus! Although it is suggested (ref) that transcribing data allows an immersion which is superior to those who, for example, may pay others to transcribe their data, I stand by my commitment to cfsid and my sustained engagement with participants which allowed me to be immersed in the data, not just during a period of transcription, but throughout the period of data collection and beyond.

When I believed I had gathered sufficient data (approximately 55k words), I began to read and then re-read. The story of the data was beginning to emerge at this stage, so I made note of my provisional thoughts before moving onto stage 2.

- 2) Generating initial codes: Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.

Although I coded the entire data set, as participants completed various activities and contributed to multiple conversations, I initially began by coding different sections of data. I coded each activity separately and then each conversation. I did this as I believed a break down such as this would enable me to be as thorough as possible at this preliminary stage before moving on to looking at the entire data set as a whole. Perhaps I gave myself an extra job, but I trusted it to be the right decision, which was reaffirmed by insightful coding.

My coding evolved into three phases. The initial phase involved coding all data in each section (as discussed above). On looking at the entire data set as a whole, I then went through all coding and began to establish commonality amongst them which I then applied to the second phase whereby I reviewed all codes according to the established commonality. At this point I transferred all established codes into a word document I then worked with a list of codes to fine tune their commonality before returning to the data. The final phase involved collating all data according to the established commonality of codes and the provisional consideration of potential themes.

- 3) Searching for themes: Collating codes into potential themes, gathering all data relevant to each potential theme.

At this stage, the collated data as reflective of the commonality of codes was reviewed in an attempt to test the potential themes that had been considered. I subsequently shortlisted the most dominant themes as to enable me to present an analysis that did both my data and the lived experience of CFS/ME for participants, justice. I then collated all data for each of the four shortlisted themes to confirm cohesion within and across all themes. On noticing the potential for elaboration in a number of areas, I returned to participants with questions. If contribution from a variety of participants was required, I posted to the group, however, if I needed extra information from specific participants I private messaged them individually. Facebook was a wonderful method as the privilege of sustained contact with participants and the privilege of requesting elaboration from participants throughout the

period of data collection and during the period of analysis meant that ultimately there were no unanswered questions or gaps in the data or analysis.

- 4) Reviewing themes: Checking if the themes work in relation to the coded extracts and the entire data set.

This stage involved a thorough review of all coded data. I initially began with a review of each theme before returning to the entire data set in an attempt to ascertain whether the shortlisted themes were aligned with the overarching story of the data. I concluded the themes were aligned with the overarching story of the data and as such moved onto the next stage.

- 5) Defining and naming themes: Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.

I began with an in depth review of all four themes to fine tune the story of each. As the current research is heavily driven by theory, the concepts of Wenger's (1998) CoP theory rippled within each theme and as such were central to each theme. However, in view of the importance of the re-conceptualisation of Wenger's (1998) CoP theory, I went back into the analysis with a heightened CoP focus as to make sure that I had not overlooked the potential to foreground CoP concepts within any of the four themes. On being satisfied that I had re-analysed all themes thoroughly, that the story of the data was transparent, and the CoP foundation was solid, I once again went back into the four themes to make sure that they were distinct from one another whilst also being cohesive. I began to consider names for each of the four themes, but at this stage I was struggling to do so and so decided to wait until I had collated the selected data for each theme in the hope that on seeing the themes in their totality, that I would be inspired.

- 6) Producing the report: The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back to the research question and literature, producing a scholarly report of the analysis.

I reviewed all data for each theme and began to shortlist in an attempt to include data that was most powerful and most transparent in its story telling. I subsequently conducted a final analysis and review whilst being mindful of research aims and the literature review before once again, considering names.

Rationale for chosen data; why so much data?

cfsid had 60 members, with 37 members giving their consent to take part in the current research. However not all participants contributed and not all of the participants who did contribute, contributed throughout the main period of data collection, something that will be discussed in C11. As I have argued for longitudinal data that allows for layering, it was imperative that the data allowed participants' CFS/ME stories to emerge. Therefore, the analysis is drawn from the data of those participants who contributed the most, those whose data was longitudinal and layered and as such the analysis represents a naturally occurring subset of cfsid members; participants. The current research has been heavily led by theory, namely, Wenger's (1998) 'Communities of Practice' theory.

However, those with CFS/ME are often marginalised, prejudiced, and discriminated against in society due to the stigma and scepticism which shrouds the illness. Such marginalisation, prejudice, and discrimination can often realise itself in the silence of those with CFS/ME. It was therefore essential that I created a safe place within which CFS/ME voices could and would be heard; cfsid.

I have been clear that I do not claim cfsid was a life space but through the immersion of myself and participants in cfsid I was granted exposure to their life spaces and in turn they were granted exposure to my lived experience of CFS/ME. cfsid was a relational platform as it enabled myself and participants to get to know each other during the months that we worked closely with each other. I do believe my insider perspective was key in participants' acceptance of me as 'one of them' and it was an acceptance that encouraged the generosity of their contribution which was invaluable. cfsid evolved as a safe place for participants as it was a virtual community whose members shared a lived experience of chronic illness; CFS/ME. My insider perspective and confirmation of participants' understanding of CFS/ME as defined by their cfsid membership, enabled trust in participants, and as such cfsid quickly became a sanctuary for a freedom of speech, and self expression. Participants' were able to be honest about their lived experience of CFS/ME, something that is often problematic in CFS/ME. Participants' voices reflected the horror of CFS/ME, and therefore the analysis predominantly reflects the horror of CFS/ME which evolved as a tension and will be discussed in C7, and C10.

My debt to participants was central to my analysis of their data and my representation of them as people and their lived experience of the illness. I had such a wealth of longitudinal data that I believed I must include much of it if I was to retain the integrity that defined my relationship with participants. I felt indebted to my participants who triumphed over adversity to participate in my research. Many of them were and continue to be very ill, yet they used their limited energy to contribute so richly, for me, for us. I understand more than most that in CFS/ME it is an 'either' 'or' situation, which means that participants will have made multiple sacrifices to participate in my research, and this I will not underestimate or take for granted. On reconsidering the generosity of participants' contribution, I could not ignore the role cfsid and my insider perspective played, but I became aware more than ever of what perhaps drove participants. They wanted to be heard, they wanted a voice, they wanted people to understand them, and to believe them; they wanted things to change. I believe they saw me and my research as a platform. On more than one occasion a number of participants thanked me for investing in them. CFS/ME is such a lonely illness and one often defined by feelings of abandonment that I believe when I put out a call for participants, that my call resonated deeply with their need for investment. I invested in them and they invested in me and their stories deserved to be told in as much detail as was possible.

My insider perspective has undoubtedly served my research well, but I was acutely aware that as a sufferer, I may be accused of representing myself in the analysis as opposed to representing the lived experience of participants, and of bias. Interpretivism does lend itself to criticism such as this, but I suspected my insider perspective would add fuel to the fire. I do believe however, that the depth of data presented in the analysis serves to spotlight participants, not me, as it is their thoughts, feelings,

opinions and lived experiences that are transparent throughout. I admit their lived experience of CFS/ME often mirrored my own, but nonetheless it is their lived experience that shines bright in the depth of data presented, not my own.

Chapter summary

The current chapter began with discussions around cfsid; plan B, to make transparent my negotiation of those with CFS/ME and the CFS/ME Facebook community. I have been as detailed as possible about cfsid activity so as to show exactly how the activities and conversations evolved in an attempt to show exactly how cfsid, from start to finish, met the aims of the current research. The chapter then moved onto the chosen method of analysis. Discussions around storytelling, thematic analyses (theoretical), and the relationship between the presentation of a wealth of participant data and an insider perspective served to lay the foundation for the theoretical thematic analysis which is to follow. The detail provided here also reflects an awareness of the need to illuminate all decisions made and the reason for all decisions made in an attempt to provide a clear and concise rationale for all methodological choices so on moving forward, there are no grey areas.

The following analysis opens with the story 'Basking in the glory of my evil'. The story provides an introduction to participants' CFS/ME stories, and in so doing, an overview of the data and theoretical thematic analysis which is to follow.

CHAPTER SIX (C6)

Commonality and continuity despite difference

As discussed in C5, stories within qualitative research can creatively illuminate data. The following short story serves to show the commonality and continuity amongst participants, despite the duration of their illness and their difference. On looking at the lived experience of CFS/ME for participants from a longitudinal perspective, the data firstly presented to me a story of commonality which illuminated the fundamental parallels amongst participants. In addition, the longitudinal data also presented a story of continuity as the continuity of experience for participants as expressed during the months of data collection; the insight gained into their lived experience of CFS/ME provided an insight into their often never ending nightmare.

Basking in the glory of my evil

People can be so stupid, I mean I have been on the attack for years, but because 'high and mighty medicine' cannot see me, they don't believe I exist *<insert evil laugh>*. I get away with murder, well almost murder, in fact some of my victims wonder if being dead would be better than being alive with me inside them; what a result. I think I should tell you what I do to people, so you can be in awe of my wickedness and I will begin with the fact that no one is safe, and I mean no one.

I gave myself extra kudos for Kate. Kate was a doctor who didn't believe in me, she saw a number of my victims whilst she was practicing medicine and although she tried her best to help them, she thought it was all in their head. That was of course until the day that she became a victim herself. She thought she was depressed **boo hoo hoo**, and that her problems were psychosomatic as that is what her training had taught her, but even when anti-depressants improved her mood and not the physical symptoms that were incapacitating her, she was still in denial. It was a colleague of hers who suggested it was me and although it took Kate a long time to accept that it was in fact me, and that I was 'real' after all of those years believing that I was not real, she eventually understood that I was real and that I had devastated her life and the lives of many others. I basked in the glory for a while over Kate, for having snared a doctor and a doctor who was a wife and a mum with an extremely full life because everything stopped after I arrived. She could not be the wife or Mum she used to be, she could not be the colleague or friend she used to be, she could not be Kate anymore. I was annoyed by the people in her life though, as they supported her, they believed she was ill which was novel. I take extra kudos for Kate because she was a doctor, but actually, I think her journey has been easier than for some as people respected her more, the people that mattered; those in primary care and those closest to Kate such as her friends and family. They didn't think she was 'faking' it, they believed she was ill and she was ill, I made her very ill. It's actually relatively early days for Kate as she has only been ill three years, but she is on the path to indefinite ruin, of that I am certain, but enough of Kate and her privileged journey, it's making me angry, now let me tell you about someone who had a very different journey and one that makes me burst with pride.

When I appeared from the shadows Ros was finding life quite hard as a single Mum so she was quite an easy win but she was persistent, I'll give her that. There were vain attempts to continue working, she tried different jobs, she went part-time, worked closer to home blah blah blah, but it was all pointless, because when I say you're life as you know it is over, I mean it. It took Ros a while to understand this. Her doctors, friends and family were the best, they thought she was mad, lazy, they didn't believe she was ill, oh it was just brilliant. Her parents disowned her, told her she was no longer their daughter! She felt alone and it was almost as if it was just Ros and I because even her daughter didn't believe her, but who was Ros? She knew who she used to be, but who was she now? You see, I hit my victims like a missile, I break them physically and it isn't a temporary break, it's one that I work hard to make permanent. Their lives and selves become historical as although their minds may sometimes be willing, after I attack, their bodies are broken. I guess you could say that I entrap them into a world of loss and grief as they often lose everything, their lives and their selves. Ros, for example wasn't Ros anymore after I attacked her as Ros couldn't really do any of the things that she used to do, the things that made Ros, Ros. Thinking about it, when I attack people, they lose themselves to me, they become me because I am so powerful that it is hard for them to be anything other than the chronic illness I inflict upon them. Ros has been mine for 14 years. I have ruled her life and self ever since I first attacked her, something which is part of my remit and as if this isn't bad (good) enough, as you can see I can also isolate and silence my victims through the scepticism of others which adds a certain *je ne se quoi* to my profile. My French reminds me of another victim.

Eleanor was living and working in Paris when I found her, and she was one hell of a find, she had endless energy, she barely slept, I guess you could say that she was burning the candle at both ends but without consequence. She needed to be taught a lesson <enter CFS/ME>. She thought she had a virus, which was typical of these people, thinking they would get better; fools. Eleanor had barely been ill her entire life so she was in for a shock. She saw lots of doctors as she was quite well off, she had everything before I ruined her, she was living the high life and thought she was invincible. How wrong she was. In Paris no one knew what was wrong with her so they kind of gave up. Eleanor then went home to England, saw more specialists and lived with her parents for a few years who were far too supportive for my liking. Eleanor didn't have any financial worries and she wasn't lonely as she had a wonderful family, namely sisters. Thinking about it, some of her friends were team CFS/ME, but she said farewell to them, which was disappointing as they could have made her life harder for me. Anyway, her life was over, well the life she had known, so long 'high flier' and hello 'low liar'; she spent a lot of time in bed. Fast forward 30 years and she's still mine, she's still CFS/ME. She's had ups and downs, mostly downs but I continue, without grace, to make her life impossible. She's a tenacious one, but this is a war she will never win and this she now understands.

When I think of Eleanor and her middle class life, I am reminded of Fiona. I feel a smidge of guilt when I think about Fiona (fleeting) because Fiona had just battled the 'big C' when I noticed her, and as we all know the big C is a war, but I was having a bad day and I didn't think she'd suffered enough so I fired a round of bullets. I gifted Fiona with a slippery slope, I attacked her progressively, but after a few months she succumbed. She too tried to continue working, seriously, what is it with these

people, but before long it was GAME OVER. She also had support in the futile fight against me as Fiona had a supportive husband. I have found that support can get in the way of misery, but then again, support cannot stop the misery because I AM THE MISERY. Fiona's doctor believed she was ill as she knew Fiona prior to my arrival (big C), so she had an easy ride there, but some family members were sceptical so that appeased me a little. I think the biggest win with Fiona, aside from the standard 'your life is over; you are mine; you are me; you are no longer Fiona', has been the financial strain I have put on her. It's an additional burden that weighs heavy, worrying about bills and having to go to different shops to pay less etc. is something, when you are as ill as Fiona that adds insult to injury. I wish I could make everyone have financial difficulties, it really is entertaining, but I guess it doesn't really change how I make them feel, how I attack them, ruin them, but it can make life harder for them, similar to a lack of support, which is most pleasing. Fiona has been ill for five years now; she sees no light at the end of the tunnel as nothing ever seems to change. You could say my job here is done.

Whether I attack slowly, as in the case of Fiona or at the speed of light, the end game is the same. I have a job to do, and I do it. Olivia was only young when I attacked her. She went to bed one night as a normal healthy teenager and woke up incapacitated. She was virtually housebound from that moment on. Her GP was clueless, so I loved her GP, naturally. Olivia could barely function but she kept being told "*come back in three months, I'm sure you will be feeling better*". No she won't. I remember my favourite exchange of primary care wisdom was during one appointment, perhaps 9 months in, when Olivia's GP suggested, wait for it, that Olivia should go swimming or prepare and cook a meal for the family. Olivia was struggling to dress herself at this stage. She left the surgery in tears and I patted myself on the back. She felt abandoned, but had one of those loving and supportive Mums, which was annoying. Anyway, fast forward a few years and Olivia was beyond ruined. She was hospitalised and doctors didn't know if she would be able to recover. I'm feeling generous, so credit where credit is due, Olivia wasn't a quitter, she never gave up, even during the years which were unbearable by anyone's standard, she continued to fight me. People thought she had 'changed', they suggested that she was different now and not the Olivia that they used to know, but she was still there, on the inside; the lights were on, she was home, but locked in a bedroom. Fast forward 20 years and Olivia is better than she was, but I'm still there, everyday, making her life hard. I have to take comfort from the fact that even if people pull away from me, that they are never free of me. I'm still triumphant as Olivia's life was changed forever by me, she was changed forever.

Some people say that I like a certain type of person, but this is utter nonsense. As you can see from the few victims I have preened over above, they were all very different people living very different lives. They don't fit a 'CFS/ME profile' as there isn't one. I guess because I'm invisible, the powers that be try to make sense of the devastation I cause by blaming it on the victims for being a certain 'type'. Talk about clutching at straws, mind you, I guess it is another blow dealt to my victims so I shouldn't really complain. I think it's safe to say that the misery I inflict is both layered and sustained. Aside from the obvious decimation of life and self through chronic illness and incapacity, there is the relentless nature of the physical suffering, the disbelief, the abandonment, and the isolation. And, I am

not the flu; I don't attack people for a couple of weeks before privileging them with recovery as my attack is indefinite, and therein is the beauty of it. People expect to get better, at first in a week or two, then a few weeks, then a few months, then even a year or two, but that isn't the way I roll, so they are continuously having to deal with disappointment, up until the point that they realise and accept that this is it for them, this is their life now and this is who they are now. So my victims may be different and although I do inflict a wealth of symptoms (my repertoire is impressive) the misery of my victims is the same. In all of them I am the same evil force and it doesn't matter if they are financially secure or financially insecure, it doesn't matter if they have people who support them or if they don't have any support, and it doesn't really make any difference if they are believed or disbelieved as the reality of me, of my assault is such that nothing can negate my impact; I destroy lives and selves, and nothing gets in the way of my objective.

I trust you can now see me for who I am; exactly how I attack people and that I can attack whoever I want whenever I want. I also trust that you will be hoping that our paths will never cross, but if I am to continue my work, I must stop reflecting on the past and look to the future; more victims, more suffering, more glory.

Story summary

Despite participants' lived experience of CFS/ME aligning with contrasting timeframes, experiences, different lives, selves, and meanings, the notion of the chronic nature of CFS/ME, the confusion, the difficulty in diagnosis, and the unavoidable withdrawal from life and self, was evident for all participants above and emerged as the CFS/ME identity. Therefore, the data suggests that the trajectory of CFS/ME is such that regardless of the potential for a variety of outside influences such as support and belief, that the trajectory of CFS/ME; chronic illness and suffering, is moreover the same for everyone. The lived experience of chronicity and suffering emerged within the longitudinal data as a story of continuity as participants provided an insight into their stories of relentless suffering.

As discussed in C5, on contemplating the fractured nature of thematic analyses, it became evident that the introduction to the analysis needed to be more holistic in its approach to provide an insight into the commonality and continuity of participants' lived experience of CFS/ME that was not fractured, but whole. As such, '*Basking in the glory of my evil*' was constructed and emerged as a colourful overture to the main show of four parts; themes, which is about to begin.

CHAPTER SEVEN (C7)

An introduction to participants

Due to the longitudinal nature of the data, my research was much more relational than that of an interview study. The time participants and I spent together on Facebook, the time participants invested in completing the various activities, answering questions and contributing to multiple conversations meant that I was able to get to know them, and they were able to get to know me, and each other. Participants gave me a detailed insight into their lives and selves with CFS/ME and their efforts to negotiate their identities through participation which gave me an invaluable insight into them as people. My participants are extremely important to me, their words, how different they are, but how alike their experiences are, so I would like to begin the theoretical thematic analysis by revealing my participants so that on moving forward, the following themes will be seen through the lens of this provisional introduction to them and the similarity of their experience.

As discussed in C5, participants were asked to complete a three part Twenty Statement Test (TST) as one of the preliminary cfsid activities. The following data comes from part one which was interested in who participants were now, which revealed participants' participation in CFS/ME; a snapshot of their CFS/ME identity:

Tessa: I AM...

ROLES: sister, 'Auntie' neighbour, good friend, occasional lover (not nearly enough imho) student, irreverent wit, mentor, group catalyst, tenacious supporter and encourager. But above all else..Gobby.

ACTIVITIES: student of textiles, seeing friends, gardening, Tv watching, resting, hopefully yoga and swimming in 2014, travel, exhibitions, making a home. host for Airbnb.

Ros: I AM...

ROLES: wife, mother, friend, daughter

ACTIVITIES: writing poems, reading, playing boules, enjoying music.

Kate: I AM...

ROLES: mother, wife, GP, leader.

ACTIVITIES: work as GP, run smallholding, support 4 daughters, local leader for patient safety.

Katie: I AM...

ROLES: mother, student, friend, laptop campaigner.

ACTIVITIES: MSc in Nutritional Therapy, mothering and domestics, singing and dancing, being in nature.

Louisa: I AM...

ROLES, wife, mother, daughter, student artist, friend

ACTIVITIES, very reduced, go to uni 3 half days per week, study at home and lots of sleep and rest. Take mum shopping and do my own. Some cooking and washing but no cleaning or ironing. Hardly anything else.

Catriona: I AM...

ROLES: Mum, wife, student and friend.

ACTIVITIES: Socialising, college, family and sleep.

Cara: I AM...

ROLES. ..Mother. .Daughter..leader. .Entrepreneur. .Grandmother..Carer..Sister Auntie. Friend..Neighbour.

ACTIVITIES. ..Carer.Mother.poetry.art. entrepreneur. Reading. Friends..cooking.

Mary: I AM...

ROLES: wife, daughter, student, volunteer.

ACTIVITIES: supporting (and in love with!) my husband, studying health psychology, walking along the seafront, enjoying contact with friends and family.

Rachel: I AM...

ROLES:- Auntie and mum to my rottweiler dog Luna. Helper (non physical) to friends.

ACTIVITIES:- Walking dog when possible. Going to Slimming world. Occasionally meeting friends and family.

Netty: I AM...

ROLES: Daughter, fiancée (near as damn wife after 13 yrs), friend, Mother (chief, cook, bottle washer, emotional supporter, nurse, carer, story teller, housemaid).

ACTIVITIES: Crocheting, knitting, talking to friends on fb, walking dog (on good days) play games with kids (board/card) Teaching Daughter keyboard, housework, sleep.

Dan: I AM...

ROLES: Husband, father, FB admin.

ACTIVITIES: Facebook, going out on mobility scooter to local cafes with dog, reading (mostly factual based fiction). AA meeting twice weekly.

Annie: I AM...

ROLES – girlfriend, friend, sister, godmother.

ACTIVITIES – chatting to friends, small trips out sometimes, art work sometimes, resting!!!, helping with domestic stuff for me and my partner, I have counselling each week, using computer as I can.

As the above is a snapshot of participants' participation in CFS/ME, it is lacking in context. However, the roles and activities listed above paint a positive picture of participants' participation; identity in CFS/ME as they define themselves by a variety of roles and suggest participation in a number of practices and activities. It would appear that communities of practice have enabled participants to nurture a positive identity within their lived experience of chronic illness; however, on the review of the first draft of C1-5, the supervisory team raised the issue of 'wellness in illness'. The bleakness of the introduction to CFS/ME (C1) and literature review (C3) in particular was questioned and it was suggested that perhaps I needed to reflect upon my insider perspective; had my insider perspective clouded my work? With the snapshot of participants' participation in CFS/ME painting a positive picture of their lived experience of identity in CFS/ME, on immersing myself further in the data, I searched for more evidence of participants' wellness in illness:

I consider myself to be mostly moderately disabled and housebound. I've had good and bad periods which is normal with this remitting and relapsing illness... I've had good periods when I've felt almost normal and then really bad periods in relapse. How can anyone understand when at times I've been well enough to paint my bedroom and then at other times so ill I can hardly leave my bed. (Ros)

There have been times when i've been able to be quite active, playing rugby, running and so on, but i've always had at the back of my mind "How will I be tomorrow". (Dan)

I seem to have periods of a couple of months where I am almost back to normal, as long as I listen to my body and don't overexert. (Mark)

After about four years rest I did feel a little better and I went back to work. All went well for a while as long as I was careful and rested when I felt tired but I was able to take up my life. Got a job, moved to Manchester, joined a gym, had a fine social life. Then I got gall stones and my body went haywire and finally this ended up as pancreatitis and a septic gall bladder. I haven't felt well since really. (Eleanor)

Wellness in CFS/ME was evident, as the quotes above illustrate, but a wellness that was periodic and fleeting, and a wellness that was underpinned by the management of potential consequences. Participation in roles, practices, and within communities aligned with participants' experiences of wellness. Practices such as DiY, sport, employment, and a social life were, according to CoP, enabling practices as it was through such practices within participants' experience of wellness that their identities were not one of illness *per se*, but of a life, and self, being lived. Such wellness however, does need unpicking. The wellness in illness literature has a strong mental health focus, for

example, Palmer et al. (2014) explored wellness, as defined by happiness, in Schizophrenia and found factors such as resiliency, optimism and personal mastery enabled better coping which in turn enabled happiness in schizophrenia. In contrast, Doran (2014) considered a mindfulness-based approach to chronic back pain whilst investigating the experience of wellness within illness. Doran (2014) found some participants experienced unexpected wellness despite their chronic back pain whilst others were found to reconceptualise wellness, meaning wellness for some participants was emotional and psychological wellness as opposed to physical wellness. As the aforementioned literature would suggest, wellness in illness, whether mental or physical, is possible. However in the case of CFS/ME, if there is wellness, despite attempts to manage the potential for consequences, it is often a wellness that is periodic and fleeting and dependent upon the privilege of participation. On thinking about the identity of participants I reflected upon the suggestion of wellness in CFS/ME and the reality of very little wellness. To be positive is arguably preferable in chronic illness to feelings of desperation, as the depths of despair do not serve coping, but being positive in CFS/ME needs to be put alongside the relentless nature of the symptoms and the suffering as the majority of participants spoke of their participation *alongside* CFS/ME; the struggle:

All my achievements have come at a cost. Throughout my years of rehab, my studies have been a priority. But they took everything I had to give, so there was little room for anything else in my life. Life continues to be such a struggle, it's a never ending balancing act. (Olivia)

I work full time have a house which I own and a family who I am close to. However I don't have a balanced life as work is what my life revolves around with little energy for anything else. (Jessica)

I too am at uni studying for an art degree. Taken as a therapy to stop me from vegetating. I hated the fact that I had to keep saying I have ME and that's why I can't do certain things. It is all I do apart from sleep... I applied for dla for a second time and got the lower rate. For me this is a success and validation that I am not able to work even though I can do a degree .. The course is only 3 days per week but I do half that and come home to sleep. I don't know how I have done it as I am exhausted all the time but I am on course for a 2.1 . A great achievement but I don't know what I will do next to stop the rot of this horrible disease. (Louisa) (Conversation data)

Here Louisa touches upon validation. Her award of DLA offered the reification that many people with CFS/ME long for; reification that that they are ill. Louisa's award of DLA confirms that her lived experience of chronic illness is legitimate, and despite the fact that she has embarked upon an art degree, she is not well enough to work. According to Louisa above, her art degree is all she does apart from sleep, and in a subsequent conversation Louisa elaborated further upon the sacrifices underpinning her commitment to her art degree:

I too am fed up of feeling ill and having a different area of pain everyday and new symptoms arising each year. I'm having physio but have been too unwell to do the exercises and feel

that I have gone backwards in the last few weeks with a relapse and unable to go to uni. I am in my final year. I don't know how I have done it, but it has been to the exclusion of every other activity known to man, or woman. Like socialising, cleaning, cooking, decorating, going on holiday, visiting friends and family and being visited. I have become very reclusive. But hey...I WILL have an art degree in June. Not that I'm likely to do anything with it, but then what next? A long rest....oh I do that anyway....

University for Louisa has enabled an identity of participation as Louisa is an art student whose participation; identity, is privileged by the defined practices of an art student. Having the identity of an art student whilst living with CFS/ME is arguably preferable to an identity of illness which is potentially one of diagnosis; I have CFS/ME; I am CFS/ME. However, identities within the lived experience of chronic illness are not black and white, but often grey. Louisa has given a transparent insight into the difficult nature of participation in CFS/ME as the reality of participation in CFS/ME for Louisa emerged as an 'either or' situation. Louisa could be an art student, but Louisa couldn't be, or do, anything else. In CFS/ME, a commitment to a certain form of participation can undermine the potential for other forms of participation meaning life can become one dimensional. Whilst the following quotes serve to add further depth to the '*participation alongside struggle in CFS/ME*' concept, they also serve to show the commitment and determination of participants to keep going, even when to their detriment, which does not support the personality theories which construct the CFS/ME suffer as weak, for example (eg. Deary and Chalder, 2010):

I stayed at home with my parents for five months and felt a little better. So I got a job in London and moved down there. I was okay for a while but soon became increasingly tired and ill... I returned home to my parents and didn't work again for three years. (Eleanor)

I was doing my best to hold down a job as an audiovisual technician which was both physically demanding (someone did a pedometer test and found we did 6 miles a day) and mentally demanding as it was about pressurised technical problem solving using decreasing cognitive functioning. I had to nap in the loos to try and keep going and sometimes I got to a point where I'd get confused and couldn't move for an hour or so. (Dan)

I then started to look at doing some temping work near to home. I started a job via an agency but I kept getting infections and needed to take so much time off. It was hardly surprising they told me not to come back. I tried a different job a few months later but that was no better. I wasn't facing up to reality and pushed myself to look for another full time job. I started a full time job right next to my house so I had only a few minutes walk to work. I had at least eliminated the problem of travel. In the year I struggled to maintain this job I had so many infections and feeling unwell that I had to once again take lots of time off work. (Ros)
(Timeline activity)

And subsequently, Ros added:

I was a single mum so had to make an effort for my daughter. Otherwise I don't know what I would have done.

Somehow I finished uni and gained my degree. I went home barely able to function... (Laura)

I then tried to work part time and build up, but symptoms always there. Came back to England 1996, got part time teaching job, then did seem to make progress and took on full time job in 1997, teaching 6-7 year olds in a private school. Began to gradually build more into my life....but then fatigue began to worsen (had never felt fully 'well' and had always needed rest) and other symptoms crept in, in 2000 began to sense things with ME getting worse. (Annie)

It is evident from the quotes above that participants did not succumb to CFS/ME readily or easily. They worked hard to keep going, to continue to participate in life, and self, even when doing so was to their detriment. The commitment of participants to participate in life in some way, whether it be employment, adult education or hobbies through to the practices and roles of communities such as family or friendship groups, is reflective of a grit and determination that only an insider would be able to fully appreciate. As such, in contrast to experiences of wellness and participation in CFS/ME, it is the struggle that overwhelms in participants' accounts of participation here, not the privilege of wellness or the reward of participation being identity (Wenger, 1998). What is apparent here is an unspoken awareness of the importance of purpose and meaning in life, even when such purpose and meaning through participation is aligned with struggle and consequence. What is less apparent however, is evidence of quality of life in CFS/ME through participation; identity. The activities and roles etc., without question gave participants purpose and meaning and in so doing enabled them to negotiate their identities, but the pressure and need to work for example appeared to further compromise their quality of life. Therefore, the personal expectation of participants to continue to 'be' and 'do' in CFS/ME, and perhaps the pressure and need to 'conform' to the 'healthy norm' was not necessarily indicative of quality of life and well-being in CFS/ME, which in part reflects the struggle of positivity in CFS/ME.

In C2 I discussed Wenger's (1998) practice as learning concept which considers how we learn and grow as people in the communities to which we belong. Participants' attempt to continue to live and participate in some way despite their CFS/ME is indicative of the practice as learning concept. Learning to live with chronic illness is about dealing with and managing change, but in CFS/ME, if one is to live, if one is to participate, part of the learning process appears to be an understanding and acceptance of 'payback'. On discussing the nature of payback in CFS/ME, participants articulated their experience and negotiation of payback:

If I did nothing that would bring on pay back.. then my life would be infinitely worse than it is. I factor in payback time so that my life becomes as varied as possible. And rich and rewarding. (Tessa)

My daughter got married early August and I wanted to be involved as much as I could be. Spent the week leading up to the wedding pacing myself carefully - lots of preparatory rest

and delegated all the responsibilities. The day of the wedding was lovely, rested in the morning but then spent the afternoon and evening with the guests watching the festivities. 6 weeks later I am still struggling spending most of the day resting with severe back pain and feeling like I have the flu. That said I would do it again! (Kate)

When you live with an illness like this you soon learn that you can't do what you want to do. But when you do function, or when you do something normal, like meeting a friend for coffee, or doing some sort of course, or venturing into town, whatever it is, you do it, and it feels good, it feels normal, you feel a bit normal even, but it comes at a price. The payback is part of life with this illness. You do stuff, but you pay for it, it's just the way it is, which is quite depressing, but you have to accept it. (Olivia)

I was invited out for dinner Saturday night, I knew it was a bit ambitious of me to go as normally in bed at 7pm on a good day. I wanted to go and so want my life to resemble anything that's 'normal'. I knew that I would suffer with payback and boy have I but for just those few hours it felt good to be out, even if I struggled and I guess it sort of for those few hours remembered the feeling prior to ME. It's always hard weighing up the pros and cons, going out for just a few hours and then really bad payback all week but I will always push myself just to get that glimpse of 'normality' and while I'm struggling and unable to do anything all week at least I can look back and say that those few hours out made me feel alive if that makes sense. X (Chloe)

It is evident in the above quotes that despite the struggle and the pay back, Tessa, Kate, Olivia, and Chloe express a need to participate, a need to experience life, and self; normality. Although the earlier quotes pertaining to the struggle of CFS/ME reflected a compromised quality of life and well-being in CFS/ME due to the consequence of participation, here the payback appears to be justified by participants as the reward of participation for life and self take precedence in their consideration of the balancing act that is a life with chronic illness; a life with CFS/ME.

The following quotes provide further insight into how participants learn to live with CFS/ME, an experience of learning which is underpinned by an acceptance of payback, and the reality of learning how to live as well as possible with CFS/ME by finding out what works and what does not work:

Since being ill life has changed in so many ways as I learned to look after myself better, listen to my body, handle my anxiety and understand that every action I take I know there will be a health consequence. (Michelle)

I knew today when I woke feeling rough that going to work for 5 hours would probably make me feel worse physically. But mentally I feel much better - I've managed to get out, see colleagues and help others in my job as an NHS receptionist. I know from past experience that if I'd stayed home, I'd have possibly felt moderately better physically but it would have triggered onset of low mood and anxiety about going outside/money/the future/ME 'winning'. I

guess the key is knowing when it's going to be bearable if you push yourself and if it's not. Like Tessa I also factor in payback time which helps. This is all when my ME is mild - touch wood it's the best it's been for a long time. (Anna Marie)

I tend to do something see how much pay back i get as to whether i do it again. (Dark Knight)
(Conversation data)

And in a subsequent conversation, Dark Knight added:

I find no-one understands M.E more than the sufferer. Some people think they do, others think whatever. Its a gamble, somethings will work, n that's great other things will knock you back, bit like that grand old duke of york. Then theres the fighters who no matter what wont let this thing grab hold any more than it has...

The thing about ME is that after you come to terms with it and learn to manage it, you never do anything casually again. Before agreeing to see a friend or go shopping, you think through what else you have on. If you accept something big, like a weekend away, then you look at your calendar for the next two weeks and make sure there'll be lots of time to rest afterwards. If you find yourself getting excited and using energy, you pull yourself back because you know you'll pay for that – adrenalin helps you in the moment but it's a bastard later. (Eleanor)

Learning how to manage a life with CFS/ME is beneficial to coping and quality of life as the consequences, which are unavoidable in this chronic illness, are at least managed and negotiated. However, as consequences are unavoidable in CFS/ME, the line between knowing what you should and should not do can become blurred, particularly when the desire to participate overwhelms:

I am awful for pushing myself if its something I really want to do. For example, last Saturday it was the local fete on the village green. I knew I would suffer by going, but went anyway. Did way too much walking, even at a snails pace with the support of a walking stick. There were loads of people, causing bearable visual sensory overload, and a rock band creating auditory overload. I ended up hardly able to put a foot in front of me and experiencing that horrible sense of confusion that we get. Sunday was spent in bed. But it was still worth going. I'll not let the illness be master of my life, so I put two fingers up to it and accept the inevitable payback for my bloody mindedness. I'm still not back to pre-fete levels of functioning as I've had my monthly ME support group meeting and a trip to the opticians this week. Life being life keeps coming at you even though you are ill, so over-doing it is unavoidable or at least a Hobsons choice. (Dan)

I only go out to the supermarket or lunch once a week for a couple of hours. It takes me the rest of the week to recover as I feel, weak and exhausted. (Louisa)

Sometimes we do things as we have no choice, or just to have a little bit of relief and enjoyment, to feel alive and above all to feel that there is a reason to live! Payback is expected but we are willing to suffer this for a small amount of pleasure gained. (Ros)

The delayed effect of effort (physical, cognitive, emotional, social) complicates payback. I ended up having to think 'what have I done already/what do I need to do?' as my pacing evolved, a shifting focus on a few days either side the day in question. It became quite natural in the end. I learned, through good advice, to keep as much as I could to the 70% rule (i.e. always leaving something in reserve). This might have been how I've ended up recovering so slowly, but I have recovered steadily. I have not been boom and bust. Although I did have a few times when I knew there would be payback, but these were big things and me insisting on having a life. I was bridesmaid for a cousin and that took 6 months to get over. More recently I have attended training days or conferences away and if too much else is going on too (mental, physical emotional overload), I have just not been right for months. Payback can still happen, but I can still function now. A big difference. The other thing that came to mind is how people see us when we are having a better day. They don't see the 'behind the scenes': the resting beforehand and payback symptoms after. Sorry it's a bit more than a couple of lines, but you always ask good questions x (Mary)

I think pushing is inevitable if you have caring responsibilities. I try not to push too often without knowing there's rest time to follow. It's a dance, where you need to anticipate rather than wait for the next move. I'm paying back for an exhausting month moving house, with a backslide into how I was a while back. I'm confident it's temporary, cause I understand why it happened and know how to recover I suppose it's a bit like borrowing money (or spoons!) you know you'll pay back with interest but sometimes it's a necessity... (Katie)

Although participants acknowledge that participation comes at a price here, sometimes participants express that they have no choice but to participate, whilst sometimes the desire and need to participate, in essence takes priority over consequence management. Participants know they will pay for it, but that is not going to stop them. Beliefs such as this, expecting payback, may be construed as negative, but payback and consequences are indicative of the reality of CFS/ME, central to which is the aforementioned struggle. If you are to participate in CFS/ME, if you are to negotiate an identity, if you are to experience 'life', you have to be prepared to pay for it which is a very different identity to those who can unthinkingly participate in anything they want to without fear of consequence. And, yes, this constant struggle to triumph over adversity can negate positivity in CFS/ME.

Chapter summary

The provisional introduction to participants initially considered participation in CFS/ME through the narrow lens of the fractured TST data which presented a lived experience of participation; identity in CFS/ME that lacked context. From the TST snapshot emerged a seemingly positive framework within which to consider the potential for 'wellness in CFS/ME'. However, on exploring wellness in CFS/ME through experiences of participation; identity, it soon became apparent that participation; identity in CFS/ME was often aligned with struggle which reaffirmed that a snapshot approach to the lived experience of CFS/ME was not preferable here. This undercurrent of struggle peppered participants' stories, conversely stories which nonetheless reflected a commitment and determination to

participation despite their lived experience of chronic illness: CFS/ME. This determination and commitment was indicative of an unspoken awareness of participants' need for both purpose and meaning and as such through practice as learning participants endeavoured to negotiate '*payback*'. Participants' negotiation of payback evolved as problematic when their desire and need to participate overwhelmed their potential to manage the consequences of participation: payback. It appeared that participants were stuck between a rock and a hard place, the reality of which being an almost no win situation.

The provisional introduction to participants has provided an insight into participants, an insight which has laid the foundation for the following theme which will explore further and in more detail, the struggle of positivity in CFS/ME when lives and selves are unrecognisable.

CHAPTER EIGHT (C8)

Losing on the swings and the roundabouts

Inherent in the lived experience of CFS/ME was often the reality of '*multiple losses and no gain*'. Personal loss reverberated within participants' accounts of their lived experience of CFS/ME. The grief for life and self lost to CFS/ME was apparent throughout which was indicative of the struggle of the self in chronic illness; CFS/ME, which reflects the struggle of participation and the reality of non-participation for participants.

As discussed in C1, according to Devins (1994), the illness intrusiveness concept captures the disruption to life caused by chronic illness which emerges as the psychosocial impact of chronic illness such as compromised functioning in domains and activities which were once of value to life and self. The consequence of no longer being able to function in valued domains and activities, according to Devins (1994) is indicative of a reduction in meaning and gratification which undermines quality of life and well being in chronic illness. The work of Devins (1994) reaffirmed the potential application of CoP; a re-conceptualisation, to the lived experience of chronic illness, particularly the lived experience of identity in chronic illness. Wenger (1998) argues that the underlying mechanism of identity is participation, and aligned with this fundamental assumption are participant accounts of shifting identities in chronic illness; illness intrusiveness. Experiences of jeopardised participation within various communities, roles, and activities ripple under the surface of participants' experience of a lost identity in CFS/ME.

The first theme: *Introduction to participants*, presented a snapshot of the TST activity: part one. In view to the layering of participants' data, the full TST data for a number of participants will be presented here in tabular form (see tables 1-7) as to enable the context that was lacking in the snapshot, and an insight into participants' shifting identities which provides further insight into their challenge to find the positives in CFS/ME:

Table 2: *Who I am now is not who I used to be* (Kate)

KATE	I AM	I WAS	I WOULD LIKE TO BE
Physical characteristics	5'7" well covered (was muscular), blonde, blue eyed	muscular, healthy, rosy cheeked, attractive	no longer pale with rings under my eyes, toned and less flabby, have strong fungal free nails, lighter (weight)
Roles	mother, wife, GP, leader	mother of 4 active teenage girls, worked part time as a GP in a deprived semi-rural practice, worked in the wider health economy investigating patient safety concerns and GP performance,	would still like a role in medicine but perhaps working for people with ME, want to be an active and fun Grandma sharing with grandchildren the fun I had with my

		helped my husband with our smallholding keeping sheep, pigs, ducks and chickens, riding horses and walking the dogs	children (no grandchildren yet), want to be a supportive wife enjoying the last 10 years of work with my husband and then an active retirement, want to be an advocate for patients struggling with the faceless beurocracy of modern medicine.
Emotions	optimistic, pragmatic, accepting, used to be dynamic	I was a high achiever, motivated, optimistic, forward looking, a doer rather than being	
Activities	work as GP, run smallholding, support 4 daughters, local leader for patient safety	I worked hard, was actively involved in my children's activities including competitive swimming, show jumping, music, drama, hockey and running. I enjoyed regular long walks with the dogs and swam 3 x a week. Whatever I got involved in I would actively participate	want to be able to go on long hikes or cycle rides, wish to get back to drama and singing. Really would love to go skiing again. Would like to be able to socialise with large groups of people.
Hopes and fears	hope to be able to use what I have learnt with this illness to help others. Hope to be actively involved in my children's futures. Fear that ME symptoms will get worse and prevent me from being involved in life.	I was hoping to increase my influence in patient safety, I was training as an investigator and had taken on the role of responsible officer in Somerset, re validating GPs. I was hoping to continue my excellent relationship with my children and their partners. I was hoping that as the girls left home my husband and I would be able to try. My greatest fear was that something would happen to hurt members of my family	my main hope is that this illness does not get worse - when I read about people with severe ME it really worries me, my second hope is that my health will improve and that I will be able to make the most of all that I have learnt in my life.

The shift in Kate's physical characteristics shows that there has been a shift in Kate's appearance and one that represents the physical impact of CFS/ME.

Kate lists her current roles as mother, wife, GP, and leader and her previous roles as mother, GP, and wife. Notably Kate gave much more detail about her previous roles even though they were listed as

the same which perhaps reflects that she previously participated more fully in such roles. Nonetheless, Wenger (1998) would suggest that through such sustained roles, Kate's identity of participation would be underpinned by a sense of identification and belonging which would contribute towards a nurtured identity in chronic illness for Kate.

Despite presenting a currently nurtured identity, when contemplating the roles she would like in the future, Kate expresses a desire for an active life within which familial roles are foregrounded. Kate acknowledges that she would like to be a supportive wife, which perhaps indicates that CFS/ME may currently limit the support she can give her husband and in so doing suggests that the familial role of wife for Kate has been compromised by CFS/ME as she can no longer fully participate in the practices of that role.

Kate's listed emotions allowed a transparent insight into Kate's shifting identity. On acknowledging herself as optimistic and pragmatic, Kate says she 'used to be dynamic'. And reflecting upon her previous emotions, Kate says she was a high achiever, motivated, optimistic, forward looking, and a 'doer rather than being'. Kate knows who she is now, and Kate knows who she used to be. By acknowledging who Kate used to be, a 'doer rather than being' Kate's pre and post CFS/ME identity is illuminated to reveal a lost life and self in chronic illness which aligns with an overarching experience of both compromised participation and practice.

Not unlike Kate's current roles, the activities which are current to Kate are her work as a GP, the running of her and her husbands' smallholding, the supporting of their four daughters and her role as a local leader for patient safety. On reflecting upon her previous activities, similarly to roles, Kate gives much more detail about her previous activities, adding a depth of insight into her work, family life, and hobbies. Kate says that whatever she got involved in; she would actively participate, which again reflects Kate's previous identity which appears to be in conflict with her current identity. On considering future activities, Kate again expresses a desire for a fundamentally active life within which participation in a variety of activities is key, including participation in the social world which echoes the importance of practices but also participation in the social world (Wenger, 1998). On discussing weekends in a cfsid conversation, Kate gave an insight into the struggle of social participation, even within the CoP that is family:

Weekends now I stay at home. Sometimes my daughters come home for weekends - my youngest still lives at home. I try to listen to their news but often find it overwhelming.

(Conversation data)

Kate's hopes and fears make transparent the uncertainty surrounding the lived experience of CFS/ME which aligns with the work of Denny (2009) and Hoth et al. (2014). Kate currently fears that her symptoms of ME will get worse and prevent her from 'being involved in life', which is indicative of Wenger's (1998) participation concept and the relationship between life and self; if Kate is to 'be', Kate has to be able to 'do'. Kate's life has shrunk, and the fear of it shrinking even further, with there being even less potential for participation, is very real for Kate. As such, Kate's main hope for the

future is that her illness doesn't get worse as when she reads about people with severe ME, that really worries her. She also hopes that her health will improve as to enable her to make the most of all that she has learnt in her life. Here Kate indicates that she has learnt a lot in her life, but that currently she is not in a position to put her knowledge and skills to good use as she is unable to participate in the communities which enable her knowledge and skills to be practiced. Kate's inability to practice her skills and use her knowledge represents an interrupted trajectory as the path that Kate was on, is no longer the path that Kate is on (Wenger, 1998). As identity is participation, all that Kate has learnt equates to 'all that Kate used to be' which represents the dichotomy of Kate's pre and post CFS/ME life and self.

Table 3: *Who I am now am is not who I used to be* (Katie)

KATIE	I AM	I WAS	I WOULD LIKE TO BE
Physical characteristics	42, leanish and long but not very strong, greenyblueygreyyed, happy to flaunt the silver streaks in my hair.	Generally excellent physical health, taking my body for granted as you do when it works!	STRONG, pain free, vibrant, clear headed, able to trust my body and take it for granted again (though will not neglect it and will continue to nurture it)
Roles	mother, student, friend, laptop campaigner	sometime carer of terminally ill friend, conscientious employee and manager, faithful girlfriend, sometimes hot single girl with enough suitors to make me feel I could choose, indie kid who loved to dance	renewed in this relationship or in a brand new one, mother still, nutritional therapist in practice rather than training, friend at a hub of friends, inspiration to others
Emotions	hope, frustration, anger, love	Anxious, always a worrier, sometimes down sometimes lonely, but quick to smile, slow to anger, ALWAYS found the silver lining and an eternal optimist.	serene, contented, laughing a lot, confident, in love
Activities	MSc in Nutritional Therapy, mothering and domestics, singing and dancing, being in nature	being with friends, usually in pubs or for meals at home or out, gigs, learning to play guitar, doing DIY (a LOT), listening, singing and dancing to music. Career woman always learning and taking on new things, doing really well. But struggled in 3 long term relationships	nurturing, learning, yoga ing, eating whatever I want, having lovely sex, singing
Hopes and fears	hope to get strong vibrant	I wanted to settle	hope to feel better

	health, and to find peace in my life and know its the life i should be living, fears are of being trapped because of my illness and fear of spoiling the lives of those who matter most because of it	down and maybe have a family but was worried that I would get bored of my partner, feel claustrophobic. That happened 3 times! Not the getting bored but the worrying about it. Which sort of becomes self fulfilling. I found work beginning to be a real strain in my late 20 s early 30s, some days only thing that got me out of bed was the thought that if I didn't today it'd be even harder tomorrow, so forced myself to keep going	than ever and feel like I've arrived somewhere and can stop searching. Fear that I never will, that I will be always looking for where I'm supposed to be / who with / what doing. Fear that my illness will trap me in a situation that makes me sicker and I won't be able to get free. Hope this will be the year I set myself free.
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Katie's relationship with her body has been affected by CFS/ME as her body is not the body it used to be and as a result Katie is no longer able to trust her body, which is representative of the physical hit of CFS/ME which takes away a lot of what was once familiar and trustworthy. Katie's inability to participate in life as she once had is indicative of a less reliable body and unfamiliar self in CFS/ME.

Katie lists her current roles as mother, student, friend, and laptop campaigner and her previous roles as sometimes carer of terminally ill friend, conscientious employee and manager, faithful girlfriend, sometimes hot single girl, and an indie kid who loved to dance. There has been a shift here in Katie's roles and on considering the future, Katie says she would like to be renewed in her current relationship, or in a brand new one, a mother still, and a nutritional therapist in practice rather than training. Although there has been a shift in Katie's lived experience of participation, Katie continues to participate meaningfully. As such it would appear Katie's current identity is one defined by participation and ambition as opposed to one defined by illness, a privilege which reflects the spectrum of CFS/ME; mild, moderate, and acute. The following quote elaborates upon Katie's desire to be a nutritional therapist in practice rather than training:

Study is hard because of brain fog and because I spend so much time researching my illness and trying to get well. This means it's taking me a very long time to qualify so that I can work.
(Conversation data)

Due to Katie's CFS/ME, although she is able to train as a nutritional therapist, it is taking her a long time to qualify which represents a compromised trajectory. She would like to work, but her trajectory is a slower trajectory than she would like due to her symptoms of CFS/ME and the time she invests in researching CFS/ME, which perhaps reflects the scepticism surrounding the illness and the subsequent lack of investment which in part renders sufferers feeling responsible for their own destiny (eg. Chew-Graham et al. 2010). Katie would like to be a friend at a hub of friends which highlights the

relationship between a connection to others and identity as described by Wenger (1998), whilst also suggesting she would like to be an inspiration to others which reflects Wenger's (1998) purpose and meaning in participation; identity concepts.

Katie's current activities include an MSc in Nutritional Therapy, mothering and domestics. Similarly to Kate, the 'mothering and domestics' would enable a sense of both identification and belonging in the CoP that is family for Katie (Wenger, 1998) which is a powerful source of identity (eg. Behari, Srivastava and Pandey, 2005; Townsend, Wyke and Hunt, 2006). Similarly to Katie's roles, there is much more detail in her description of her previous activities in contrast to her current activities which reflects the narrowing of life and self in CFS/ME (eg. Ware, 1999; Asbring, 2001; Clarke and James, 2003). On looking to the future, Katie would like to be nurturing, learning, doing yoga, eating whatever she would like, having lovely sex and singing. There is a shift here from her previous activities, and as such Katie does not appear to want to return to her previous activities, instead prioritising different activities (eg. Clarke and James, 2003; Whitehead, 2006) which reflects the practice as learning concept (Wenger, 1998) as Katie appears to be negotiating how to live well with CFS/ME which involved a re-evaluation of both life and self as to enable quality of life and well-being in chronic illness through negotiated participation (eg. Dickson, Knussen and Flowers, 2007; Edwards, Thompson and Blair, 2007).

Katie's current hopes and fears include hoping to get strong vibrant health, which makes transparent the uncertainty in CFS/ME (Denny, 2009; Hoth et al. 2014), and to find peace in her life whilst knowing it's the life she should be living, which is indicative of an awareness of her interrupted and potentially altered trajectory; will I be able to live the life that I was supposed and expected to live? She fears being trapped by CFS/ME and spoiling the lives of those who matter most because of it. Her future hopes and fears again foreground improved health and a desire to 'find her fit' in the world whilst living in fear of being trapped by CFS/ME in a situation that compounds her illness. Wenger (1998) would argue in order to 'find one's fit in the world' one has to actively engage in practice with others, which is not synonymous with being 'trapped' and as such, isolated by CFS/ME, but this year (2015), Katie hopes to be able to set herself free.

Table 4: *Who I am now is not who I used to be* (Louisa)

LOUISA	I AM	I WAS	I WOULD LIKE TO BE
Physical characteristics	mousy hair, but dyed chestnut brown, 5ft 4in, green eyes, weigh more than I should.	At least 2 stone lighter.	Thinner
Roles	wife, mother, daughter, student artist, friend	Mother to 3 kids. Wife. Daughter. Good friend. Reflexologist and reflexology lecturer at Derby university. Prior to that a development worker and debt adviser at CAB. But still	Better wife, mother, daughter, friend

		had mild symptoms at this time.	
Emotions	loss of emotions due to tablets and depression, more sad than happy.	Content, laid back. With bouts of depression at long intervals.	To have more confidence. To have more contentment and to have some happy moods.
Activities	Very reduced, go to uni 3 half days per week, study at home and lots of sleep and rest. Take mum shopping and do my own. Some cooking and washing but no cleaning or ironing. Hardly anything else.	Squash. Gym. Singing in group. Out with friends.	To be able to work in the jobs I have trained for. Have a social life. Do more activities
Hopes and fears	I hope that I will get better but fear that I will not as I have been ill for far too long. Just have to manage it	None really just living in the present. Wishing I was more active	Hopes and fears. For better health and happiness. Fear that its never going to get any better. That life will be miserable if I cannot manage this illness. That my marriage will break down as a result of a lack of intimacy.

Familial roles are foregrounded in Louisa's current roles, for example, wife, mother, and daughter which reflects the importance of such familial roles for identity through participation, identification, and belonging in chronic illness (Wenger 1998). She also lists being a student artist and a friend, which again are roles that are not defined by chronic illness, and that are enabling of identity through participation. Louisa's previous roles are listed as mother to 3 kids, wife, daughter, and a 'good' friend. Louisa was a reflexologist and a reflexology lecturer prior to which she used to be a development worker and debt advisor. The shift in Louisa's roles depicts a narrowing of life and self (eg. Ware, 1999; Asbring, 2001; Clarke and James, 2003), however the roles she would like for herself in the future reflect a certain degree of contentment as she wishes to be who she is now in terms of being a wife, mother daughter and friend, although she would like to be a 'better' wife, mother, daughter, and friend. The framing of future roles within a desire to be 'better' perhaps suggests that Louisa currently cannot fully participate in such roles in the way that she would like, or perhaps thinks she should which could represent the conflict between contentment and an interrupted and altered trajectory.

Louisa acknowledges that her activities are 'very reduced'. She goes to university three half days per week, she studies at home with lots of sleep and rest. She takes her Mum shopping (does her own shopping also) but her domestic duties are limited and Louisa says she hardly does anything else. It is clear from Louisa's description of her current activities that there has been a substantial shift in her life and self. Although unlike other participants, there is less information regarding Louisa's previous activities, the activities listed reflect the privilege of health such as playing squash, going to the gym, singing in a group and going out with friends. Louisa would like to be able to work in the jobs she has

trained for which foregrounds the reality of a trajectory that has been sabotaged by CFS/ME, she would like to have a social life, which reflects the importance of a connection to others in identity (Wenger, 1998) and do more activities, which suggests Louisa is content with her current roles, but less content with her current activities which are unable to compete with her previous activities as defined by her previous experience of health.

The lived uncertainty of CFS/ME features in Louisa's hopes and fears, both current and future. She hopes that she will get better but fears that she won't as she has been ill for 'far too long' and so thinks she will just have to manage it which requires acceptance of an interrupted trajectory being an altered trajectory. Management such as this is indicative of the practice as learning concept which is underpinned by an understanding that life and self are different and if one is to grow within this shift, acceptance is central to coping (Wenger, 1998). On looking to the future Louisa hopes for better health and happiness but fears it won't ever get any better. Despite being aware that CFS/ME is something that Louisa may just have to manage, she worries that life will be miserable if she cannot manage it.

Louisa worries that her marriage may break down due to a lack of intimacy. A concern such as this represents a compromised familial role. Louisa cannot be the wife she would like to be as she understands that part of being a wife is to be intimate. CFS/ME has compromised her ability to fulfil this part of her familial role and as such she worries that this could fracture her CoP that is family, a CoP that is currently central to Louisa's nurtured identity in CFS/ME.

Table 5: *Who I am now is not who I used to be* (Netty)

NETTY	I AM	I WAS	I WOULD LIKE TO BE
Physical characteristics	Overweight, 5ft 5, blonde curly hair, grey eyes, wear glasses,	Overweight, 5ft 5, blonde curly hair, grey eyes, wear glasses but wore contact lenses more, tanned. (kind of, but not pale like I am now)	Slimmer, back to wearing contact lenses more, spot free, less hair loss
Roles	Daughter, fiancé (near as dam wife after 13 yrs), friend, Mother (chief, cook, bottle washer, emotional supporter, nurse, carer, story teller, housemaid)	Daughter, student, fiancé (near as damn wife after 13 yrs), friend, Mother (chief, cook, bottle washer, emotional supporter, nurse, carer, story teller, housemaid)	Daughter, fiancé (near as damn wife after 13 yrs), friend, Mother (chief, cook, bottle washer, emotional supporter, nurse, carer, story teller, housemaid)
Emotions	Tired, scared, happy, anxious, worried	Anxious, happy, optimistic, stressed	Happy, less anxious,
Activities	Crocheting, knitting, talking to friends on fb, walking dog (on good days) play games with kids (board/card) Teaching Daughter	Studying to be a primary ed teacher, walking, going to park with kids, attending university. Going on holiday to Devon and	Swimming with children, do a craft fair with my crocheting and knitting, see friends, go walking without

	keyboard, housework, sleep	seeing friends	pain or exhaustion. Learn a language, be reading a lot again
Hopes and fears	Scared for children's future, hope that I can turn my crocheting into earning money, happy with my family. scared this illness may ruin my relationship. scared of falling asleep and something bad happening because I am unable to stay awake and not being the responsible adult I should be	Worried about passing uni and completing teaching practises, looking forward to finishing and becoming a teacher, earning more money and my children having a better future. Worried about stress and my workload on family life	That my ME will get worse, hope that it will improve as will my knees. Hope that I can lose weight. Fear that I won't lose weight. Fear that my children will hate me for being ill and it affecting their childhood. Hope the knowledge of ME is greater and that they never get it.

Netty is unique here as her current, previous, and future roles are identical apart from the fact that she used to be a student. This would suggest that Netty is content with her current roles: daughter, fiancé (near as damn wife after 13 years), friend, mother (chief cook, bottle washer, emotional supporter, nurse, carer, story teller, housemaid) as Netty has managed to sustain her previous roles which centre around the family which supports the work of, for example, Dickson, Knussen and Flowers (2007) and Edwards, Thompson and Blair (2007) who suggest that familial roles can enable a strong sense of identity in chronic illness.

According to Netty, on becoming ill:

The headaches have gotten progressively worse and I have been unable to get well enough to go back to the course, so now I will have to do other things. (Timeline activity)

Netty was unable to continue with her studies which represents an altered trajectory, meaning Netty had to find other ways to participate. Netty's current activities are crocheting, knitting, talking to friends on Facebook, walking the dog (on good days), and playing games with kids (board/card). She also says she is teaching her daughter how to play the keyboard, does housework, and sleeps. In contrast, Netty's previous activities included studying to be a primary education teacher, walking, going to the park with the kids, attending university, going on holiday to Devon, and seeing friends. On considering what activities she would like for the future she lists going swimming with her children, doing a craft fair with her crocheting and knitting, to see friends, and go walking without pain and exhaustion. It is likely that Netty's desire to do a craft fair is underpinned by a need for greater purpose and meaning (Wenger, 1998). Although having a hobby in chronic illness would enable a sense of purpose and meaning, having a hobby that could make money could compensate for a lack of traditional employment whilst also enhancing the lived experience of purpose and meaning for those whose life and self has been felled by chronic illness. Netty would also like to learn a language, and read a lot again, and the desire to read a lot again is a desire to return to her previous life and self as according to Netty:

I could read a book in a day, got the Twilight series for Christmas and read all four in the week between Christmas and New Year!" (Timeline activity)

Netty's current hopes and fears are familial which is perhaps not surprising considering Netty's roles and activities centre around her family. She is scared for her children's future; and provides further insight into her desire to do a craft fair on making the link between her fear for her children's' future and the fact that she hopes she can turn her crocheting into earning money. She admits that she is scared that CFS/ME will ruin her relationship, whilst also being scared of not being able to be the responsible adult that she should be and falling asleep and something and happening:

I am never left alone with my 5 and 10 yr old alone. Other half is there or my eldest is (12) as I can just fall asleep on the sofa and that is not safe. (Timeline activity)

Although Netty's previous, current and future roles were identical (aside from student) it is apparent here that Netty's role as a Mum and perhaps partner has been compromised by CFS/ME which is problematic for identity, particularly when a familial trajectory has been interrupted such as this. Netty became a Mum, Netty was a Mum, but now she can no longer fulfil that role, a role which has been linked to coping in chronic illness (eg. Townend et al. 2006). On looking to the future, Netty worries her illness will get worse, but hopes that it will improve which again reflects a lived uncertainty in CFS/ME. She also fears that her children will hate her for being ill and it affecting their childhood:

My kids do so much to help, they keep their own rooms clean and tidy, put their own washing away and change their bedding. They also help with filling and emptying washer and drier. (Timeline activity)

As Netty cannot fulfil her role as Mum, and due to the demands of her illness on her children she also worries that because of their affected childhood, they will grow to resent her. Netty's CoP that is family will have undergone a substantial shift during the progression of her illness as the joint enterprise, mutual engagement and shared repertoire of her family CoP will have been further casualties of CFS/ME. There will have been multiple shifts within Netty's CoP that is family as responsibilities had to be delegated, and new roles adjusted to. Fundamental shifts such as this equate to a transition that would have involved a period of practice as learning (Wenger, 1998) for all members of this community, including Netty who will have had to adjust to a new way of being within her familial CoP.

Table 6: *Who I am now is not who I used to be (Ros)*

ROS	I AM	I WAS	I WOULD LIKE TO BE
Physical characteristics	petite, auburn, slightly overweight, freckly	thin, fit, healthy, more auburn	thinner, fitter, healthier, younger
Roles	wife, mother, friend, daughter	daughter, mother, wife, activist	an employee, a famous writer, someone who makes a difference
Emotions	happy, relaxed, resigned, concerned	downtrodden, abused, loss of self worth, then	stress free, less anxious, content,

		freedom and happiness	satisfied.
Activities	writing poems, reading, playing boules, enjoying music	work, helping others, discovering new and exciting things, experimenting	see my friends, be reunited with family, have more freedom, be more active
Hopes and fears	hope that there is a cure for M.E. in my lifetime and it's not too late to get back to where I left off over ten years ago. Fear that I will die before I have a chance to do some of the things I used to love doing and can no longer do	Hoping to make a difference, hoping to start over, hoping to find love, fear of being on my own.	hope to recover my health in my lifetime, hope to see my Mum again and have a long chat with her, hope to once again put on my hiking boots and go for a long walk, hope that the cause of M.E. will be found and a cure and at long last I can say to all the doubters "I told you I was ill!"

The physical characteristics listed by Ros show that Ros would like to be how she used to be 'thin, fit, and healthy' with the addition of being 'younger' which represents the reality of the many years that Ros has lost to CFS/ME.

The roles Ros currently identifies with are wife, mother, friend and daughter. Ros used to be a daughter, mother, wife and activist. There is little change here aside from a change in order and the addition of 'activist' and loss of 'friend' which perhaps reflects a sustained identity in CFS/ME which is indicative of Wenger's (1998) identification and belonging concepts which have been harnessed through Ros's participation in mostly familial roles. On considering the roles she would like for herself in the future, Ros lists an employee. Ros's efforts to continue working are clear in the following quote which illuminates further Ros's desire to return to work and the relationship between employment and identity which reflects the work of Townsend, Wyke and Hunt (2006); Whittemore and Dixon,. (2008); Dennison et al. (2010); and, Hunt, Nikopoulou-Smyrni and Reynolds (2014):

I stayed off work for over 6 months and eventually I had a visit from personnel who wanted to discuss getting me back to work. I didn't see how I could manage the travelling to work and a full day at work. I didn't know what to do. I wasn't getting any better. I felt like I was in an impossible situation. In the end I took the decision to resign from my job. Looking back I now know that was the wrong thing to do. I then started to look at doing some temping work near to home. I started a job via an agency but I kept getting infections and needed to take so much time off. It was hardly surprising they told me not to come back. I tried a different job a few months later but that was no better. I wasn't facing up to reality and pushed myself to look for another full time job. I started a full time job right next to my house so I had only a few minutes' walk to work. I had at least eliminated the problem of travel. In the year I struggled to maintain this job I had so many infections and feeling unwell that I had to once again take lots of time off work. I was in danger of losing my job. I hadn't told my manager about my health

problems. In the end I was once again in a big relapse with lots of dizziness, pain and fatigue. I couldn't go back to work. (Timeline activity)

Ros was committed to employment, it appears to have been very important to her and as such her efforts to continue to work as presented in the quote above, align with the practice as learning concept (Wenger, 1998). On becoming ill, Ros could no longer function as she once had and as a result had to approach employment from a variety of angles in an attempt to find a way to continue working. Alas despite such valiant efforts, work was ultimately not possible for Ros.

Ros also says she would like to be a famous writer, and someone who makes a difference which again represents the practice as learning concept (Wenger, 1998) as Ros has accepted that her life and self are different and therefore her ambitions for life and self have had to fall within the parameters of a life with chronic illness: CFS/ME. Ros would 'like to make a difference' which is indicative of the scope of the purpose and meaning concepts of CoP theory. Not only does Ros aspire to have purpose and meaning in her private world through writing, but she also aspires to become a famous writer who makes a difference which is a purpose and meaning that transcends the private world to the wider world and in so doing would perhaps enable a greater sense of purpose and meaning for Ros in her lived experience of chronic illness.

Ros's current activities are mostly independent pursuits, for example writing poems, reading, and enjoying music although she does list playing boules which moreover requires social participation. The shift in Ros's identity is evident here as, Ros's previous activities were work, helping others, and more broadly speaking, discovering new and exciting things, and experimenting. And, on considering the future, Ros would like to see her friends, be reunited with family, have more freedom, and be more active. Ros foregrounds a desire to connect and reconnect as Ros would like to be able to see her friends, which according to Wenger (1998) is a connection to others that is instrumental in both the development of and sustaining of identities. Ros would also like to be reunited with her family, who have been less than supportive:

I've had and still have from some of my family total disbelief and refusal to accept or understand my illness. When I first became ill my parents told me to 'pull myself together and get back to work'. I no longer see them or have any communication with them. They have poisoned other members of the family with their malicious lies and words. It was many years before my brother would accept that I was ill. When he finally did he said that he accepted I was ill but didn't understand. I still don't know if my sister accepts my illness. My parents have said that I am no longer their daughter. They have said that they think it's disgraceful that I haven't worked for the last years. They have said it's all in my mind and that I am lazy!!!! (Conversation data)

It would appear that on becoming ill, the CoP of family, a CoP that engenders a strong source of identity through familial participation, practices, and roles, was unable to nurture Ros's identity due to the scepticism surrounding CFS/ME.

The desire to be more active reflects Ros's previous activities, such as work, and helping others, whilst a desire to have more freedom is aligned with her previous broad reaching activities regarding discovering new and exciting things, and experimenting, which reflects a desire to return to her previous life and self which is not indicative of a life with CFS/ME, something which echoes the work of Ware (1999); Asbring (2001), and Whitehead (2006).

Ros's hopes and fears are however indicative of a life with CFS/ME as uncertainty ripples. She currently hopes there is a cure for ME in her lifetime and it's not too late to get back to where she left off over ten years ago, which reaffirms her desire to return to her previous life and self and the reality of an interrupted and compromised trajectory in CFS/ME (Wenger, 1998). She fears that she will die before she has the chance to do some of the things that she used to love doing and can no longer do. What is evident here is an apparent grief for old life and self (eg. Ware, 1999; Asbring, 2001; Whitehead, 2006; Dickson, Knussen and Flowers, 2007; Edwards, Thompson and Blair, 2007) which presents a theme of dissatisfaction regarding the current constraints of life which do not allow Ros to do what she would like to do; Ros cannot be who Ros would like to be. In consideration of her future hopes, Ros hopes she can recover her health in her lifetime and see her Mum again. She also hopes she can once again put on her hiking boots and go for a long walk. She also reiterates that she hopes the cause of M.E will be found and a cure so that at long last she can say to all the doubters "*I told you I was ill!*", which reflects the relationship between the history of CFS/ME and the lived experience of the illness as defined by multifaceted scepticism and struggle.

Participants often strive to participate in their life with CFS/ME, but such participation is moreover a struggle due to the nature of their chronic illness. What appears to keep participants going in this struggle is an innate need for purpose and meaning; identity (Wenger, 1998). The full TST data serves to demonstrate that the participation in which participants' are enabled in CFS/ME is not always sufficient to negate the dissatisfaction in life embodied by participants as their participation is often a far cry from their previous experience of participation in life and self prior to the onset of CFS/ME. However, the following TST data serves to show that with the passage of time and improved health, it is possible for participants to 'move on' to a life that is not always overwhelmed by dissatisfaction:

Table 7: *Who I am now is not who I used to be* (Tessa)

TESSA	I AM	I WAS	I WOULD LIKE TO BE
Physical characteristics	curvy, blond, green eyes, 4 ft 11 and 3/4 inches...	small, compact, extremely strong, tough, short green hair	fit, walking up hills, going on gentle treks around the world. Flexible
Roles	Sister, 'Auntie' neighbour, good friend, occasional lover (not nearly enough imho) student, irreverent wit, mentor, group catalyst, tenacious supporter and encourager. But	Social Worker, Acrobat, Trapeze artist, Clown and Mime. Co -producer mof 3 Theatre companies.	Wife, Step mum to kids, Artist of beautifully reworked dresses, lingerie and corsets,

	above all else..Gobby	Animatronics performer and wrestler. Location Manager for Tv and Films	guesthouse Host in a warm country, owner of beautiful house and veg garden in the country
Emotions	anxious, upset, overwhelmed, sad, obsessive, angry, with gratitude, vaguely happy and occasionally joyful.	Personality type A. Unstoppable, happy, driven, fierce.	Happy, peaceful and less anxious. Resilient.
Activities	Student of textiles, seeing friends, gardening, Tv watching, resting, hopefully yoga and swimming in 2014, travel, exhibitions, making a home. host for Airbnb	travel, workshops, physical exercise, doing stuff	MA in Fashion and the Environment, Curator of my Mum's design work from the 30's, gardener, home maker, Artist making outRAGous lingerie for older women
Hopes and fears	I hope to marry a man whom I love and adore and live with him in a big house. I hope that there shall be minimal impact on my life by ME/CFS. I fear I shall never get rid of ME/CFS and that it will stop me climbing mountains.. however small they may be	I had hoped to be famous, have an Italian house with a big kitchen, to be financially well off. Fears: of becoming mundane, of being alone and old. No fears for the present as I thought I was invincible	That I shall still be humping my husband when I am 90. That I shall live in comfort and ease, that I shall have love around me. Fears: that I shall never get rid of ME and that is shall shorten my life

Similarly to other participants, there has been a shift in Tessa's physical characteristics, however if we look at the physical characteristics she would like to possess, on leading with 'fit' Tessa then goes on to list activities that such fitness would enable which makes transparent the relationship between physical characteristics and the physical being; doing.

Tessa identifies herself as having a variety of current roles. Foregrounded are the familial roles of sister, 'auntie' neighbour and occasional lover, whilst Tessa also identifies as a student. Her previous roles however, are quite different in nature which represents a substantial shift in identity for Tessa. Tessa was a social worker, an acrobat, a trapeze artist, and a clown and mime artist. She was a co-producer of 3 theatre companies, an animatronics performer and wrestler, whilst also being a location manager for TV and films. However, when considering what roles Tessa would like to embody in the future, Tessa reaffirms familial roles take precedence now as instead of a desire to return to her previous roles, Tessa says she would like to be a wife and a step mum. It would appear that through her lived experience of CFS/ME and arguably the practice as learning concept (Wenger, 1998), that Tessa has reflected upon what is important in life if a life with CFS/ME was to be as good as it could be; a life defined by quality and well-being. As such, indicative of the work of Dickson, Knussen and

Flowers (2007) and Edwards, Thompson and Blair (2007) Tessa's previous onus on work has been replaced by the priority of familial relationships and roles whilst also suggesting that she would like to be an artist of beautifully reworked dresses, lingerie and corsets, which aligns with her current role of student (textiles).

As above, the current activities for Tessa include being a student of textiles, seeing friends, gardening, TV watching, resting, and being an Airbnb host. The activities that were indicative of Tessa's previous life included travel, workshops, physical exercise, and 'doing stuff'. On looking to the future Tessa would like to do an MA in Fashion and the Environment, be a curator of her Mum's design work from the 30's, a gardener, homemaker and an artist making outrageous lingerie for older women. An innate desire and need for purpose and meaning through participation not only ripples under the surface of Tessa's current activities but also under the surface of the activities that she would like to realise in her future.

There has been an undeniable shift in Tessa's identity. Her capacity to participate in life as she once knew it was compromised by CFS/ME which forced her to find a new way to be in the world which reflects the work of Whitehead (2006); Edwards, Thompson and Blair (2007); and, Arroll and Howard, (2012), and it would appear that Tessa has been successful in this pursuit. She participates in a variety of roles and activities which according to Wenger (1998) would contribute to her sense of self and identity through participation, and a sense of self and identity which appears to transcend chronic illness. As such, the struggle for Tessa appears mostly historical. For example, on discussing her CFS/ME story:

I had always been fit and worked very hard I carried on until I literally drove myself into the ground, and I got something called ME. ME put simply is your harddrives gone or you're working on an empty battery and I carried on working, just feeling dreadful until basically my body stopped. ME is incredibly isolating, you're on your own most of the day, you can't have conversations with people, you're usually lying in a dark room. I got to a stage where I thought if this is always going to be so, what can I do? And what airbnb has enabled me to do is contribute, is meet people from all over the world who are on the whole really really interesting. I can do things at my own pace, I can have people when I choose, I don't have to worry about the financial future, being on my own and thinking how on earth can I be with this, to a situation where people come to me, and it gives me energy, and it inspires me. I've discovered a whole creative side to me. There was a time in my life when I was so lonely that the wind would whistle through me. I thought this is it, I'm never going to feel different from this, this will always be so and this will always be so is the biggest hurdle to get over, and I had that for many years, and I don't have that now. (With permission from Tessa, guided to, and taken from <https://airbnb.com/stories>)

Therefore, perhaps Tessa has come through the eye of the storm to a positive place in a life with CFS/ME as Tessa's life is one within which identity, quality of life, and well-being are transparent.

Tessa's hopes and fears do not fully transcend CFS/ME however, as lived uncertainty is apparent in Tessa's hopes and fears, both current and future. She currently hopes there will be minimal impact on her life by CFS/ME whilst living in fear that she will never get rid of CFS/ME and that it will prevent her from climbing mountains, however small they might be. And on considering future hopes and fears, she reiterates that she fears she will never get rid of CFS/ME and that it will shorten her life. Although Tessa appears to be living well with CFS/ME, her hopes and fears are harnessed by the reality of a life with chronic illness for Tessa as her hopes and fears represent an uncertain life and future which is not indicative of the privilege of unrestrained participation; health.

Table 8: *Who I am now is not who I used to be* (Mary)

MARY	I AM	I WAS	I WOULD LIKE TO BE
Physical characteristics	long brown hair, brown eyes, wear glasses, 5'6".	pale, weak, sound-and-light sensitive, using a wheelchair.	fitter, toned, half a stone lighter, stronger.
Roles	wife, daughter, student	an ME sufferer, a home tutored pupil, a house-bound person, cared for by my mum.	a Health Psychologist, a mum/aunt, a better friend/sister, part of my local community
Emotions	calm, hopeful, frustrated by living in slow motion, determined.	positive, grateful for what I could do, isolated, sad	vibrant, more focused, happier, more connected.
Activities	supporting (and in love with!) my husband, studying health psychology, walking along the seafront, enjoying contact with friends and family	resting in a dark room, reading/studying when I could, taken on trips out in the wheelchair, able to listen to audio books when I couldn't read	Able to go for longer walks, regularly practicing yoga, swimming, able to travel abroad with my husband.
Hopes and fears	I hope I can fulfil my potential, I hope my husband and I have a long, happy life together, I fear continued disappointment with life, I'm afraid of feeling a sense of emptiness in life without having children	I hoped I would get better, I feared never being in love, I hoped I would be able to study for a degree, I feared I would not have the kind of life I wanted	No hopes or fears, just trusting in life.

Mary's current roles are wife, daughter and student. Her previous roles were an ME sufferer, a home tutored pupil, and a house-bound person cared for by her Mum; Mary's health has improved meaning the insight Mary gives here into her lived experience of CFS/ME is mostly historical. Similarly to Louisa who expressed a wish to be a better wife, mother, daughter, and friend, on looking to the future, Mary would like to be a Health Psychologist, a mum/aunt, and a 'better' friend/sister. The following quotes give further insight into Mary's desire to be a better sister:

Things were difficult at home, I felt really bad for my brother and sister who were just two years younger. They would sometimes have to be quiet while I was resting in my dark room. It was awful not being able to be a proper big sister to them. (Private message)

I felt bad that my siblings were asked to be quiet with friends if I was particularly ill. I wanted to see my brother play football, I didn't want my sister to be the one having to push boundaries. (Private message)

Mary knew what it meant to be a big sister; however Mary was unable to follow the trajectory of a big sister as she was unable to participate fully in the role of 'big sister' which is something that she found difficult. An inability to participate fully in the role of 'big sister' is likely to have been experienced as a further crisis of identity in CFS/ME for Mary as when the crisis of identity moves beyond the individual to the roles of which they are unable to fulfil, the crisis of identity becomes layered and multidimensional. Mary suggests she would like to become part of her local community which resonates with the following quotes which demonstrate the importance of community for Mary:

I did have qol because I had family who loved and supported me, and I could take part in what everyone else was up to even if that just meant hearing about it; I had three friends from school who kept in touch with me, but mostly friends through Ayme and Tymes Trust, giving me a sense of community and not being alone in having ME. (Private message)

And Olivia, one thing you have said that has surprised me is your reluctance to engage with the ME community... I don't know how I could have hoped to have survived without others with the condition to light my way. (Conversation data)

I think having a label helps make it more manageable. It means we can all come together and offer each other support, even though each of us is affected differently. It was more being part of the ME community that helped me feel better than a diagnosis. I wasn't alone. The diagnosis was positive because it led to legitimisation through community. (Conversation data)

Wenger (1998) argues that participation within the communities to which we belong enables identity. Mary's identity was sabotaged by CFS/ME, but through a sustained commitment to community, Mary's experience of CFS/ME was reified, validated, and guided by the CFS/ME communities which enabled not only a sense of community but also identity, through participation.

Mary's current activities are listed as supporting (and in love with!) her husband, studying health psychology, walking along the seafront, and enjoying contact with friends and family. It is evident here that Mary's story is different to the majority of other participants as Mary has been able to recover from CFS/ME enough to negotiate a new life and self which is not necessarily governed by CFS/ME. Her current activities are not only enabling of identity, but also quality of life and well-being. In contrast, Mary's previous activities were resting in a dark room, and reading/studying when she could,

which are not synonymous with a life defined by quality or well-being. However, during the worst years Mary's education was important both to Mary and her parents:

But I think most of all my parents helped me to focus on what I could do instead of what I couldn't. They fought for my education. Tymes Trust provided expertise with that, getting me a SEN statement. (Private message)

Although I suggest that resting in a dark room, and reading/study when able are not synonymous with a life defined by quality or well-being, an education is of course synonymous with normality. Mary was therefore lucky to have parents who were invested in her education and therefore enabling of her education through negotiated participation within the CoP of family. Unlike Ros, Mary's familial CoP both nurtured and enabled her identity by shifting in response to her illness. The practice as learning concept (Wenger, 1998) is relevant here as due to CFS/ME Mary was unable to participate in her education as she once had, but through practice as learning, and an enabling familial CoP, Mary and her parents understood the kind of support necessary to enable Mary's education and in so doing, when much of life and self was becoming unfamiliar, as in the case of CFS/ME, Mary's identity of a pupil was in some way able to survive.

Mary also used to be taken on trips out in her wheelchair, and listened to audio books when she could not read. Although Mary's CFS/ME was severe, it appears Mary did negotiate participation; identity during those years. Mary did not have the opportunity to discuss these years at length here, but in another private message she did which provided a greater insight into how Mary negotiated her CFS/ME identity during the worst years:

My world reduced to the size of my room. Although I was never as ill as some people can get, that room became my sanctuary. It was a place I filled with things I loved. I had posters and postcards all over the walls - places I wanted to go one day. I felt my bedroom expressed my identity to me in a way that at that time I was unable to do myself.

For most of my teenage years, my bedroom was pretty much my world. It was a sanctuary in some ways, a safe space. Not that I was scared of the outside world. But there I could just be myself. I could express myself. I didn't really feel part of normal life.

I might not have been able to do all the things a teenager usually does, but that did not stop me enjoying possibilities and surrounding myself with images I liked. I was very lucky to have a loving family: my parents, my brother, and my sister. But during those years you need more. Those walls were in a way my friends.

In the above quotes it is evident that Mary knew who she was whilst being aware that she was unable to represent herself and her identity whilst shackled by CFS/ME and so she found other ways to express herself as to show the people around her that she was more than her illness, something which Mary reaffirmed in the following quote:

So my identity might not have been expressed so much with friends out in the world, through things like clothes or going to gigs, but I showed very clearly in my room who I was, who I could be, who I should be, who I would be. I remained very much an individual not defined by illness. I had personal preferences, some creativity, and a lot of interests in all sorts of things. My walls clearly demonstrated that. If I couldn't speak much, those walls spoke loud and clear, even if it was mostly to me and my family. It reminded us there was more to me than illness. (Private message)

Although Mary's identity was largely confined to the walls of her bedroom, her walls not only reflected her identity, but also the fruit of Mary's lived experience of purpose and meaning in CFS/ME. The choices she made in that room, the consideration behind her choices and the fine tuning of her displays gave Mary both purpose and meaning, and a purpose and meaning that was intertwined with hope for the future. Having hope, and looking to the future through a lens of positive change, appears to have contributed towards Mary's coping.

Mary suggests she would like to be able to go for longer walks (she currently walks, but she would like to walk more), to practice yoga regularly, to swim, and travel abroad with her husband. Her current hopes and fears are that she can fulfil her potential, and that she will have a long and happy life with her husband. Mary currently fears continued disappointment with life. Even though in better health, Mary is not able to adhere to the trajectory of full health and as such fears 'continued disappointment' as the reality for Mary is that she still cannot be and do in ways that she would if she was not residing within the aftermath of CFS/ME.

Mary also expresses a fear of feeling a sense of emptiness in life without having children which Mary previously acknowledged whilst in conversation with another participant:

I also struggle with the knowledge that I probably won't be a mum. (Conversation data)

Not all women can have children and therefore women with CFS/ME may also, through happenstance, be unable to have children, but moving the potential for infertility to one side, when a chronic illness such as CFS/ME prevents you from even trying to have children, this is a compromised and altered trajectory that is underpinned by injustice, which as above, is a difficult burden to bear.

Mary's previous hopes were that she would get better, which reflects the uncertainty of CFS/ME. She feared never being in love, and she hoped to be able to study for a degree whilst worrying she would not be able to have the kind of life she wanted which again reflects a compromised and altered trajectory as defined by an uncertain future. Mary suggests she no longer has any hopes or fears as she trusts in life, which perhaps suggests that through Mary's lived experience of chronic illness and improved health that Mary understands that life will be what life will be.

The TST data presented here serves to add depth to the story presented in C6, 'Basking in the glory of my evil'. Despite participants being very different people who were living a variety of lives prior to the onset of CFS/ME, the TST data illuminates their similarity; the commonality in their lived

experience of the illness, and the continuity of that lived experience. Participants had been ill from 4 to 34 years, but their journeys, their CFS/ME trajectories, reflect a continuity of experience; the never ending nightmare of non-participation in CFS/ME.

The reality of 'non-participation' for participants

The full TST data has provided a comprehensive insight into participants' shifting identities. Some participants such as Tessa and Mary have perhaps moreover moved beyond their struggle of identity in CFS/ME, whilst the majority continue to struggle with the reality of their shifting identities. According to CoP, identity shifts such as those presented throughout the current theme are central to the crisis of identity in chronic illness, and to understand identity shifts in chronic illness; it is experiences of non-participation that can allow the greatest insight. Looking at participants' crisis of identity in their lived experience of chronic illness, it was not what they could participate in, or the communities to which they continued to belong, but instead their crisis of identity was framed by what participants could no longer do and the communities within which they could no longer belong. Losses such as this reflect most powerfully the struggle of identity in chronic illness. As discussed in C2, CoP is participation focussed, and although non-participation is theorised in CoP, it relates to experiences of peripherality and marginality which do not fully capture the lived experience of identity in chronic illness. As such, an awareness and focus on non-participation is indicative of another attempt to move the theory forward. If thinking around the lived experience of identity in CFS/ME is to be revolutionised, the relationship between non-participation and the crisis of identity in chronic illness needs to be considered.

In an attempt to further illuminate the relationship between non-participation and the crisis of identity in CFS/ME for participants, data from another preliminary cfsid activity: the timeline activity will now be presented:

Data from Julia's timeline activity:

Very active and full life, had two children, various work to fit around family. Later qualified as humanistic counsellor and looking into teaching the course after graduation as well as private practice. I would cycle, walk, swim and be out most of the time, cinema, socializing, or creating and learning at home.

No longer working, at home mostly. Xxx

Julia suggests she had a very active and full life before the onset of CFS/ME which involved various communities, activities, and roles; purpose and meaning. Julia's life was aligned with a transparent trajectory, which was interrupted on becoming ill. Julia had been working towards a career, but Julia can no longer work and as such the past, present and future interact here in the reality of a lived experience of participation, to a lived experience of non-participation in which future participation appears unlikely. In contrast to a life which appears to have been defined by a connection to others, Julia now spends most of her time at home. Isolation such as this reflects the social hit of chronic

illness. From being a social being, Julia's life now lacks the social interaction that according to Wenger (1998) is central to identity. Wenger (1998) foregrounds the relationship between a connection to others and identity as it is through participation, community membership, identification, and belonging that an identity is enabled. Julia's shifting identity is therefore aligned with an inability to participate with familiar others in practices and communities which were once central to life and self. On facing a life of fractured trajectories, compromised participation, unfamiliarity, and a life with a considerable reduction in purpose and meaning, the fact that Julia's life is now mostly confined to the four walls of her home is something that is likely to compound the reality of not only a life, but also self lost to chronic illness: CFS/ME.

Data from Michelle's timeline activity:

I worked full-time as a clerical officer and receptionist at HRI. I worked hard and played hard. After work I trained in Thai Boxing 3 times a week, weight trained, went swimming and went out partying with my friends multiple times a week (I had more money than sense).

I was pretty much bed bound for 2 years but luckily I lived at home and my mum looked after me. I felt terrible guilt for being such a burden to her but I appreciated her care too. The pain was excruciating and I felt so ill I often wished not to be around anymore. I felt imprisoned in a body that wouldn't work, wracked with pain and the frustration of not being able to do anything or read anything... life has changed in so many ways.

According to Michelle, she worked hard and played hard. Her life was full and active. She participated in various communities and activities, which were the foundation of her identity (Wenger, 1998). She worked full time, and her hobbies appeared to fill her spare time prior to CFS/ME and as such there was much purpose and meaning in Michelle's life. Michelle's pre CFS/ME life is in stark contrast to Michelle's post CFS/ME life. Being bedbound and unable to 'do anything' resonates with the underpinning mechanism of identity being participation. Being unable to do anything was imprisoning for Michelle in what appears to be an unrecognisable life, and arguably self through an inability to rehearse the many facets of her identity within familiar communities and practices which were once intrinsic to Michelle's identity (Wenger, 1998). Non-participation in CFS/ME such as this is indicative of an experience of grief for a life and self lost to chronic illness. According to Wenger (1998), doing is being, and therefore as Michelle could no longer 'do', Michelle could no longer 'be'.

Data from Annie's timeline activity:

Had had no significant health problems as a child, and had a great stable upbringing. Had always been active, and played sports to a reasonable level. Eg county hockey. Had qualified as a primary school teacher specialising in Physical Education. Had a busy social life, holidays etc. Was teaching at a British School in the Netherlands

In 2001 forced to cut down to part time due to ME. 2002 had to stop teaching altogether, had 2 viruses in quick succession leading to very severe relapse. Have never been able to return

to work and have been told I now will never be strong enough to. Several years literally housebound and suffering severely.

Annie presents a healthy life prior to the onset of CFS/ME which included participation in a variety of communities and practices. Annie attempted to sustain her career by going part-time, which as discussed in C2 and C3 is not uncommon in chronic illness when life and self are assaulted, as there appears to be an innate instinct to try to hold onto whatever you can in an attempt to hold onto 'you' (e.g. Asbring, 2001; Whitehead, 2006). However, similarly to others with CFS/ME such as those presented by Clarke and James (2003), this was not sustainable. There has been a fundamental shift in Annie's trajectory, not only in terms of her teaching career, but also because Annie has been housebound and '*suffering severely*' for a number of years. Being housebound is not indicative of the privilege of participation in communities, roles, practices, and activities which are enabling of identity and as such according to CoP, Annie's sense of self and identity as previously expressed through various forms of participation would have been jeopardised by the reality of a life with chronic illness; a life without participation.

Data from Chloe's timeline activity:

I was diagnosed with Crohns disease at 16 and had an operation to remove part of the diseased bowel at 17 but then just got on with life. I trained as a hairdresser, had lots of friends and enjoyed going out socialising. Life went on and after a few years I starting working in a fashion shop which I loved and made friends with a lot of the staff.

I couldn't understand why I felt so rotten weeks after having the virus, I was too weak to get out of bed and even opening my eyes was painful. Suddenly my life stopped... I dont have a quality of life, Ive spent years housebound and bed bound unable to do the things I once took for granted.

Chloe's story begins with her Crohns disease, but then becomes one of participation, particularly social participation. According to CoP, we do not become who we are alone, it is through a connection to others that our potential to belong is enabled and belonging enables identity through mutual participation in various communities and practices. Chloe's life was stopped suddenly. She could no longer participate in the communities, roles and activities that were once central to her life and self. As a consequence of the severity of the hit of chronic illness, Chloe's quality of life became a further casualty of CFS/ME. Being housebound and bedbound is not indicative of participation but is indicative of non-participation and non-participation such as this is unlikely to interact with well-being. When non-participation is at the severe end of the spectrum such as this, when there is little purpose and meaning in life, a lack of belonging and opportunity for identification, life and self can often be profoundly compromised which renders one's identity vulnerable to the dichotomy of life and self as defined by the longed for glory of then and the painful horror of now.

A conversation about weekends provided further insight into participants' lived experience of loss in chronic illness and their pre and post CFS/ME lives which are synonymous with compromised participation:

Weekends are currently mostly sleep-filled for me. I guess it's sort of the sacrifice I make for having to work... Weekends used to be about seeing friends, making art and being sociable. I still try to see at least one friend over the weekend. (Anna Marie)

sleep sleep sleep and a little bit of eating in between. before i got ill i was never in the house at the weekends, i was always out visiting family and friends. (Catriona)

I agree with sleep. I've just started work again so sleep, Internet food shopping and thinking of employing a cleaner as too tired for housework. I try to see friends but always affects me for the following week. I'm trialling waking up at the same time at weekends as in the week and then relaxing all day. Before ill would do exercise and clubbing on weekends but no more xx (Jessica)

Before I was ill weekends were very busy 4 children involved in various sports so often swimming competitions where I announced, riding competitions (show jumping, xcountry or tetrathlons) where I was general groom, chauffeured and warmed up horses, watching hockey, netball or athletics depending on season and rehearsals for plays or pantomimes, otherwise working on the smallholding if I wasn't working out of hours shifts. Weekends now I stay at home. Sometimes my daughters come home for weekends - my youngest still lives at home. I try to listen to their news but often find it overwhelming. On good days I will wander into the garden to watch my husband working and last weekend I even attempted a roast! Unfortunately my timings were a bit out so soggy veg and undercooked lamb! I blame brain fog because I used to cook roasts regularly and didn't even have to think! (Kate)

It is evident here that when CFS/ME strikes, life and self are attacked. Participation is compromised and trajectories are interrupted. Life evolves into the polarity of 'before and after'. Life and self in chronic illness; CFS/ME can often be unrecognisable as life and self are lost within the uncharted territory of an illness for which there is no cure, no explanation, and a lack of participation, particularly social participation. Uncertainty such as this interacts with participants' futures and as such, futures in chronic illness; CFS/ME can often be misaligned with prior expectation:

I think the hardest thing for me was accepting I was so ill and that my life had to change and would not be the life I thought (and was expected) that I would have. (Laura)

I have decided not to pursue a relationship or have children because having those expectations was more frustrating. (Jessica)

I still have a sense of loss for what could have been if I had been well sometimes. (Mary)

Trajectories can be seen as a guiding light, or a path in life. We negotiate their beginning, but once engaged they can be relied upon for purpose and meaning. We look to the future and our trajectories reflect our potential to participate in various communities, activities, practices, and roles, but when trajectories are interrupted, as in the case of participants' lived experience of CFS/ME, they are faced with a future that is not the future they had expected for themselves and a life that is often peppered by voids:

...I feel like progress has stopped - everything is on hold - and maybe if i had 3 or 4 years of this the word 'void' would become more appropriate. The baby I will probably never now have might turn out to be the biggest void. (Katie)

Greatest void was just living a normal life.. 1st 4 years dominated by fear, loneliness, feeling appalling, seeing only the 4 corners of my home... minimal contact with others.. void of life. (Tessa)

I missed and still miss the routine of going to work, meeting people, seeing friends, talking with them every day, catching up with news of the weekend, talking about what was on the tv last night, talking about things in the news, having a laugh and a joke - the stuff of life. I felt like my life had come to an end with no purpose and no reason to get up every day. I was a single mum so had to make an effort for my daughter. Otherwise I don't know what I would have done. Like Tessa I felt alone, scared and wondered how I could cope. (Ros)

During the worst years, life was one big void, I literally couldn't do anything. My life was empty really and being housebound and detached from 'the real world', being left behind, that was just awful, psychologically it was really difficult. I just existed and hoped for better. (Olivia)

My void was having a normal life. My world reduced to the size of my room. (Mary)

My void was no longer being able to get out in the fresh air and countryside. I've always loved the outdoors, running, climbing, canoeing, camping. It was what made the everyday stuff bearable. Now, I can't even contemplate these activities. (Dan)

My biggest void was losing my identity. I was a doer, involved in anything and everything and constantly looking to do more, I too was involved in musical drama with my children, I had a stressful job I loved and was going places in the NHS hierarchy involved with quality and patient safety, I actively encouraged my children to be involved in various sports, I helped my husband with our smallholding, played skittles, swam, walked etc. All that stopped when I became ill and now I'm not sure who I am. (Kate)

I asked participants about any voids in their life as to enable their stories to reflect their reality of multiple losses. When chronic illness strikes, the hit of chronic illness, the physicality of it, the worry, and the suffering can overwhelm, but the lived experience of CFS/ME can be a life defined by grief. The issue of quality of life for participants was often bound by their inability to be who they used to be as they were unable to do what they used to do. They could no longer participate in the communities,

practices, and roles that once enveloped and encouraged their sense of self and identity as their lives had shrunk, which in turn caused a narrowing not only of life, but also self and identity. A narrowing such as this often appeared to coincide with a life not defined by living, but existing for participants, which was not indicative of a life defined by quality. On considering a life defined by existence, a conversation about quality of life in CFS/ME subsequently revealed the following:

Initially, my quality of life was particularly poor - I couldn't read, puzzle, watch TV or socialise. All basic pleasures were simply too much for my brain to cope with and my body to have the stamina to manage. My self worth was very low, with frequent thoughts of suicide. The whole thing was compounded and exacerbated by my inability to continue as the major family wage earner, and therefore needing State support. (Dan)

It is impossible to have a quality of life when you are so ill, rotting at home with little self worth, the horror of stuff such as bed sores, and being bathed by your Mum or 'cared' for by nurses who made you feel even more ashamed. Admittedly this was me at my worst, but even beyond these years, the suffering, the daily suffering, the battle of life with CFS/ME which makes you think 'if there was a switch to end this, I might'... these things are not the things of well-being. You're just existing, you can't do anything. Thinking about this is quite depressing. (Olivia)

When I first became ill I felt I had little quality of life; I felt extremely ill and spent the majority of my life in bed (for two years) and I was also acutely aware of the world passing me by. (Michelle)

*I don't think my quality of life is very good living with CFS/ME.....
Still feel I've lost so much - energy, physical fitness and strength - even though I never saw myself as a particularly fit person due to various aches and pains I had, but my work required me to be v active and pretty fit..... such a contrast to how I feel now - feeling physically challenged by the stairs up to the loo or getting achey and puffed-out after a few mins. sorting or hanging the laundry (inside rack)..... arms aching then up and into my body after washing a couple of pans/baking trays (not needing scrubbing).....
I used to work, mix with people every day and earn my own money - that has all gone..... I have no income now and our household income is low..... and I feel bad depending on my husband..... (Fiona) (Private message)*

In a subsequent conversation about life with CFS/ME, Fiona elaborated upon her struggle:

The positives are totally outweighed by the negatives..... for me losing my independence, having no income, unable to do so much that people take for granted and having no idea if there will be an improvement, feeling my creative switch is still off in my brain so really missing my former escape into that world as I had since being a child..... etc etc..... (Private message)

Knowing you are different and not knowing if you will ever be 'you' again is problematic for identity in CFS/ME as who you are now is not who you want to be and who you are now is governed by your inability to participate in all that was familiar; all that was 'you':

I was me on the inside, but I couldn't be me... So people said I was different, really quiet and shy, they just didn't get that I was trapped inside. I avoided thinking about how I would cope if I was going to be like this forever, which is actually quite difficult when you have no idea if you will ever be well again. The limbo can be unnerving, but I always had hope, I think it's how I coped, unless it was more denial? But, you've gotta do what you've gotta do. (Olivia)

Sometimes life with CFS/ME is defined by goals, goals which enable you to get closer to the person you want to be, the person you perhaps should have been but such goals are not always fruitful as Olivia and other participants discussed in a subsequent conversation:

I endured years of rehab, but in the end, I was only able to function at about 30%. I still didn't have a life, I had to face up to this perhaps being it, that all the years of hope had been in vain. I had to accept that this, this life might be my future, and I couldn't bare it. I did contemplate an escape route as I had tried so hard for so many years, because this life, this me, was not what I had been working towards. I couldn't bare to be in the world in this way, being an ambitious person who wanted so much more, oh it was awful, such sad desperate times for me. I felt I had done my time, served my sentence, I'd suffered enough and if this was going to be my life, then I didn't want it.

The burden of CFS/ME was a burden that appeared almost too difficult to bear for Olivia in the above quote. Evidence of hope was elusive, which is something that was touched upon by other participants:

I think it is impossible to have hope in an illness that is poorly recognised or acknowledged, is so life changing and where there is so little reliable information available about prognosis and proven treatments and the only people that appear to be offering help want to make money from you. (Kate)

Mary offers a similar insight into the lived experience of scepticism in CFS/ME:

I know I have talked about positive things like appreciation for what I have, love from family, etc. But having the stigma, having the uncertainty re prognosis, the truly unrelenting nature of it, even when supposedly better, is really really tough.

When the struggle of CFS/ME is aligned with uncertainty, a lack of investment, poor management, and scepticism, the capacity for hope in CFS/ME can evidently be compromised.

Chapter summary

Experiences of multiple losses and few gains rippled throughout the current theme. All the practices and communities that made participants who they were, were now often practices and communities that lived in the archive: *'my life and self before this'* which was compounded by the uncertainty surrounding CFS/ME as in CFS/ME there is no way of knowing if life will ever get better. The lived uncertainty of CFS/ME was illustrated by participants' expressions of hope and desire for more, whilst fearing CFS/ME was not an illness, but a life. The reality of shifting identities; a life in which you are no longer able to *'be you'* and a future that is so uncertain, is not a reality to be underestimated. On moving beyond the TST snapshot to participants' full TST data in context, the role of longitudinal data in the current study became increasingly transparent as it became evident that there is a complex relationship between participation and identity in CFS/ME which is not black and white or wholly positive for participants. Practice as learning (Wenger, 1998) enabled participants to negotiate their potential to participate in CFS/ME. However, despite their negotiated participation, their participation was often less fulfilling, defined by struggle, and moreover not indicative of their previous fulfilling experiences of participation; identity. As such, the TST data revealed that only when a new life and self had been enabled by improved health in CFS/ME, were participant accounts of shifting identities no longer overwhelmed by dissatisfaction.

The timeline activity and conversation data added another layer to participants' stories which demonstrated the fundamental role of non-participation in their lived experience of the crisis of identity in chronic illness: CFS/ME. The value of CoP: a re-conceptualisation was reaffirmed here on acknowledging that CoP needed to account for the relationship between the crisis of identity and non-participation in the lived experience of chronic illness: CFS/ME, a relationship that was not solely governed by experiences of peripherality and marginality, and one that allowed for the provisional consideration of the reality of CFS/ME; a no hope illness.

Hope in CFS/ME appeared problematic due to the lived uncertainty that often overwhelmed participants' stories, within which positives were few and far between. It would appear the current theme provided a provisional insight into the relationship between the lived uncertainty, problematic hope, limited positives in CFS/ME, and the history of CFS/ME as discussed in C1. On moving forward, as to provide further insight into the multifaceted struggle of participants in their lived experience of chronic illness, the following theme will transcend the affect of CFS/ME on the lives and therefore selves of participants to the distributed nature of chronic illness: CFS/ME, as underpinned by the history of the illness.

CHAPTER NINE (C9)

It's not just about me

We live in an individualised society. We may have support from others but in essence our lived experience of life and self is an individual experience. When, through chronic illness you realise you cannot do this alone, and how important other people are to you, the individualised society that you perhaps believed once served you and your independence, no longer does. The lived experience of chronic illness; CFS/ME is hugely distributed. Participants lived experience of CFS/ME was often underpinned by the history of CFS/ME as participants' stories often reflected experiences of scepticism and abandonment both in primary care and familiar communities such as those of family and friends. Chronic illness not only affects the individual diagnosed, but also everyone in their lives to a greater or lesser degree and participants' experiences clearly illuminate that some people in their lives have been exercised by CFS/ME and in so doing cannot and do not deal with it. This realises itself in a lack of support for and isolation of, participants, both in primary care, familiar communities and wider society. Participants were often exposed to profound hostility which ultimately appeared to silence them.

The current theme will begin with an insight into the relationship participants have with the name CFS as CFS remains prevalent; CFS continues to burden:

I've just had a meeting with an Occupational Health Doctor (high level of sick leave in my job). He told me that I can't use the term 'M.E' anymore and that I must use CFS instead. Personally I feel that the term 'Chronic Fatigue Syndrome' can be quite misleading (that there is only one symptom) and that it also sounds quite trivial... Also, this guy was unbelievably dismissive and quite rude. (Anna Marie)

I agree I prefer the term ME. Chronic fatigue does not even describe 1/10 of the symptoms we experience. (Kate)

I have always hated the term 'Chronic fatigue syndrome'... sounds so woosy and pathetic...'fatigue ' is such a vast understatement... (Tessa)

Unfortunately in France they only seem to know and recognise 'Le Syndrome de fatigue chronique'. CFS just sounds like I am just tired all the time. M.E. is so much more than that. The list of symptoms is very long. Anyway fatigue or tired are inappropriate words... I know what normal tired feels like and this is absolutely nothing like it. In fact if anything I just feel ill. (Ros)

I use the term ME because when I say chronic fatigue other people say "yes I'm tired too" but it's much more than that. (Louisa)

As discussed in C1, since 1969 ME has been classified by the World Health Organization (WHO, 1969) as a neurological disorder in the International Classification of Diseases (ICD) and in

consideration of the construction of CFS in the 1980's, CFS has been classified by the WHO as a mental and behavioural disorder since 1994 (WHO, 1994). In 2002 the Working Group for CFS/ME recommended the amalgamation of CFS and ME to pacify the ME community who were at odds with CFS. I have argued in C1 that although CFS/ME features heavily in the literature, in fact CFS appears central to many studies, not ME (or CFS/ME). The data would suggest the literature reflects the dominance of CFS and the psychosomatic construction of the illness within primary care.

It is evident that the dissatisfaction amongst the ME community which underpinned the recommendation of the Working Group for CFS/ME to amalgamate CFS and ME in 2002 remains prevalent and a source of conflict within the lived experience of CFS/ME. It would appear the psychosomatic construction of CFS does not enable understanding as according to participants the construction of CFS does not represent their lived experience of the illness. There is a relationship between a lack of understanding and compromised participation in CFS/ME as participating within communities, with people who do not understand your lived experience of chronic illness is arguably a different experience to participating within communities, and with people who share your understanding of CFS/ME. Therefore, being struck by chronic illness is a burden in itself, but when the construction of a chronic illness negates understanding and participation; identity, life becomes one of struggle and conflict for participants. Such conflict reflects the work of Chew-Graham (2010) as discussed in C1 as Chew-Graham (2010) highlighted the conflict between doctor and patient within primary care regarding the 'nature' of CFS/ME; psychological versus physical. As discussed in C2, the history and construction of CFS/ME reflects the reality of patriarchal medicine and the history of hysteria. Thus, when women present with a complex illness such as CFS/ME, an illness which cannot be seen under a microscope, medicine reliably relies on the history of women's illnesses to diffuse uncertainty within their discipline; community, whilst providing an explanation for the complex illness that is CFS/ME; the 'alleged' psychogenic disorder.

The lived experience of CFS/ME is often misaligned with the construction of the illness within primary care interactions within which the psychiatric and psychological models of the illness are foregrounded:

As things didn't improve I had more tests a few years later with the same result, everything negative, told I had CFS and given anti depressants, not sure which ones. (Louisa)

So in March 2011 I went to see the doctor and he said I was depressed and whacked me straight onto anti-depressants. (Rachel)

Since this time [original diagnosis] I have moved areas and moved doctor's surgeries twice. My experience with these places has been pretty dire. Some were disbelieving and constantly checking my bloods and making sure depression wasn't causing the problem. (Michelle)

I am aware that anti-depressants are prescribed for a variety of medical problems other than depression, for example, Amitriptyline is an anti-depressant which is prescribed for nerve pain (Serpell, 2013). However, the propensity of medicine to use depression as a diagnosis crutch whilst

treating those with CFS/ME within primary care only serves to support the psychosomatic construction of the illness which can be problematic when CFS/ME is overlooked. For example:

GP thought I had an 'unspecified anxiety disorder' although later found her notes had thought of ME/CFS but not addressed this. I was prescribed citalopram (antidepressant) to help with anxiety and sleep. (Julia) (Timeline activity)

It would appear Julia presented with symptoms of anxiety, so one could forgive her GP for considering an 'unspecified anxiety disorder'. However, Julia later elaborated further on the symptoms discussed with her GP:

I had described how tired I was all the time, low energy despite feeling hyperactive/vigilant with the anxiety. I was having memory difficulties too. (Private message)

It would appear Julia did present with symptoms of CFS/ME but such symptoms were overlooked within diagnosis which reflects the work of Bayliss et al. (2014) as discussed in C1 who asserted GP's can favour a diagnosis of depression over a diagnosis of CFS/ME, which is reaffirmed by Julia in the following quote:

I don't why she didn't talk to me about any possibility of CFS/ME she only wrote that in her notes that she'd thought of this but didn't think it was...although had not asked me to check any other symptoms that could have been associated with CFS/ME. (Private message)

Evidently medical scepticism does not encourage investment in CFS/ME, particularly when there is an opportunity to suggest the role of psychological dysfunction, something which is reified by the involvement of psychiatry and diagnoses of depression:

I spoke to a GP who thought I might be depressed (I was a bit and had some NHS counselling - felt a bit better mentally but no other change) and another who was totally dismissive and put it down to the transition into the real world of work after being a student (I had been working about 7 years by then). (Katie)

After a few months of being housebound, I was pretty desperate, so I did get upset during an appointment with my GP. I was then referred to a psychiatrist. She came to see me at home. Asked me lots of questions and concluded I wasn't depressed, a danger to myself or the community. I was thankful she saw me for who I was, which was not someone who needed sectioning but it was bitter sweet as the referral alone suggested to the world that I might be crazy. (Olivia)

I first approached my GP when the fatigue was becoming a real problem -I couldn't understand why I felt constantly tired. My doctor sent me for sleep apnoea tests, but they proved it to be only mild. I was then referred to St Thomas's in London for sleep study tests - I had three in all plus an MRI scan of my brain. No problems showed up other than poor sleep

levels. I was then referred on to the psychiatric dept who put me through counselling and CBT. Absolute waste of time. (Dan) (Timeline activity)

Dan gave further insight into his experience of primary care on completing the timeline activity:

My GP had been treating my condition for as far back as I can remember as a psychiatric condition, ie all in my head.

Participant accounts of primary care interactions here reflect the scepticism that is underpinned by dominant patriarchal approach to medicine and the history of CFS/ME as without proof of physical illness, the mind of sufferers evolves as the 'go to'. Practices such as this did not enable participants in their lived experience of chronic illness, which appears to reflect the disabling community that is primary care within the lived experience of CFS/ME for participants. During a cfsid conversation, some participants tried to unpick their difficult primary care interactions. For example, according to Mary:

The problem in this country has been the power of psychiatric involvement. It has held things back.

And Kate, cfsid's resident GP who has CFS/ME, concurs:

...the general perception by medical profession and public is that people who feel tired all the time are unfit, lazy or psychologically affected - of course this does not apply to patients with ME but it is impossible for us not to take this perception on board...

Having an insider perspective such as Kate's was invaluable. Kate has been on both sides of the CFS/ME fence; clinician and sufferer which allowed an illuminated insight into the difficult primary care interactions which peppered the data. The data reaffirmed the relationship between the CoP that is patriarchal medicine, a CoP that is rigid in its approach to complex chronic illnesses which have a higher prevalence among women, and the reality of difficult and disabling primary care practices and interactions as discussed in C1.

The current theme has begun to demonstrate the problematic nature of CFS/ME within primary care in terms of the psychosomatic construction of the illness and associated ramifications for patients such as the prevalence of alternative psychosomatic diagnoses which support and reify the psychosomatic construction of the illness and in so doing undermines understanding and opportunities to participate within the comfort of an enabling community. Primary care has evolved as a disabling community for those presenting with CFS/ME as participants reliably faced hostility whilst having to negotiate the reification of alternative diagnoses such as depression which are in conflict with their lived experience of chronic illness: CFS/ME. Having explored in some detail the crisis of identity as experienced by participants in the previous two themes, the current theme has also begun to illuminate further the problematic nature of identity; participation in CFS/ME.

In C2 I rehearsed the value of CoP when looking at the lived experience of chronic illness. I explored the many concepts of CoP in some detail so as to illustrate the potential to apply a re-conceptualisation of CoP to the lived experience of chronic illness: CFS/ME. The psychosomatic construction of CFS is not enabling of participation; identity as the psychosomatic construction of CFS does not reflect the lived experience of CFS/ME for participants. Wenger (1998) foregrounds the role of communities of practice and community membership in identity. Participants have acquired membership in a community of practice which rests on the psychosomatic construction of the illness. According to Wenger (1998), through community membership we become who we are, and who we are is our identity. However, belonging to an 'alien' community, a community which does not represent you and your lived experience of illness is not a community that is enabling of participation; identity as community membership such as this lacks congruency and in essence is disabling. The mutual engagement, joint enterprise and shared repertoire of community membership, as discussed by Wenger (1998), is compromised here by contrasting beliefs; models of illness. Participants do not have a rite of passage to meaningful community membership which is enabling of participation; identity as their community membership is bound by a model of illness which does not reflect their lived experience of chronic illness. The conflict between the physical and the psychological in CFS/ME is a tug of war and when participation in primary care is akin to a tug of war, the tug of war is not an experience of meaning in CFS/ME which enables participation; identity, but an experience of meaning which harnesses peripherality and marginality. Participants may be positioned within a community, but not one within which they feel they belong and as such they are strangers in that community, strangers who reside on the periphery due to an inability to recognise themselves in others. For example, belonging whilst on the periphery of an ill fitting community which dictates a trajectory of marginality is understood to be a difficult challenge to overcome:

There is just this shadow hanging over you when you have CFS/ME, you feel so misunderstood, and alone. The doctors have their own beliefs and they are rigid to say the least and once there is a black mark against your name, it feels as if that's kind of it for you, if you know what I mean. You're labelled as one of them, but you're not. (Olivia)

Olivia understands the stigma surrounding CFS/ME, she understands the burden of doctors' beliefs when they are at odds with her own, something which she experiences as isolating, and arguably disabling. Olivia also believes that once you have been stereotyped as a particular type of person with a particular CFS/ME identity, there is almost no going back even though you cannot identify with the stereotype. Olivia is not alone in her struggle to identify with the psychosomatic construction of CFS/ME.

Dan considered his psychiatric referral, counselling and CBT to be an "*absolute waste of time*" as Dan did not appear to believe in the psychosomatic construction of CFS/ME:

Been dealt with since teenager as having a psychiatric problem... Sent to local CFS clinic, still treating it as psychological. Had to wait a year for an appointment, 9.30 am and a long bus

ride. Clinic nowhere near bus drop off points. Totally inadequate for MEeps ! STILL banging on about it being psychological.

However, the restricting trajectory of the psychosomatic construction of CFS/ME within primary care can also act as a barrier between patients and their own lived experience when the psychological model is deeply embedded in their own understanding of CFS/ME:

For example, according to Kate:

I had great difficulty persuading myself that I had ME and that it wasn't psychological. The very limited teaching I have had during the 30years I have been training and working said that this was a psychological condition and that the fatigue symptoms were related to de-conditioning! (Conversation data)

Kate elaborated further in a subsequent conversation:

I was not able to accept my illness and as I've said before so entrenched in the psychological model of the illness that I couldn't relate to my own experience.

Kate was not able to accept and relate to her own experience of illness as her understanding of the illness as gained through medical training was that CFS/ME was psychological. When personal beliefs and personal experience are misaligned, the identification concept as discussed in C2 (Wenger, 1998) is a challenge to negotiate. According to Wenger (1998) Kate's potential to identify as someone with CFS/ME would have been compromised by her beliefs (training) as the reification (the psychological model) associated with CFS/ME would have been in conflict with her personal experience of the illness which jeopardised the potential for meaningful participation; identity. In C2, Wenger's (1998) practice as meaning, practice as community, and practice as learning concepts were applied to patriarchal medicine in an attempt to unpick the dominant psychosomatic construction of CFS/ME. I argued patriarchal medicine was a generative mechanism and as such the negotiation of meaning, the community that is primary care, and medical training (learning) is governed by the strong arm of patriarchy, fore fathers, and tradition which compromises the potential for change. Thus, only when Kate became ill with CFS/ME was she in a position to reflect upon her prior beliefs of the illness and negotiate her CFS/ME identity that was not dictated by the practices of a disabling community; primary care.

As discussed in C1, according to Horton et al. (2010) some areas of professional practice continue to deny CFS/ME exists with some GP practices refusing referral to specialist services on the grounds of disbelief. Gilje et al. (2008) found disbelief to be a greater burden than the symptoms of CFS/ME and according to Hannon et al. (2012) patients were desperate to be believed and for their experience of illness to be validated. Such a longing for validation represents the isolation experienced within a community that fails to enable. I will begin with Jessica's story to illustrate the disbelief and hostility experienced by participants and how such experiences reflect a disabling community:

I moved to be closer to work but the GP practice does not believe in the condition. One GP said if I held a gun to your head would you go to work! (Jessica) (Timeline activity)

Jessica subsequently elaborated:

My current GP practice does not believe in acronyms including ME/CFS/IBS... I go to my GP on a regular basis when I can't work as exhausted and when I struggle with lots of viruses. They always do a blood test and then tell me to exercise more everyday to keep doing housework and 1 said that if I lived in the 3rd world I would have no choice but to work... I have recently completed a post graduate diploma and wanted to take my results to prove to my GP that I'm not lazy, as that's how they make me feel. I feel disgusted by the discrimination I get from my GP and how they can put people down. I have had glandular fever twice during the 10 years, but only because a nurse told me that was what it was, the GP does not admit that and always puts 'post viral malaise'. I think my practice believes ME is all psychological otherwise they would treat it more appropriately. (Conversation data)

And, in a subsequent conversation, Jessica gave an insight into the detrimental effect of disbelief:

I've had counselling in the past as struggled with 10 years of GPs at my practice and their disbelief about ME.

Jessica's story is one of profound scepticism. The hostility she has encountered in primary care reflects the role of Wenger's (1998) identification concept in CFS/ME as in CFS/ME you are often identified as 'mad not ill'. A practice such as this not only stigmatises but isolates participants within the disabling community of primary care which compromises their potential to participate alongside CFS/ME. When participants' experience of illness is bound by scepticism and aligned with the psychological model of the illness, their experience of illness is often one of abandonment. Jessica was not the only participant to have negative experiences pertaining to scepticism and disbelief:

My mum confirmed that the GP I had at the time did not believe in the diagnosis. We kind of fell into the ME world after the [Post Viral Fatigue Syndrome] PVFS diagnosis from a consultant microbiologist. I was offered no treatment or much advice... I had been ill for 5 years before getting the diagnosis,... Our surgery has not been great, and I did complain formally. One doctor said that ME was a useless diagnosis. This may be true, but it's hardly helpful. (Mary)

...I didn't feel that anyone believed me. I was passed from one consultant to another. I even questioned my sanity. I was in my teens at the time and I was told that I'd never work. (Erin)

i have been ill for over 5 years now with multiple complaints. for a long time i was back and forward at the doctors with fatigue and mysterious pains with no explanation, i thought i was going mad. after a while i stopped going to the doc's as i felt they thought i was a hypochondriac... I approached my doctor 5 months ago and the only reason he took me

seriously is that i demanded to see a specialist, after my first appointment i was diagnosed.
(Catriona)

I went to different Drs in my practise but felt I wasnt being taken seriously. My life had stopped, I was housebound/bed bound and just felt so alone and didnt know where to turn.
(Chloe) (Timeline activity)

Highs and lows epitomise Chloe's experiences within primary care as noted on completing the timeline activity:

8 years after becoming ill I saw a new female GP at my surgery who referred me to an ME consultant. Within minutes of the consultation he said it's obvious that you are suffering from ME, I felt so relieved and so happy that suddenly someone was listening... Meanwhile the new GP that was really understanding left the practice after a couple of years and since I've just seen unsympathetic Drs who have suggested exercise and going to the gym which left me really upset and frustrated.

CFS/ME is a chronic burden in itself, but the additional burden of scepticism and disbelief appeared to weigh heavy on participants. The following quotes provide an insight into 'belief; a relief' as although many participants had endured and continued to endure disbelief, some claimed the relief of belief which illuminates the potential for primary care to be an enabling community:

I have never pushed for a diagnosis of M.E/CFS even though my GP accepts that this is what I call it. I am just grateful to have him believe me that I am ill. (Laura)

My other GP (I saw 2) and the clinic at Seacroft Leeds were wonderful and the understanding and the fact that they BELIEVED you was reassuring as many others did not, which was and is very upsetting. (Michelle)

My gp is understanding but I had to go to tons of doctors before I found her. (Susie)

Felt upset, frustrated and helpless that doctors were dismissive. Wondered whether I was imagining things. About 4 or 5 years ago I finally got a GP who took things seriously... (Katie)

In C1 I referred to the work of Bowen et al. (2005) who acknowledged the relationship between doctors' personal experience of CFS/ME and belief in CFS/ME which resonated with Laura's story:

Somehow I finished uni and gained my degree. I went home barely able to function and saw my family dr. I was fortunate as he took one look at me and said that he knew what was wrong but only because a good friend of his, also a dr, had just been diagnosed with M.E. He told me that had I been to see him 6 months previously that he didn't believe in M.E...

The disbelief of Laura's GP is aligned with the personal beliefs of cfsid's resident GP:

I have just been to a meeting with approx 30 GPs some of which I knew. I find it very difficult explaining why I have been off work with 'ME or chronic fatigue, or whatever you want to call it....' I usually then say something like 'I never really understood or believed in ME but now I've realised how wrong I was. (Kate) (Conversation data)

Having previously offered an insight into why doctors are sceptical, in a subsequent conversation, Kate offered further insight into why GP's may lack understanding whilst also acknowledging how beneficial it can be to have a prior knowledge of the patient presenting with CFS/ME which echoed the experience of other participants:

I think one problem as far as GPs understanding is that many people before getting ME are very fit and well so that the GPs never see them. From the GPs perspective once the individual is ill they have a multitude of seemingly unconnected symptoms for which there is no diagnostic test so they struggle to see that it can be anything other than psychological, and they have no prior knowledge of the person healthy to compare to. At least in my case my GP knew me well as a friend and knew that my personality was not one to imagine things or exaggerate - in fact I think he believed in the physicality of my symptoms before I did, but then I have always been very hard on myself...

My experience with the medical profession: When I first became ill I had a very supportive GP who actually listened and believed me. She'd known me a long time and so saw the change in me instantly... (Michelle)

Due to my previous illnesses I was seeing my GP regularly so I suppose she could see the change in me..... and believed me..... she did some basic blood tests. Then she said she believed I had now got CFS..... (Fiona)

Being believed is a privilege in CFS/ME as the scepticism surrounding CFS/ME in primary care is underpinned by medical training which is bound by the psychosomatic construction of CFS/ME and the psychological model of the illness; patriarchal medicine. As discussed in C3, Clarke and James (2003) assert the contentious nature of CFS/ME does not breed legitimacy and as such those with CFS/ME are unable to adopt the legitimized sick role as they are often reified as suffering psychological dysfunction. A lack of legitimisation and sick identity such as this was found to coincide with feelings of loss as participants were separated from the roles which once defined them. To reiterate, Clarke and James (2003) did not theorise such experiences but CoP can. When your life and self are unrecognisable your identity is vulnerable as you are unable to participate in the communities, practices, activities, and roles which once underpinned your identity. Through chronic illness your life lacks purpose and meaning, which is exacerbated by a lack of legitimisation as you are unable to be who you once were and you are unable to draw upon a legitimate sick identity as you are constructed as a fraud by a disabling community; primary care. A lack of belief such as this contributes to experiences of peripherality and marginality within primary care and beyond as you are resigned to the shadows of disbelief (through a lack of proof) in a world that requires evidence to

support you and your claims. If belief in CFS/ME and the CFS/ME sufferer was achieved widely in primary care, and as such if primary care was to become an enabling community whose practices served the CFS/ME community, experiences of illegitimacy could be negated. As such, legitimising practices of primary care could help people with CFS/ME to negotiate a sick identity which could support their need to find a new way to be in the world through practice as learning (Wenger, 1998). Wenger (1998) suggests that the negotiation of meaning is a productive process and as such through practice as learning we learn who we are which enables us to negotiate a way of being in the world. It is through the negotiation of meaning and practice as learning that those with CFS/ME have the potential to learn how to live, not just exist, with chronic illness, but such negotiation of meaning and practice as learning is beholden to enabling communities within which positive CFS/ME identities are enabled and reified.

When an illness not only lacks legitimacy, but when a model of illness is also at odds with the lived experience of the illness, both participation and reification are fractured which compromises meaning, identity, and arguably coping. However, as discussed in C1, whether believed or disbelieved in primary care, medical training in CFS/ME is limited (Horton-Salway, 2007; Anderson, Maes and Berk, 2012; Chew-Graham, 2008) and therefore doctors are ill-equipped to deal with the complex illness even if they do believe in it:

My dr found another 'specialist' to send me to. I believe these people had an interest in chronic fatigue but that they really didn't know what to do and this second one I believe did it to earn more money. He told me to take cold baths - I found out later these should be supervised and for a few seconds - and I should exercise outside as the fresh air would do me good. I went for a run as that is what I believed him to mean. Somehow I made it home and was found collapsed on the doorstep. My dr was supportive but didn't know how to help.
(Laura)

Came back to England for summer holidays in 1993 (age 26) and picked up a gastro type of virus. Never seemed to recover to pre illness levels and began to struggle and have bouts of illness, especially after activity. Told by Doctor to keep doing stuff (I now know this to be awful advice!!) Blood tests were fine. In January 1995, insisted on being seen by another Doctor. Did this privately and following further tests was diagnosed with M.E - diagnosis took 18 months. (Annie)

I went with my Mum to see the doctor as I didn't see how it could be the flu. She hadn't got a clue. In fact she said "What do you expect me to do?". At that point I walked out in disgust and asked to change my doctor. (Ros) (Timeline activity)

And on completing the timeline activity, Ros explained:

After a year of being ill and getting worse instead of better I was glad to finally have a diagnosis. I was told at hospital (not even sure of the department) that I had Chronic Fatigue Syndrome. I was told that there was nothing they could do for me and only suggested that I

try graded exercise. I was ignorant back then and so tried to follow their advice. That was a mistake and only made me feel worse. I read all I could about CFS and found out it was originally called M.E. but my doctor said the name had changed.

Revisiting her story, Ros gave further insight into the costly nature of bad advice:

They explained that there was nothing they could do for me but suggested I go away and do graded exercise. I was relieved but ignorant. I trusted the doctors back then and tried to do graded exercise. It nearly killed me... (Conversation data)

The reality of patriarchal medicine and associated practices underpins the quotes above. Medical training, as governed by tradition, does not enable primary care workers to enable people with CFS/ME to negotiate their lived experience of chronic illness as a lack of training and understanding can evidently be costly when the advice given to patients is ultimately to their detriment. If people with CFS/ME are to be able to participate in both life and self, the negotiation of their chronic illness needs to enable participation, not exacerbate symptomatology and in so doing undermine the potential for participation; identity (Wenger, 1998).

The previous theme: *Losing on the swings and the roundabouts*, considered from the perspective of participants, the lived uncertainty of CFS/ME; a no hope illness, which in part reflected an unsuccessful practice; a lack of medical training. An unsuccessful practice such as this is evident above as the relationship between a lack of training, bad advice and poor management is illuminated. The current theme will now attempt to unpick and elaborate further upon participants' experience of lived uncertainty by initially drawing upon the work of Denny (2009).

According to Denny (2009), living with chronic illness engenders feelings of uncertainty surrounding diagnosis, symptoms and trajectories and such uncertainty is central to the lived experience of chronic illness. Hoth et al. (2014) discuss the uncertainty in illness theory which considers meaning making in chronic illness. According to this theory, uncertainty evolves cognitively as the lived experience of illness and associated meanings are problematic to negotiate, and thus in illness, uncertainty is a complex construct. Hoth et al. (2014) assert as Western culture is driven by predictability, uncertainty is repelling as uncertainty jeopardises previously established personal control. When personal control is jeopardised by uncertainty, research indicates more incidences of depression and anxiety in chronic illness, which aligns with a reduction in QoL (Mishel, 1984; Mischel, 1999; Bailey, Landerman and Barroso, 2009; Stewart et al. 2010; Keiko et al. 2012; Hoth, Wamboldt and Strand, 2013). Exacerbation of symptoms, as expressed by participants above, has also been linked to the lived uncertainty of chronic illness (Mishel, 1984; Mishel, 1999; Bailey, Landerman and Barroso, 2009; Stewart et al. 2010; Kim, Lee and Leeks, 2011; Keiko et al. 2012; Hoth, Wamboldt and Strand 2013) whilst social support has been flagged as a determinant in uncertainty (Mischel, 1990). Uncertainty in illness theory asserts social support enables comprehension. Through engaging, and participating with similar others, or others who understand your experience of chronic illness, one is able to familiarise with the illness which appears beneficial to coping (Mishel and Braden, 1987;

Mishel and Braden, 1988; Bennett, 1993; Sammarco, 2001; White and Frasure-Smith, 1995; Kang, Daly and Kim, 2004). To reiterate however, due to the contrasting models of CFS/ME, conflicting forms of reification, such as an over reliance on psychiatry and anti-depressants by primary care workers who are governed by the dominance of patriarchal approaches, social support through engaging and participating with similar and/or understanding others is often compromised in CFS/ME.

According to Wineman (1990), whereas social support can help to negotiate feelings of uncertainty, sometimes social contact, and once again arguably participation, can have an adverse effect when such social contact/participation is not experienced as supportive. The lack of investment in CFS/ME within primary care peppered participants' stories, which reflects the relationship between the lived uncertainty in CFS/ME and a lack of investment in CFS/ME which equates here to a lack of support within a disabling community. A lack of support such as this, according to Edwards, Thompson and Blair (2007) compromises coping. A complex illness such as CFS/ME requires support, support in coping, and adjustment, but the paucity of support for CFS/ME in primary care renders participants vulnerable to abandonment in illness which does little to serve their vulnerable identities:

The only way I was diagnosed was through studying my symptoms on my own. Glad to know what's wrong with me now. (Catriona)

I had tests and most came back normal, but they said I tested positive for anti bodies to glandular fever and diagnosed me with ME. No treatment given. (Louisa)

Did not really know what ME was, and was given no real advice on how to handle/ manage condition, nor was giving any treatment options. (Annie)

...The blood test normally comes back showing nothing and nothing further to do. This has been going on for 10 years, there is no consultant or anyone they can refer me to for accurate diagnosis on the NHS or privately. Most times I go to my GP I feel more depressed and hopeless afterwards... (Jessica)

I would say the diagnosis did not really help, since it did not lead to any specialised support, although it must have been a relief to know that what I had was not going to be life-threatening. (Mary)

Not sure entirely how I felt as just ended up at a dead end as previously stated that I got my diagnosis from the immunology department in November 2012 and there was no help available from this department... So all in all it took 2 years and 6 months to get any help. I suppose at the end of it at least I have a name to what I have. (Rachel)

I've had a very recent 'diagnosis' but not an equivocal one really. I feel relief that I can explain why I do all the weird things I do (diet, yoga, meditate etc), frustration that it's a 'by exclusion' diagnosis so doesn't really tell me anything to help me get well, concern I might be consigned to the 'we can't do anything for you now' bin by the NHS. (Katie)

I had every test the French health system had to offer but they finally said they didn't know what it was and gave up... My doctors are fine but I don't have much to do with them, I don't think the medical profession knows what to do and the one time I went to a chronic fatigue clinic, I thought the guy was patronising and stupid, so I never bothered going back. (Eleanor)

My GP was useless. Kept telling me to go back and see her in 3 months and that I would be better by the next appointment. Told me to go swimming, prepare and cook a meal for the family (I was virtually housebound and barely able to function at this time)... This went on for a year. I felt abandoned and very alone... I was referred to a consultant (and finally saw him having been ill 18 months) who diagnosed ME. It was a relief to finally have something definitive to tell 'people', but also shattering as there was no cure. He referred me for Occupational Therapy. My GP told me I would be making buns and weaving baskets. Clearly clueless. I never received an appointment. (Olivia)

After I had been ill for a year I asked my Dr for a referral to the ME services - I still haven't received an appointment 12 months later! (Kate)

After sending me for more blood tests I saw the consultant a 2nd time and was referred to an enablement team who gave advice on pacing etc I was due for a 3hrs appointment with my ME consultant when I was told that he had taken a job elsewhere and would not be replaced as the health authority (Shropshire) decided that there wasn't a need for a replacement! (Chloe)

CFS/ME is an attack on life and self, but the abandonment expressed by participants exacerbated the reality of the lived uncertainty surrounding their chronic illness. For example, some participants spoke of the reality of an elusive cure:

I was relieved to have a diagnosis, although no idea if I would ever recover as there seemed to be no cure. Further treatment has not been possible as the clinic is too far away and serves to be counterproductive. (Julia)

This is a hard question to answer, it took me a long time to fight back against the doctors who seemed unwilling to give any answers on what was happening to me, when I got the answers I was after (a diagnosis) I was then presented with new questions and a horrible feeling of doom (sorry for the melodramatics) but finding there is no treatment or cure really got to me. (Catriona)

And, Fiona compared the lived experience of CFS/ME to the lived experience of cancer which highlighted the uncertainty in CFS/ME:

It wasn't too long after that I got a referral to the ME clinic in Leeds and the immunologist also confirmed my diagnosis, but unlike with my cancer, there was no talk of a treatment, recovery time..... and being able to get back to normal life..... (Conversation data)

And on being asked to compare the symptoms of chemotherapy to the symptoms of CFS/ME by Kate, Fiona asserted:

I did get v fatigued after chemo - probably made worse cos I got v sick too (they said that would be unlikely on those drugs, so i was unlucky) but all the time I knew it was only temporary..... suppose though I was weak, I was fighting it and focused on the end of treatment and recovering.....counting down the weeks..... I have felt on my worse ME days that its worse than after chemo.... it's also worse because with the ME there is no idea when it will end..... that feels so much worse..... (Conversation data)

Living with an illness for which there is no cure, no hope, and very little medical support compounds the lived experience of chronic illness for participants. Participants' lives and selves are unrecognisable in CFS/ME as they struggle to participate in either life or self. Participants are also faced with disbelief and a lack of medical support within the often disabling community that is primary care. When we become ill, we reliably turn to those who are known to be there for us, to those whose job it is to help us in our time of need by supporting and enabling us to get better. In CFS/ME, these societal expectations are decimated by primary care practices and interactions as participants faced disbelief, a lack of investment, elusive support, and often hostility. The isolation born out of such practices and interactions is not enabling of participation within the one life domain within which one would naturally expect empathy and support. To reiterate, a lack of legitimisation negates a sick identity (Clarke and James, 2003), and when your life is struck by chronic illness legitimisation would arguably help you to face the world in which you are now different more confidently. When you face disbelief in the one domain in which you would not expect to face disbelief, feelings of loneliness and hopelessness can ensue:

Most of us feel abandoned with little help, support and understanding. We feel alone and neglected... (Ros)

When my doctor didn't have a clue, I just thought, what am I supposed to do now? I need help, I was desperate for help. God I felt so alone and hopeless. I was so angry, how was it OK to leave me to rot like that? I was so poorly, I was incapacitated, I couldn't function, I was housebound!? I just wasn't being taken seriously. Scary times. (Olivia)

However, not only in primary care do participants face scepticism and feelings of abandonment as participants' stories reflect scepticism at large; family, friends and colleagues which echoed the work of Dickson, Knussen and Flowers (2007); Travers and Lawler, (2007); Larun and Malterud, (2007); and, Arroll and Howard, (2012). For example, Ros, similar to a number of other participants not only spoke of a lack of support within primary care:

I've had and still have from some of my family total disbelief and refusal to accept or understand my illness. When I first became ill my parents told me to 'pull myself together and get back to work'. I no longer see them or have any communication with them. They have poisoned other members of the family with their malicious lies and words. It was many years

before my brother would accept that I was ill. When he finally did he said that he accepted I was ill but didn't understand. I still don't know if my sister accepts my illness. My parents have said that I am no longer their daughter. They have said that they think it's disgraceful that I haven't worked for the last years. They have said it's all in my mind and that I am lazy!!!! (Conversation data)

Could really do with much less stress about money, keeping warm, doing my best to beat the ME and family members who don't seem to understand..... (Fiona)

A really frustrating one is my soon to be sister in law - a newly qualified doctor. We had an argument a little while back - her saying something along the lines of 'my friend is only 22 and has M.S and she just gets on with it so why can't you' etc.... I was in a bad place at the time and it didn't help. We avoid the subject now and I don't see her often so it's ok. Xx (Anna Marie)

About 2 yrs ago, before I was diagnosed, but when I first began to realise how unusually tired driving long distances made me, I didn't attend my sisters 18th birthday dinner 4 hrs drive away. As a result I was 'cut off' by my step mum and sister who still now won't speak to me. (Katie)

My ex husband didn't believe I had ME and thought I was using it as an excuse to not do things. Hence he is my ex... My sister when visiting from Australia made me angry as she expected me to get up and go out and do things with her, I couldn't keep up, but she just called me a wimp. I then emailed her a list of symptoms of the illness and gave reasons for why I was like this. It caused some tension for a while. (Louisa)

I agree with the mixed bag. I don't think anyone else really gets it. My mum really tries to understand. I have a couple of friends who are supportive. The rest of my family don't get it at all and think a bit of motivation could change things. My cousin thinks I'm weak and pushes me beyond my limits despite what I say. However that side of the family don't really acknowledge illness so can't expect them to understand me. (Jessica)

Relieved that it wasn't just in my head, I wasn't faking it, even though friends kept saying mind over matter, just push through. I knew that pushing through didn't work as I became more exhausted. I went swimming whilst we went away and spent the next two days sleeping, not much of a holiday! (Netty) (Timeline data)

And during a conversation, Netty elaborated further:

My partner and kids have been really supportive, my sister in law has as well. Others I think have looked and thought that I can control it.

People think they are being helpful when they say "you need a holiday" that's my worst nightmare because I am not well enough to go on one and be able to enjoy it. I also get

people saying "go out , get some fresh air, have a nice walk it will do you good" or "have you tried swimming" when I do these things my battery runs down even more, not like ordinary people who are just getting over the flu and benefit from these kind of things. (Louisa)

Luckily I've had really good support from family and friends (I dropped friends who asked me if I couldn't just pull myself together and lots of relationships have gone by the wayside because I have to cancel so much). (Eleanor)

Suddenly my life stopped, the friends that I thought I had made from work suddenly didn't want to know and just made horrible remarks about me skiving. (Chloe)

Let's just say I've learned who my friends are - although I think that happens as we get older anyway! (Anna Marie)

Anna Marie subsequently elaborated:

I think you're right - although the 'friends' I was referring to were also work colleagues. They were kind and sympathetic to my face and let's just say not so behind my back. Among other things, they reported me to my boss for not pulling my weight, saying that I was lying about the extent of my condition. I don't think that's excusable.

When scepticism and disbelief transcends primary care to the private worlds of participants their capacity to participate and to negotiate their identities is compromised even further which echoes the work of Travers and Lawler (2007). Communities such as family and friendship groups could be enabling communities, and therefore akin to salvation in chronic illness as such communities could provide an opportunity to rehearse and sustain facets of one's previous identity by shifting in response to the needs of those with CFS/ME. However, when such communities doubt your experience of chronic illness, even if they don't turn their back on you, their lack of understanding evolves as an experience of isolation in CFS/ME within a disabling community. As such, the very communities that could serve the fragile CFS/ME identity can also contribute to its fragility, which reflects the work of Wineman (1990) and Marcille, Cudney and Weinert (2012) who suggest it is not always the chronic illness per se that compromises familial participation but the problematic coping of family members and it would appear also friends and colleagues which can inhibit participation; identity in chronic illness.

In cfsid discussions around issues of legitimisation and widespread scepticism, some participants made reference to the media which, according to Noelle-Neumann (1974) equate to an influential social system and as discussed in C4 are known to perpetuate negative stereotypes (Cottle, 2000; Van Dijk, 2000; Veno and van den Eynde, 2007; Voorehees, Vick and Perkins, 2007; and, Freston, 2009) such as CFS/ME the psychogenic disorder most attributable to women, and CFS/ME the non-disease (Johnson, 1996; De Wolfe, 2009). For example:

My knowledge from the media about 'yuppie flu' and Chronic fatigue had not encouraged me to take it seriously... (Kate)

There was a lot of stuff in the press at that time about yuppie flu and it seemed this was what I had. (Eleanor)

I don't want to be judged unfairly, but I always anticipate that I will be. I must say, people often surprise me and respond better than I thought they would, but I guess that is only a surface response; I won't always know what they are 'really thinking' if their CFS/ME education has been at the hands of the media for example! (Olivia)

The media is ignorant too. I get sick of the 'previously known as yuppie flu' thing... (Mary)
(Conversation data)

And Mary went on to say in a subsequent conversation:

Compassion goes a long way and we are not immune from cultural messages...

With the prominence of the media in today's society it is impossible to escape the cultural messages as referenced by Mary, and as such the scepticism at large; primary care, family, friends, and colleagues as experienced by participants is indicative of the media portrayal of the illness. The scepticism born out of ignorance as experienced by participants appeared to be silencing as a number of participants discussed their lack of voice in their lived experience of CFS/ME:

i have been ill for over 5 years now with multiple complaints. for a long time i was back and forward at the doctors with fatigue and mysterious pains with no explanation, i thought i was going mad. after a while i stopped going to the doc's as i felt they thought i was a hypochondriac. (Catriona)

I don't often share my diagnosis. I see it as a negative, possibly due to doctors negative reaction and friends saying 'I get tired too'. I'm always embarrassed to talk about it and fear the reaction!! (Jessica) (Conversation data)

And in a subsequent conversation, Jessica elaborated:

I'm not sure if people will truly understand if they don't have a chronic illness as its often invisible and I often keep it that way so I can't expect people to understand. What I do expect is understanding that I'm not lying or lazy and that ME restricts my life. A little compassion would be nice.

I was the alien. Alone and misunderstood. And, I didn't even have the strength to defend myself, I just internalised and continued to 'exist'... (Olivia) (Conversation data)

In a subsequent conversation, Olivia gave further insight into her experiences:

I found I only told people when I had to or when I trusted them. I very much avoided wearing ME on my sleeve, for fear of recrimination and cynicism. x

... A really frustrating one is my soon to be sister in law - a newly qualified doctor. We had an argument a little while back - her saying something along the lines of 'my friend is only 22 and has M.S and she just gets on with it so why can't you' etc.... I was in a bad place at the time and it didn't help. We avoid the subject now and I don't see her often so it's ok. Xx (Anna Marie)

Now I haven't told anyone really, apart from my boyfriend, of my diagnosis... I've tried to talk to my mum but she's kind of in denial, she either blames my fatigue on my relationship situation at home or makes pointed remarks like 'we just had to get on with it' or 'at my age you stop worrying about x' which makes me think she thinks it's all psychological. (Katie)

...My kids don't acknowledge or talk to me about my illness, or ask me how I am, but they are too caught up in their own lives to understand. My mum was the worst, saying things like, get yourself better, do this, do that, and condescending, putting me down all the time for being tired... (Louisa) (Conversation data)

And in a subsequent conversation, Louisa elaborated:

My friends have dwindled but partly because I haven't kept up the contact required. I only have those around me who are supportive. A lot of the negativity about how people might respond is in my head as they haven't said anything to my face.

I was a single Mum when I became ill and my daughter has always found it hard to accept my illness. Even now she doesn't want to talk about it and likes to pretend that there is nothing wrong with me. At times she can be very cruel and sarcastic. She says that at least I'm not dying!! (Ros)

I didn't share my diagnosis for the first 18 months - I was not able to accept my illness and as I've said before so entrenched in the psychological model of the illness that I couldn't relate to my own experience. (Kate)

I used to hide my illness because I didn't want to explain or people to patronise me or treat me differently in anyway but I'm past caring now. I explain in a matter of fact way and get on with things as best as I can. (Michelle)

I do not share. My self esteem went down the tubes. (Helen)

Participants' stories demonstrate how the scepticism surrounding CFS/ME silences them. They are sometimes silenced following difficult interactions and sometimes they self silence as to protect themselves from such difficult interactions; scepticism. Either way, the CFS/ME community is not a community with voice, and participants' lived experience of the illness and their identity is compromised by their silence as their potential to participate within various communities such as family and friendship groups which could be enabling communities, can be additionally undermined by their lack of voice; their self silence. Wenger (1998) discusses the relationship between non-

participation, marginalisation, and a restricting trajectory that can become so embedded in a community that an alternative trajectory may never be realised. The CFS/ME community has for many years been shackled by scepticism and as a result those with CFS/ME, as evidenced above are often silenced. Such silence does not necessarily serve the CFS/ME community as in silence, ignorance can breed and flourish. The silence of the CFS/ME community could be deemed to reify the illegitimate nature of the illness, for both sufferers and non sufferers. However, despite the silence of participants being a form of coping, this does not mean that participants do not want and/or need to be heard:

I think it's really great what you're doing and giving us ME/CFS sufferers a voice, keep up the good work. (Chloe)

If things are to change, we need people to want to help us, to fight our fight when we cannot. (Olivia)

Chapter summary

The current theme illuminated the lived experience of CFS/ME for participants as being hugely distributed. On becoming chronically ill, life as an independent individual was over when the help of others became a need aligned with survival. It transpired that the history of CFS/ME and the medical scepticism surrounding CFS/ME was central to the lived experience of the illness for participants. The construction of CFS, the name, and the diagnostic criteria for CFS reified CFS/ME as an illegitimate illness. Such reification did not reflect the lived experience of CFS/ME for participants which was found to be problematic for participants within primary care when facing disbelief and doubt; scepticism. The scepticism surrounding CFS/ME meant that participants were not privileged with a legitimised sick identity and as such their participation in CFS/ME was compromised. Participating in an illness may not be seen as a useful form of participation, but through participation in an illness and practice as learning, a new identity has the potential to evolve, a sick identity that can legitimise an experience of illness and encourage acceptance, adjustment, and the support of others. For example, learning to live well with chronic illness involves the need for renewed purpose and meaning, but in the case of CFS/ME the shadow of scepticism and the lack of legitimisation compromised the potential for participants to participate meaningfully in CFS/ME. As such participants were often left feeling alone and unsupported in their lived experience of unfamiliarity within the disabling community that was primary care.

Participants not only faced scepticism within primary care, but also within familiar communities such as those of family, friends and colleagues. The medical establishment construct CFS/ME in a certain way, the media portray CFS/ME in a certain way and as a result wider societal understanding and knowledge of the illness rests on a foundation of disbelief and stigmatisation. When society relies upon the medical establishment and the media for understanding and knowledge of CFS/ME, CFS/ME is ultimately reified and largely understood to be a non illness. Facing disbelief within primary care was hard enough for participants but facing disbelief in familiar communities, communities which

could have enabled participation; identity, was an additional burden for participants. Thus, not only in primary care did scepticism inhibit participants' potential to participate in CFS/ME meaningfully but opportunities to participate and rehearse facets of participants' previous identities were also compromised by the scepticism of familiar others who evolved as doubters. Not only were participants lost in primary care but they were also marginalised and on the periphery of their private worlds. The vulnerability of participants' identities as influenced by the scepticism of primary care was exacerbated by familiar communities when family, friends and colleagues also questioned their experience of illness.

The overwhelming nature of such scepticism was ultimately silencing and such silence did not equate to participation; identity for participants. As such participants were often alone in their lived experience of CFS/ME and subsequently as a community they appeared to lack voice. A number of participants acknowledged that keeping quiet did not serve them well as keeping quiet contributed to the scepticism surrounding CFS/ME, but moreover after suffering CFS/ME for many years it was a fight they could no longer fight.

I argued that the context of chronic illnesses interacts with the lived experience of the illness as when an illness is legitimised, there is acceptance of and support for that illness as opposed to the disbelief and isolation that is associated with CFS/ME. It is impossible to know from the data here, if legitimacy makes a chronic illness an easier lived experience, but if the history of CFS/ME was not there, would those with CFS/ME have more opportunities to participate? If CFS/ME was not reified as a non illness, would the CFS/ME journey be less problematic? There would be more potential to participate, despite indifference in physical symptoms as those within primary care, and those closest to them in terms of family and friends would be more likely to be supportive and therefore less likely to be hostile which could reduce the isolation and silence of those with CFS/ME. It may also be true that if the history of CFS/ME was not there and as a result the fight for legitimacy was not all consuming, that there could be more health in illness in the lived experience of CFS/ME as symptoms would not be exacerbated by the stress of scepticism and illegitimacy.

Having considered the interaction of the history of the illness, medical scepticism, scepticism at large, and silencing in CFS/ME which appeared to render participants vulnerable to isolation it became transparent in the current theme that such isolation undermined opportunities for participants to participate in a life and self with CFS/ME. The identities of those with CFS/ME can be beholden to the understanding of others who believe they are not mad or lazy, but ill and in so doing enable them to participate in their life and self with CFS/ME. Being enabled such as this is important in CFS/ME when experiences of grief for the life and self lost are reliable as discussed in the previous two themes. Despite having argued for limited positives in the lived experience of CFS/ME, moving forward the current analysis will attempt to transcend the struggle and the scepticism underpinning the lack of positives in CFS/ME which appear central to the lived experience of CFS/ME, to participants' experiences of coping. The following theme will therefore attempt to unpick participants' coping as to illuminate the potential for coping; positives in chronic illness: CFS/ME.

CHAPTER TEN (C10)

What you going to do?

When your life is struck by chronic illness; CFS/ME your journey of discovery begins. You have to accept your life has changed and you have to adjust to a new life that you would not necessarily ever choose. 'What you going to do?' reflects an attitude that appears necessary to coping. Unless you can get to the point where you are able to shrug your shoulders and open your mind to a new way of being, coping almost certainly would remain problematic, and perhaps elusive in CFS/ME. The current theme illustrates how participants live with CFS/ME, how they cope and the source of their coping. I will begin with an insight into acceptance and adjustment as a number of participants foregrounded the need to accept their new lives and selves with CFS/ME if they were going to be able to adjust to a life with CFS/ME which echoed the work of Van Damme et al. (2006); Dickson, Knussen and Flowers (2007); and, Edwards, Thompson and Blair (2007) whilst reflecting the practice as learning concept (Wenger, 1998):

Psychologically I have found acceptance of how I am as useful and being mindful. (Jessica)

I think I have accepted how things are.... I quite soon realised that if I let the frustration/stress of it take hold, I would feel much worse..... (Fiona)

You have to accept that this is your life now, I only ever considered it a temporary thing, I think that's how I coped, but you have to accept in order to manage it, a life with CFS/ME, which takes some managing! (Olivia)

Having accepted a life with CFS/ME, participants realised in order to live as well as possible, they had to learn how to pace which reflected the work of Edwards, Thompson and Blair (2007); Larun and Malterud (2007); and, Wilson, Whitehead and Burrell (2011). Pacing is indicative of adjusting to a new way of life with CFS/ME:

I have learnt so much about this illness and how to pace the best I can so I don't deteriorate. (Ros)

I try to manage my illness by limiting my exertion and saving my energy. One late night out will mean I could be bed bound for days. (Mark)

Now I try to rest regularly 3x a day however I feel and meditate. When I crash the 3 rest periods tend to be much longer and merge into one! I have also noticed that if I rest I sleep better and other physical symptoms improve. Tramadol helps. (Kate)

2 years ago I went back to uni full-time to study Occupational Therapy. It's really helped me pace better. (Rachel)

I eventually had home tuition and managed 2 GCSEs and 1 A level. I got support from Tymes Trust to get a SEN statement so my home tuition could be continued into A level. As part of

the package, I saw a clinical psychologist, who was very helpful in the end. The first one I saw I hated because she told me I was trying to do too much – all I wanted was to go to school! This was the painful first step in learning to pace myself. (Mary) (Timeline activity)

And subsequently, Mary gave further insight:

The main way for me to cope was pacing. The most important bit of advice I had was the 70% rule - always leaving something in reserve. I found that if I lived right up at my limits, then life would just be intolerable. So while it has been so so difficult to hold back, that has really been the only way forward. This took a lot of adjustment psychologically, but physically it helped a lot not to push. Gradually I had less symptoms and improved. Although living day-to-day can be important, I found myself having to live with an awareness of what I have done, what I need to do, and how to manage that without doing too much. At first that took a bit of effort, but once I'd got the hang of it, it became a way of life. (Conversation data)

It would appear that pacing enables coping in CFS/ME, whilst also enabling identity through the reward of pacing; participation. Despite the fact that pacing sometimes enabled participants to regain some control in their lives, pacing was difficult as pacing reified a life with CFS/ME was not participants' life of choice:

I have learned to take one day at a time, make few plans, if any, and be grateful for what I have, although don't always feel this way. I find pacing very difficult, still having a lust for life, restless and prefer to be out and about. (Julia)

Pacing was essential, and it wasn't really a choice, you just had to pace, but it just stared you in the face, the change in you and your life. I used to long for my old life. (Olivia)

The reflection of change was difficult for some participants but it transpired that a positive outlook was beneficial to participants' coping which echoed the work of Edwards, Thompson and Blair (2007):

Important thing is not to look at what you can't do but appreciate what you can do (however little). If you are constantly measuring yourself against the unattainable 'previous you' then you will never be happy or appreciate what you have got. Life immediately got easier for me when I realised that. (Kate)

I have to try and make myself not think beyond each day and just take each day as it comes or I know that I would get really down, I try not to think of how my life could of been and what I'm missing out on but try and focus on the small things, for instance, I went into town for an hour with my mum Wednesday just to browse around the shops, enjoyed it but really had to push myself which resulted in payback of course. Before I got ill I'd started a counselling course which I was really enjoying but had to give up when I started with my symptoms of ME, it's still a dream of mine one day to be able to do this but at the moment brain fog bad enough just doing emails lol. (Chloe)

When I joined FB, I made a pact with myself that I would use my experience strength and hope in a positive way, drawing on my prior experience of being a member of AA. Again, this ratcheted up my damaged self worth, realising that I was able to turn a negative experience into something of value to others. (Dan) (Conversation data)

And in a subsequent conversation, Dan expressed:

We have to go through the negativity of loss of so much to get to a place where we can start to look at what we do have and to rebuild on new foundations that embrace the illness in a more positive manner.

There are times when I have to refuse invitations and that hurts. Every day is different with M.E. and I try to make the best of each and every day if possible. There are days when I have to give into the illness and stay in bed. Those days are tough. I suppose I'm mostly a positive person and so maybe I cope better than others. (Ros)

I have learned to take one day at a time, make few plans, if any, and be grateful for what I have, although don't always feel this way. (Julia) (Timeline activity)

In a subsequent conversation, Julia gave further insight into the role of positivity in her coping which was indicative of the experiences of other participants:

We all have our own ideas about what being positive means to us. For me, and the ethos of the lighter side [CFS/ME facebook group], positivity is about being real. Supporting each other, acceptance and a willingness to live our lives as best we can.

To know that we are people who live with an illness, not ill people. There is much more to us than an illness. We are creative, caring, fun and colourful.

Living the best way possible may not cure the illness but it sure helps. We all know that emotions such as anger and frustration can be draining for us, not to dwell on or deny these emotions can help us move forward.

*Letting that which does not matter go and embracing what we have... and we have a lot ☺
xxx*

I have tried many alternative treatments, some have helped, others made me worse and some I wish I'd not spent my money. I try to be positive and am finding that this is helping me most. (Laura)

I would cope day by day, always being optimistic about the future and contemplating 'life when I'm better'. (Olivia)

Knowing I wasn't the only one having to do things differently, and certainly not being the worst off in the ME community, made me appreciate what I did have. I loved receiving post from penpals. This was the pre-internet or texts days! But I think most of all my parents helped me to focus on what I could do instead of what I couldn't. (Mary)

Mary acknowledges the love she had for post from pen pals and the role her parents played in her positive outlook, which reinforces the value of a connection to others; support and coping in chronic illness. As discussed in C2, Wenger (1998) acknowledges the role a connection to others plays in participation; identity, and here it is evident that a connection to others was of value to Mary in her lived experience of CFS/ME, something which she subsequently elaborated on:

I did have qol because I had family who loved and supported me, and I could take part in what everyone else was up to even if that just meant hearing about it; I had three friends from school who kept in touch with me, but mostly friends through AYME and Tymes Trust, giving me a sense of community and not being alone in having ME... Having family and friends and interests, having lots of support, made all the difference. Knowing I wasn't the only one having to do things differently, and certainly not being the worst off in the ME community, made me appreciate what I did have... AYME gave me community, friendship, a voluntary role and through that eventually a husband... I still have friends who have ME. Some have stayed the same, got worse, got better. Some have partners and/or a child. Some have degrees, one is doing her PhD. My qol and identity is framed within the wonderful sense of wholeness and well-being having them all gave me. (Private message)

Mary also reflected upon how life would have been had she not had the support of loved ones:

I cannot imagine the pain, isolation and fear of having ME and not having supportive loved ones. That would indeed be hell. (Private message)

A number of participants also discussed the value of others:

My Mum helped me to still be someone, I was her daughter and she loved me. Other than that I didn't really feel of much value to anyone. I used to think if I disappeared, my disappearance wouldn't be particularly impacting. (Olivia)

I think there are some variables that influence how well people cope with long term chronic illness - at what age you become ill, how seriously ill you are, what help, support and understanding you have from friends, family and the medical profession and how your own personality and character helps you through. (Ros)

My kids do so much to help, they keep their own rooms clean and tidy, put their own washing away and change their bedding. They also help with filling and emptying washer and drier.

We have a dog who doesn't get walked as often as she should, but is loving and knows when I am bad. (Netty)

The things that help are my wonderful, supportive husband - he is retired now, so we are together nearly all the time..... it's a good job we get on so well

Finding new MEfriends at the local support group and online has helped brighten my days and take away some of the isolation.....

Seeing my step-grand-daughter and niece (ages 4 and 5) occasionally helps too.... (Fiona)
(Private message)

Fiona subsequently added:

I am so lucky that my husband is happy to be my chauffeur..... I'm sure I'd be even more isolated otherwise + plus my confidence, which was never great, has gone down..... not knowing how long my legs will manage walking etc..... I'm sure my symptoms would be worse too without his help and support. (Private message)

Luckily I've had really good support from family and friends (I dropped friends who asked me if I couldn't just pull myself together and lots of relationships have gone by the wayside because I have to cancel so much). I've now been ill for 23 years, I can't really imagine every feeling well again. But more positively, I do enjoy my life but that's probably because I'm fortunate enough to have a job which I love which pays me enough to live well and a good support system. (Eleanor)

I have amenities very close by, spitting distance, so I can, when up to, take a very short stroll and I'm with people. Sometimes on my own and just people watch or read or sometimes meet friends. A short drive and I have another choice of venues. My children, both adults give me immense quality, pride. I've always been a single parent and life has been tough going with both of them so to now see them blooming into well rounded adults fills my cup. I love spending time with them, either as a family or one on one. (Julia)

When I was first ill I lived with my parents and had an excellent support system but through the years I was alone and I drove myself to the limit and had little well being... In a nutshell; purpose, appreciation, achievements no matter how small, good support system and hope help towards well being and a better quality of life for me. (Michelle)

In the lived experience of chronic illness, a connection to supportive others can enable participation both in life and self; identity. As discussed in the previous theme: *It's not just about me*, a connection to others is not always bound by support which is enabling of participation; identity due to the problematic coping of significant others. However, a number of participants expressed the role of others and their support system in their lived experience of CFS/ME which resonated with coping. The isolation of CFS/ME is problematic for participants, but when participants had a connection to others

and a support system their outlooks appeared more positive as the people in their lives enabled a better quality of life in CFS/ME which reflects the work of Vassilev et al. (2014) who highlighted the relationship between social participation and health and well-being in chronic illness. Here, through a connection to others, participants were able to negotiate their identities, as their support systems enabled them to participate in ways that they would not have been able to had their significant others not invested in enabling them to participate. CFS/ME is a chronic illness that acts as a barrier to participation; identity, and so when participants had people in their lives who wanted to help them, the barrier to participation was negotiated and this appeared to contribute towards participants' positivity in CFS/ME, which as rehearsed throughout, can often be elusive due to the complex and problematic nature of the lived experience of CFS/ME.

Finding a new way to be in the world

In the current theme I wanted to be able to break through the surface of loss and struggle in participants' lived experience of CFS/ME to draw upon further experiences of positivity in this chronic illness. One participant, Ros, writes a blog and on asking participants about their experience of purpose and meaning in CFS/ME, Ros shared one of her articles, which resonated loudly with my thoughts on how to find a new way to be in the world of CFS/ME:

When we become ill with M.E. or another chronic and long term illness our lives change. We can no longer go out to work or do all the things that we used to love and enjoy. We have to learn to change and adapt. What we can now do depends on the level of our illness, our symptoms and our resources. I recall in the early days of becoming ill I spent many hours watching mind numbing day time tv and hoping that this would just be a temporary situation. But it wasn't and over the years I've had to find other ways to fill the never ending days. Otherwise I might have gone mad or become very depressed!! (Ros – blog shared on Facebook)

I will now present participants' negotiation of purpose and meaning; identity in CFS/ME in an attempt to reflect the possibilities in CFS/ME as the majority of participants did provide an insight into the opportunity for possibilities in CFS/ME. The following data also reflects the beneficial layering of data which adds a depth and nuance to participants' contribution:

I consider myself to be mostly moderately disabled and housebound. I've had good and bad periods which is normal with this remitting and relapsing illness. I have also written many poems about life with ME and have recently published a book. I want to raise awareness and understanding as well as funds for the charity Invest in ME. At least this way I am trying to make something positive out of a terrible and life destroying illness. (Ros) (Timeline activity)

Here Ros gives an insight into her life with CFS/ME by sharing that she writes poems and indeed has published a book. She also says that she wants to raise awareness and funds for an ME charity which rests on her desire to turn her illness into a positive. Purpose and meaning ripple under the surface

here, which reflects a life and self not totally lost to CFS/ME. In the following quote Ros gives further insight into her lived experience of CFS/ME:

It has made me appreciate so much more in life and life itself. It has shown me that you can take nothing for granted. I have developed other facets to my character and other skills because of this illness - but that's just me: I'm getting there slowly albeit very difficult. At least I feel more calm and in control of my life. As to answer your question - I suppose the obvious thing to first say is that I have turned to writing much more and especially poetry. This has helped me, as well as others, to cope with long term chronic illness and to develop my creative skills. Although I had written a few poems before becoming ill I have had more time to explore that side of myself. Maybe I would never have done so if I had continued working.
(Private message)

Here Ros frames her illness quite positively as alongside her illness is an experience of personal growth. She again foregrounds her poetry and its contribution towards her coping and the coping of others, whilst also reflecting upon how her illness has enabled her to explore her creative side, something which may not have been realised had she not become ill and continued working. In C2 I argued that the reconceptualisation of CoP needed to account for participation that was not bound by community, as independent participation also had the potential to negotiate identity within the lived experience of chronic illness. The participation and practices expressed by Ros, such as her writing and her poetry, are arguably independent. However, Ros takes such independent pursuits to the next level by sharing her work with others. Ros therefore suggests that her poems not only help her, but also others and as such, Ros's poetry transcends the boundary of the self to the world of others; the CFS/ME community.

The following quotes give an insight into the ways in which Netty has negotiated purpose and meaning in CFS/ME:

I have been unable to get well enough to go back to the course, so now I will have to do other things. (Timeline activity)

I rarely read now, if I do it's crochet or knitting patterns. (Timeline activity)

I have taken crocheting and knitting back up as I can work at whatever pace is best for me, I have been trying to sell what I make and plan on doing a craft show next year and hopefully I can sell lots there. (Conversation data)

What I do enjoy though how much it has made me slow down and appreciate other things, like time with my kids, taking small steps and allowing myself to see that as a positive that I don't have to reach big to do well. I crochet a lot and I get a lot of joy out of that.
(Conversation data)

Netty presents a story of her negotiation of purpose and meaning; identity, in CFS/ME which reflects a journey of realisation in which she finds a new way to be in the world through her CFS/ME friendly

hobby and her adjusted outlook to the world. Similarly to Ros, Netty's negotiation of purpose and meaning is by definition, independent as crocheting is something she does alone. However, Netty's aspirations which transcend the four walls of her home are evident in the 3rd quote on acknowledging her desire to sell her work at a craft show. An aspiration such as this could represent the negotiation of a new trajectory which could contribute towards a new and more positive identity for Netty in CFS/ME (Wenger, 1998).

The following quotes present the relationship between chronicity, struggle and the renegotiation of life and self in CFS/ME for Kate:

I am very limited in what I can do I can walk approx 500m max on a good day. My concentration and memory are affected. I am unable to work or do very much around the house, I cannot do the shopping regularly or get out to socialise but I have discovered that using shop mobility I can occasionally visit the local town. (Timeline activity)

I have tried to focus on what I can do rather than what I can't and have tried to adapt my life so for example I use a wheelchair or mobility scooter when out so that I can still get involved in activities. I pace my life carefully. I spend time online learning about different things eg I have signed up for a couple of free online university courses on psychology and Buddhist teaching and another on performance and mindfulness. I have also taught myself how to sew, crochet and embroider and plan to learn some new skills next year. (Conversation data)

Kate's first quote is indicative of the physical constraints inflicted by CFS/ME, whilst her second quote reflects a useful positive outlook in which Kate focuses on the positives. Here Kate, gives an insight into her negotiation of participation; identity in CFS/ME through the use of a wheelchair or mobility scooter which enables her to be a part of her local community, whilst also enabling her to participate in activities that she would be unable to take part in if it was not for the privilege of a wheelchair or mobility scooter. The practice of relying on a wheelchair or mobility scooter would not necessarily be considered a positive practice, but in the case of chronic illness, learning to live well with CFS/ME involves both acceptance and adjustment, and Kate's acceptance and adjustment here through practice as learning, has enabled her to participate in life and therefore self. Such identity work reflects the findings of Arroll & Howard (2013) as discussed in C3, which illuminated that if one is to live well in CFS/ME, one must let go of one's previous life and self, as it is within the letting go that a new positive identity within CFS/ME can emerge. Kate also talks about learning in a variety of formats which makes transparent her need for purpose and meaning in illness which reflects her previous self as discussed in C8, the potential for personal growth in CFS/ME and as such the potential for Kate to be 'Kate'.

In the introduction to the current section, it was acknowledged that the majority of participants demonstrated the potential for positives in CFS/ME. However, the following participants align more succinctly with the reality of both positives and negatives in CFS/ME despite their commitment to purpose and meaning:

Catriona makes transparent her need for purpose and meaning in CFS/ME:

After 2 and a half years i decided to go to college, i left school with no qualifications so didn't think i would be accepted into a science course, im now doing my HND in biomedical science and have applied to uni to enter 3rd year biochemistry.my future plans is to find a cause, treatment and cure for this nightmare. (Timeline activity)

I'm the same as you in the adult education, it makes me feel as if i am still here if that makes sense, but what annoys me is telling someone im studying towards a degree and they then think there is nothing wrong with me. (Conversation data)

Catriona's first quote reflects her need to do something in her life with CFS/ME and her choices not only reflect purpose and meaning in the present, but her goal to find a cause, treatment, and cure for this nightmare which reflects a much wider lens through which Catriona is viewing her current potential to participate in CFS/ME. The lack of support within the lived experience of CFS/ME ripples under the surface of Catriona's aspirations, whilst her second quote gives further insight into her CFS/ME identity as negotiated by adult education. Adult education evidently gives Catriona both purpose and meaning as she asserts it makes her feel as though she is still here. However, she also acknowledges that negotiating an identity in CFS/ME that is indicative of participation, can give the wrong impression which reflects the role of reification in understandings surrounding CFS/ME; Catriona is studying for a degree so she must not be as ill as she says. Of course this is not true, but books are often judged by covers, and as such people with CFS/ME who are able to negotiate participation within their lived experience of chronic illness, can run the risk of being isolated further by the reification that suggests they are not in fact as ill as they say.

The following quotes reflect the tug of war between the positives and the negatives for Tessa:

I shall never say that it has had a positive effect but I have a different life of being an artist and an Airbnb Host... but I do say that this has had a worse impact on my life than my parents dying. (Conversation data)

I got to a stage where I thought if this is always going to be so, what can I do? And what airbnb has enabled me to do is contribute, is meet people from all over the world who are on the whole really really interesting. I can do things at my own pace, I can have people when I choose, I don't have to worry about the financial future, being on my own and thinking how on earth can I be with this, to a situation where people come to me, and it gives me energy, and it inspires me. I've discovered a whole creative side to me. There was a time in my life when I was so lonely that the wind would whistle through me. I thought this is it, I'm never going to feel different from this, this will always be so and this will always be so is the biggest hurdle to get over, and I had that for many years, and I don't have that now. (With permission from Tessa, guided to, and taken from <https://airbnb.com/stories>)

Tessa initially acknowledges her different life with CFS/ME in which she is an artist and an Airbnb host whilst asserting that her illness has been worse for her than her parents dying. So here, aligned with positives is an overarching negative. The second quote from Tessa provides a greater insight into how Tessa has negotiated her life with CFS/ME. She asserts that she had to consider what she could do with this life, a life with illness and in so doing found Airbnb. Tessa asserts being an Airbnb host has enabled her in many ways. Through Airbnb, Tessa can contribute, she can meet interesting people, she can pace, she can be more confident about her financial future and a future less lonely whilst also being inspired and energised by her role. Airbnb has evolved as an enabling practice for Tessa, as Airbnb is the source of Tessa's participation; identity, and QoL in CFS/ME. She acknowledges that there was a time when she wondered how she could 'be' in this illness, but that this burden is no longer felt which illuminates that through practice as learning, Tessa has been relieved of this burden by having found new ways to participate; a new way to 'be' (Wenger, 1998).

Michelle initially acknowledges how different her life is now, before foregrounding how she enabled purpose and meaning in CFS/ME:

Since being ill life has changed in so many ways as I learned to look after myself better, listen to my body, handle my anxiety and understand that every action I take I know there will be a health consequence. I managed to strengthen myself and ease the pain initially by practising yoga everyday in my bedroom, no matter how ill I felt - I literally crawled out of my bed to do my yoga routine made up from using a book I found on my bookshelf. I saw and felt progress so from this, I set goals like passing my driving test (to help work on my concentration), going to college, Uni and having a child. Although something's didn't work out I've tried to progress and catch up on what felt like lost years as my health improved and has now plateaued. My life now is pretty stagnant as I'm trying to get work but have limited capabilities and no work experience since I last worked 14 years ago. (Private message)

And subsequently:

I was hoping and building up to working too or having some purpose but am currently experiencing a relapse health wise. The point of me setting goals and going to Uni was with the long term goal of getting better, being self sufficient and to work again but a few months ago I tried working, managed three days (part-time) and have been ill ever since. I am having to face reality that I may have reached as far as I can go with the illness and progressing with working life. There's a line between having hope and acknowledging the reality of the situation. (Private message)

Michelle's first quote gives a depth of insight into her CFS/ME journey in which she has negotiated participation; purpose and meaning throughout her years of illness, an insight which is moreover framed positively. Michelle's second quote however, presents a less positive insight as this quote reveals the struggle of participation in CFS/ME. Michelle acknowledges that throughout her years of illness she set goals with a view to being in a position to work. However, moving on from the first

quote in which Michelle declares despite her efforts to achieve goals, she was struggling to find work; the second quote tells us that she did find work, but that her three days of employment resulted in a considerable health consequence. The reality of this situation for Michelle has caused her to reflect upon what is possible for her, and what, despite her wishes, is not which reflects a continuing crisis of identity as defined by compromised participation in chronic illness: CFS/ME (Wenger, 1998). Despite Michelle's drive for more, the reality of struggle persisted. Sustained struggle such as this required Michelle to reflect once again upon her life and self with CFS/ME as the life and self she was trying to negotiate through negotiated participation, purpose and meaning, evolved as an elusive life, and therefore an elusive self.

The following quotes present a journey in which Louisa has had to find purpose and meaning, but purpose and meaning that is burdened by struggle:

I don't think I had a void as the onset was really slow, but now I miss going out for walks, going to the pub and theatre and socialising with friends and family. I took up art and that has filled the void, but I still miss all the other things. (Conversation data)

I too am at uni studying for an art degree. Taken as a therapy to stop me from vegetating. I hated the fact that I had to keep saying I have ME and that's why I can't do certain things. It is all I do apart from sleep... I applied for dla for a second time and got the lower rate. For me this is a success and validation that I am not able to work even though I can do a degree .. The course is only 3 days per week but I do half that and come home to sleep. I don't know how I have done it as I am exhausted all the time but I am on course for a 2.1 . A great achievement but I don't know what I will do next to stop the rot of this horrible disease. (Conversation data)

And in a subsequent conversation, Louisa added:

I too am fed up of feeling ill and having a different area of pain everyday and new symptoms arising each year. I'm having physio but have been too unwell to do the exercises and feel that I have gone backwards in the last few weeks with a relapse and unable to go to uni. I am in my final year. I don't know how I have done it, but it has been to the exclusion of every other activity known to man, or woman. Like socialising, cleaning, cooking, decorating, going on holiday, visiting friends and family and being visited. I have become very reclusive. But hey...I WILL have an art degree in June . Not that I'm likely to do anything with it, but then what next? A long rest....oh I do that anyway....

Louisa's first quote acknowledges the multiple voids in her life with CFS/ME that she has attempted to fill with art. Her attempt to fill the voids has not been completely successful as she acknowledges that she still misses all the things she used to do prior to illness. Her second quote however, gives greater insight into her art, as she tells us here that she is in fact doing an art degree which she hoped would stop her from vegetating and enable her to be more than her illness. Louisa does make it very transparent that her degree is a great struggle, but that she appreciates her achievements in the face

of adversity. Louisa's final quote reflects the reality of her life with CFS/ME as defined by her art degree as here she suggests that she has had to make multiple sacrifices in order to pursue her studies, which reflects further losses and experiences of isolation in her life with CFS/ME. So, Louisa's art degree gives her purpose and meaning through participation which negotiates a positive identity in CFS/ME, however, in order to pursue her studies, the consequences are such that her quality of life has been further compromised by her studies. This fine line demonstrates the struggle of identity in CFS/ME as in order to 'be' there are often consequences which can be counterproductive to quality of life in CFS/ME.

Although it is not always possible for experiences of struggle in CFS/ME to be overruled by the potential for positives, it would appear that finding a new way to be in the world, new ways to participate as to negotiate purpose and meaning in CFS/ME can contribute both to coping and QoL in CFS/ME through the reward of participation; identity. Through participation some participants were able to be more than just their CFS/ME and they were able to do something with their lives and as opposed to being a slave to circumstance, they negotiated their potential in CFS/ME by negotiating a lived experience of purpose and meaning. However, I feel it is necessary here to return to the participation concept as discussed by Wenger (1998). It appears that there is participation beyond communities of practice, which does not necessarily fit with Wenger's (1998) CoP theory. Participation is not limited to interaction, but that participation can equate to '*doing*', even when such doing is independent in nature which reflects the work of Hunt, Nikopoulou-Smyrni and Reynolds (2014) who looked at the beneficial role of art making in MS, as discussed in C2. In chronic illness, it is not unreasonable to suggest that joining a community is often problematic due to chronicity. Similarly, it is hard to claim that crocheting, for example, represents a CoP. However, the very act of doing and practising crochet has the potential to legitimise one's identity and in so doing represents something meaningful in, for example, Netty's life. I would therefore suggest that CoP needs to account for the role of meaningfulness outside of social interaction in identity as meaningfulness, for participants appeared to be a source of identity and QoL in their lived experience of chronic illness: CFS/ME.

Despite the experience of meaningfulness expressed by participants in their accounts of negotiated participation above, I believed it was necessary in C8: *Losing on the swings and the roundabouts*, to conceptualise participants' challenge to find the positives in CFS/ME due to the undercurrent of loss and unfamiliarity in their lived experience of CFS/ME. The layered data throughout the current analysis could be accused of being contradictory as I have presented both positive and negative subthemes. However, lived experience in general is layered and the current research has enabled a multifaceted insight into participants' lived experience of chronic illness: CFS/ME which has indeed illustrated both positives and negatives. Arguably, the negatives have taken centre stage, but the lived experience of chronic illness is not a lived experience that naturally exudes positive experiences.

The tension between the positives and the negatives

In C7 (p.119), I referred to a conversation that evolved within supervision where the evident lack of positivity within the current research was questioned. I reflected upon the said conversation and as such on immersing myself further within the data, I began to look for 'wellness in illness'. As discussed in C7, in sum, there was some wellness for a minority of participants, but it was periodic and fleeting. In an attempt to unearth the positives, having considered participants' positive outlook in C7, on exploring participants' experiences of purpose and meaning above, I have attempted to shine light on the positives and possibilities in CFS/ME, which could arguably transcend CFS/ME to other chronic illnesses. However, it is evident that despite participants' innate need and commitment to purpose and meaning in CFS/ME, positivity does appear to be a challenge in CFS/ME. This reality caused me to return to the desire for positives in chronic illness research as it had become a tension within my own.

For supervisor A, the data presented 'survivor stories'. It was suggested that despite having lost a lot, that participants had made adjustments, and that they had been incredibly tenacious to keep as much of their lives and selves as they could. As such for supervisor A, the CFS/ME identities within the data were triumphant identities that needed to be celebrated. Supervisor A does not have CFS/ME. Myself, and supervisor B, do, and therein lies the tension within interpretations of the data, which also tells us something about the nature of analysis being neither right nor wrong, but reliably complex. For myself and supervisor B, participants' CFS/ME identities *could* be seen as triumphant, and as such *could* be identities worthy of celebration, but the word 'could', is operative. To an insider or outsider, participants had much to be proud of, and that was never in question. But, as insiders, myself and supervisor B understood that what was needed here was not a pat on the back, but a reality check for those less in the know; outsiders.

Participants' participation alongside CFS/ME is a huge achievement, but in no way did I want the current analysis to isolate people with CFS/ME by blinding the reader with an adherence to positives. Coping is positive, but participants were forced to cope, forced to adjust to a life they would have never ever chosen for themselves. I felt driven to return to participants to discuss the emerging tension. I asked participants what they thought about the suggestion that my work lacked positivity:

Sometimes getting up in a morning is an achievement, but I don't want that to be an achievement, that pisses me off. It can be really hard to be positive. (Olivia)

I would say the lack of positivity in M.E stems from the lack of understanding and cohesion from medical professions, NICE and the general public. M.E was stigmatised as Yuppy Flu in the 80's. Many medical professionals will not recognise the ME is an actual illness and will dismiss patients as being hypochondriacs, leaving them to fend for themselves in a world where many put it down as being a mental illness as opposed to a physical illness. That being said, why can M.E/CFS patients not give blood or donate organs. If this illness is all in our minds why are there physical markers that stop us from doing certain things. Positivity would come forth if medical professionals would agree on a path of treating/helping ME sufferers

instead of treating them like second class citizens. If half of medicine will not recognise us what hope do we have from not being stigmatised by the general public and the government who are hell bent on not believing us either. (Nettie)

The quote from Nettie above echoes much of what has been rehearsed throughout the thesis in an attempt to illuminate the relationship between the history of CFS/ME and the lived experience of the illness as being one defined by multifaceted struggle; few positives.

It might be good if they had the personal experience of the illness!! It is pretty shit living with it. Only then would they understand. I know I have talked about positive things like appreciation for what I have, love from family, etc. but having the stigma, having the uncertainty re prognosis, the truly unrelenting nature of it, even when supposedly better, is really really tough. (Mary)

Here Mary has inadvertently acknowledged the tension between insiders and outsiders in subjective understandings of CFS/ME. As such, as supervisor A did not have CFS/ME, the current analysis looked biased, whereas in fact it was not biased, but knowing. The following quotes from Katie and Eleanor show how positivity can be problematic in CFS/ME:

People say, "Ooh look, you're doing a degree"... but you can't jolly me out of this, I'm not just a little bit upset, my life has been shattered, and it hasn't been put back together, it's constantly on the edge of being shattering. (Eleanor)

Hmmm will ponder this...but echo what others say, first step is acceptance by others...too many of us experience people thinking our illness is caused by negative thinking, so being positive makes them all think we're OK. It is a really isolating long term illness with no widely accepted treatment so not much to be positive about...humans need connection, belonging and purpose to be content. (Katie)

The proposed triumphant identities of participants are underpinned by a very poor QoL. Participants can be seen as 'doing', but due to their very poor QoL, the achievement surrounding their 'doing' does not privilege them with what might be expected. There was pride amongst the community, but a pride that was burdened by loss:

I think I've achieved a lot, I feel quite proud of myself, but I still feel crap, my identity has been jeopardised, it feels very fragile. (Eleanor)

I am proud of what I've achieved, but I would sacrifice all of my achievements for a better QoL; I can't fulfil any role in life. I was once at the centre of my life, but even though I do participate in life now, I remain peripheral, kind of pushed to the margins. (Olivia)

It is wonderful that people can 'do' in CFS/ME, and this should be celebrated as it is a definite achievement, but an achievement that is aligned with bleakness, despair, grind, and struggle, and in order to understand the lived experience of CFS/ME, there is a need to understand that these

experiences exist side by side. During the period of data collection I wanted to allow participants to be true to their lived experience of chronic illness, as an overarching and unwavering objective was to give participants voice. I wanted to not only listen to their stories, but to hear their stories, stories which reaffirmed that the lack of positivity in the current work was reasonable. I do understand the conflict surrounding a commitment to participants' stories as it is not useful to focus on the negatives, and as such, the answer here was not to say there were no positives, but the tension between the negatives and the positives was really quite subtle. Within health psychology, there is an onus on the relationship between positives, wellness in illness and the enabling of people to cope with chronic illness (Murray, 2004). Ontology such as this closes down the voices of reality. If someone with CFS/ME shares their symptoms with a primary care worker or an outsider, who then comes back at them with a need for them to find the positives, that is silencing. As a researcher with an insider perspective, my interpretation of the literature and data was questioned by someone who was not part of my community. Supervisor A's constructive criticism of my work was not wrong, and we were in essence able to see the same things within the data, but through different lived experiences which engendered a need for different interpretations. As an insider I understood the need for an uninhibited voice:



Figure 1: *An ill person's reality is seen as negativity by the positivity police (ME/CFS Ghost, 2013)*

During the period of data collection, participants were privileged with the freedom to be true to their lived experience of chronic illness. They were able to talk about their symptoms etc. in the knowledge that their words were being received by people who understood. This sense of community also privileged participants with the confidence to discuss positives, such as their participation in CFS/ME in the knowledge that they would not be misunderstood; Yes, I can participate alongside CFS/ME, but that doesn't mean that I am well, and that doesn't mean that I am faking it. The enabling community that was cfsid provided an insight into why participants never spoke more positively than when engaged about their '*virtual community*'; Facebook.

The renegotiation of life and self through a 'virtual' connection to others, and the mediating effect of social media support; purpose, meaning, and an enabling community

I set up a Facebook group to help both myself and others in similar situations which has been a huge source of encouragement, purpose, support and a way to feel part of the ongoing world. I have made some amazing people that I can now call friends. (Julia) (Timeline activity)

Here Julia suggests Facebook provides a gateway to self help and an opportunity to help others, which has been a source of encouragement and purpose for Julia, which perhaps reflects the scepticism surrounding CFS/ME and the innate need for purpose and meaning as indicative of an identity of practice. Julia also suggests that the support of and connection to others; new friends, on Facebook enabled Julia to '*feel part of the ongoing world*' in her lived experience of chronic illness: CFS/ME. For Julia, Facebook appears to have been an enabling community, not just in terms of identity, but also QoL through the reality of purpose, meaning, and friendship.

And subsequently in a private message, Julia spoke further about her experience of a virtual community:

Knowing the group I created as a safe place for people to express themselves (born out of being oppressed in another group and thought I'd have a go at creating my own...never believing it would take off as it has) is still astonishing to me..it can be hard work at times but bloody well worth the effort. That people love being there and have formed bonds is overwhelmingly magnificent for me. I guess I'm really chuffed with myself for having come up with the idea of the lighter side.

The '*safe place*' Julia refers to here represents Facebook as an enabling community as it is alleged that members of Julia's Facebook group '*feel free to express themselves*'. Such self expression reflects the role of reification in the virtual community of Facebook, as members can arguably recognise themselves in others and in so doing their lived experience of chronic illness is reified which enables them to share their experiences freely. The privilege of such reification is not to be underestimated as, as rehearsed throughout, CFS/ME is largely experienced as an illegitimate illness and as such the CFS/ME community often falls silent. However, the '*safe place*' that is Facebook for Julia, and the members of Julia's group reifies CFS/ME as a legitimate chronic illness, which allows members to be legitimately ill which in turn allows them to 'be' and to perhaps unburden themselves.

Through Facebook Julia also appears to feel as though she has triumphed over adversity. Julia's triumph reflects the purpose and meaning concepts of CoP whilst also being indicative of a new and positive identity in CFS/ME. It is evident in the quotes above that Facebook has been and continues to be hugely rewarding for Julia, which echoes the sentiments of Fiona:

I am so glad to be on Facebook and have found a lovely ME group on there. We have a local ME group too who meet regularly for cuppa and chats. (Fiona) (Private message)

For Fiona, Facebook has transcended 'virtual' to 'real' as not only is Fiona a part of the virtual Facebook community, but that community also comes together in the real world, which would compound the experience of belonging, identification, community, and identity for Fiona through a reaffirmed connection to others; participation (Wenger, 1998). Facebook for Fiona has therefore been an enabling community, not only in the virtual sense, but also in the real world sense.

Fiona subsequently added:

I feel I have some purpose in my online MEgroups supporting others with ME, especially when they are feeling much worse than me..... it's good to brighten someone's day/help them thru a bad day/week..... (Private message)

It is evident in the quote above that Facebook gives Fiona a sense of purpose, and meaning as despite Fiona's own struggle in CFS/ME, Fiona continues to help others, which would arguably help Fiona to feel good about herself and contribute towards a nurtured positive identity within her lived experience of chronic illness and struggle of CFS/ME. The CFS/ME dynamic as discussed in C5 is evident here. Although the reality of a CFS/ME hierarchy; peripheral versus established participation within the practices of CFS/ME, is not discussed explicitly in the quote above, it is there, hidden within the support Fiona gives to others. Fiona has been ill for 6 years, and during those 6 years, Fiona has grown to know and understand CFS/ME. Her participation within the practices of CFS/ME is therefore established, and as such she is able to offer support to those whose position may be more peripheral, to those who have not been ill for long as Fiona. The help that Fiona is able to give others online reflects the role of reification in such communities, as the support Fiona gives others is not independent of the understanding of CFS/ME and associated reification such as familiarity of symptoms, that breeds in such groups through the openness of its members and privilege of free speech.

The following quote from Dan gives an insight into the multifaceted value of Facebook in the lived experience of CFS/ME:

I came to FB because my local support group had/has a page. Prior to that I had no interest in FB at all. I joined a few FB ME groups and began firstly to get an understanding of ME and its implications for myself. FB then became a place where I could share my symptoms and experiences to help me know that what I have is normal in and abnormal illness. Now it is a place where I can help support others coming in new and has provided me with a safe haven

and community that is ostracised from the mainstream due to politics, bad science and bigotry. (Conversation data)

Through Facebook, the established participation of fellow members in the practices of CFS/ME, and CFS/ME understandings as reified by commonality of experience, Dan was able to learn about the reality of CFS/ME which reflects the lack of investment in CFS/ME which causes sufferers to turn away from primary care and towards any guiding light, which in Dan's case, was Facebook. Similarly to the members of Julia's group, Facebook also allowed Dan to identify with others through the reflection of his own unfamiliar experiences in the experiences of other, more established members. Dan's participation within the practices of CFS/ME on joining CFS/ME Facebook groups was peripheral, but with the passage of time, Dan's experience of the practices of CFS/ME became such that his role within CFS/ME Facebook communities became one of support; established participation. A supportive role such as this aligns with an experience of both purpose and meaning for Dan, which according to Wenger (1998) would contribute towards a more positive identity in CFS/ME, a positive identity which was not enabled in the real world due to the scepticism surrounding the illness. Facebook for Dan has been an enabling community in many ways, and in a private message, Dan gave further insight into Facebook; an enabling community:

From my support group, I found they had a Facebook presence. I hadn't used FB before and eventually managed to get a profile and become a regular FB user. At this point I was still housebound - again, a major factor in helping me was the online support and comparison of symptoms. The "Do you get this happening?" sort of question. Something I hadn't realised was that I am a gregarious individual who needs social contact. I'd believed myself to be an independent loner sort, but the illness imposed isolation followed by the almost live virtual contact showed me that I badly needed social contact and that my sense of self-worth was affected by not having any.

When I joined FB, I made a pact with myself that I would use my experience strength and hope in a positive way, drawing on my prior experience of being a member of AA. Again, this ratcheted up my damaged selfworth, realising that I was able to turn a negative experience into something of value to others.

The first quote above adds more depth to the insight given by Dan into the relationship between Facebook, legitimacy through reification, and the established participation of others in the practices of CFS/ME. Although Dan was chronically ill, it would appear Dan's lived experience of chronic illness prior to joining Facebook, did not align with an experience of support and understanding in the real world. Thus, it was through the virtual support and reflection of more established others within the enabling Facebook community that allowed Dan to understand his chronic illness; Dan was ill, but Dan was no longer alone and unfamiliar. Despite Dan's chronicity, he claims a knowing need for social contact and through Facebook Dan was able to interact with, and connect to, familiar others. According to Wenger (1998), such interaction would nurture identity. Dan has also used his capacity

to help others on Facebook to counter the negatives of CFS/ME by drawing positives from his personal experiences on Facebook; purpose, meaning, and identity.

According to Julia, Fiona, and Dan, Facebook has been a place to negotiate purpose and meaning; identity whilst also being a place to find familiarity and comfort through reification; knowing you're not alone, which was echoed by a number of participants:

I came to Facebook to find people who suffered the same as myself, this gave me a feeling of comfort that i was not alone in this. (Catriona)

Can answer all three in the same way...information to help me take control of my own healing, community, validation, support. And I get all of these here, thanks people x (Katie)

I searched by accident to see if there was any pages found a few and have not regretted it, I found like minded people with the same symptoms makes me feel better about this illness but not at the same time. (Dark Knight)

Facebook groups help me feel normal and not alone when facing disbelief and lack of support from others. The experiences I have seen from others mirror my own and give me a greater belief in fighting for our rights xx (Jessica)

As discussed in C1, there is considerable discontent amongst the CFS/ME community regarding the psychological model of CFS/ME which does not reflect the lived experience of CFS/ME. The previous theme: *It's not just about me*, gave an insight into participants' experience of this which highlighted that participants were not enabled in their potential to belong to a community of chronic illness within primary care and beyond, when the community within which they were positioned was at best ill fitting. According to Wenger (1998), it is through the mutual negotiation of meaning, the formation of trajectories, and the unfolding of histories of practice; from peripheral participation to established participation, that an identity of community is enabled. As such, participants often do not feel that they belong and as a result often struggle to identify. The identification concept as discussed by Wenger (1998) suggests we '*identify as*' and we '*are identified as*'. The stigma of CFS/ME is relevant here as although participants do not identify with the psychological model of the illness, people such as those in primary care, family and friends sometimes do associate them with the psychological model, and as a result participants are identified and reified as being a certain type of person suffering a certain type of chronic illness, which is problematic and burdening. Although there is an undercurrent of isolation and illegitimacy in the quotes above, here participants are providing an insight into the enabling virtual community that is Facebook, a community that is supportive of their lived experience of chronic illness and therefore one that allows a sense of both belonging and identification. Through the reflection of participants in the reflection of others, and the established participation of others in the practices of CFS/ME, participants' lived experience of CFS/ME is reified and therefore legitimised. Through such reification and legitimisation comes a voice and a presence that appears to negate the isolation of CFS/ME:

Now it is my main contact with the outside world. but in my last 2 yrs I have met some lovely people who know what I am going through, understand the aches, tiredness and frustration. I also use it to play scrabble, a small way of keeping my brain active. it has it's good uses and bad as sometimes you just sit staring at a screen to find people to talk to, but it's mainly a good thing as I can talk to like minded people and helps that I can vent without my family knowing ☺ (Netty)

Facebook helps me to keep in contact with other people and groups. Without it I would have no social life as I don't go out to socialise and don't like talking on the phone. The lighter side ME group has helped me when I have an unexplained symptom and found that others have the same and they understand without judging you. (Louisa)

I have been a user of Facebook for quite a long time as it allows me to keep in touch with a wide range of friends and family especially my daughters when they went off to university. When I became ill Facebook was a lifeline - with limited concentration and unable to get out it gave me a window onto the world which I could access as much or as little as I was able. After a while I started researching about ME and discovered various blogs and Facebook pages which gave me an insight into other peoples' lives and helped me to realise I wasn't the only one. Now I have made new 'ME' friends on Facebook which allows me to talk about things that I wouldn't want to bore my friends and family with, it has also given me opportunities to look at helping people with ME and I have been in contact with other healthcare professionals with ME to share our experiences. (Kate)

Do you know I've been on facebook so long I can't recall why or when I first came to it. BUT I know why I love it so much and what it means to me. Facebook has replaced the world I used to have. Ok it's a virtual world but some of the friends I have made are real. The first thing I like to do in the morning is to check what's happening on face book and how my friends are each day. I have found wonderful friendship and support and would be totally lost without it. It's also a very powerful and useful way of disseminating information, especially about my illness M.E. It stops me from feeling lonely and isolated. It helps me to know that there is always someone who will understand how I am feeling. It's a form of entertainment when I'm unable to do much else. It's a place to go for help and advice when I'm having any sorts of problems. It gives me a sense of purpose and satisfaction. It enables me to contact people from all round the world. It enables me to have contact with members of my family. I use it a lot to raise awareness and understanding of M.E. I help others to understand M.E. In fact I think it's wonderful!! (Ros)

I love what you said Ros :) I wish fb had been around when I was ill as a teenager. I now see some of my severely affected friends having a virtual life and that is so precious. I used to have to wait for post - which was fun too, but it's not like the interactive and wide-reaching support of fb. I didn't come to fb looking for ME groups and I barely interact with any although I do get news from the ME Association and liME. I can connect with friends in a lovely,

undemanding way. I can 'see' people and what they're getting up to, although I have often not been part of it. I can be there for friends who are more ill. I have not used fb for ME support, but that's because I haven't needed it. But it does make maintaining friendships easier. Friendships in the real world can be difficult - not being able to see people that regularly, etc. So fb helps with that. (Mary)

The reality of Facebook for participants was one of enablement; familiarity, acceptance, support, purpose, meaning, and community. Participants were able to negotiate their identities on Facebook through their participation within a community that was able to reify their experience of chronic illness which enabled their legitimate CFS/ME identities. Thus, the virtual community of Facebook helped participants to belong and identify with others whose established participation, not only within the practices of CFS/ME, but also within the virtual CFS/ME community, was a guiding light. As opposed to feelings of isolation and unfamiliarity as expressed on discussing the real world, participants reflected upon experiences of togetherness and familiarity in their virtual world that was Facebook. Within the enabling Facebook community, participants may have initially acquired a peripheral position, but a peripheral position that did not marginalise or silence. The peripherality and marginality concepts as discussed in C2 (Wenger, 1998) are disabling concepts as they rarely lead to full participation, whereas the re-conceptualised peripheral participation rehearsed in the current section is an enabling concept. As such, the reliable trajectory within CFS/ME as defined by peripheral participation in the practices of CFS/ME to established participation in the practices of CFS/ME within the virtual CFS/ME community enabled participants to 'be' on Facebook, perhaps for the first time in many years, and as rehearsed throughout, an ability to 'be' in chronic illness enables an identity in chronic illness. As such, CoP would suggest an identity would struggle to be sustained when the overarching experience of life is one of isolation as isolation is not indicative of participation; identity. However, in the current theme on exploring coping in CFS/ME I initially foregrounded the partnership of acceptance and adjustment as the foundation of coping in CFS/ME. I then discussed how the support of others in CFS/ME also appears beneficial to coping as the support of more established support of and connection to others is virtual, but appears of equal value to participants in their lived experience of identity and QoL in CFS/ME. In C2 I acknowledged that although the current research is heavily focussed on identity, that the relationship between identity and QoL may emerge within the analysis. It would appear the reality of Facebook for participants not only reflects their nurtured identities in CFS/ME but also the negotiated QoL of participants as their ability to 'be' alongside 'legitimising others', and the journey from peripheral participation to established participation on Facebook, a journey underpinned by emancipation, appeared to be a privilege to both life and self in participants' lived experience of chronic illness: CFS/ME. The reality of such emancipation as discussed here is currently virtual, and as such, although Fiona's virtual Facebook community enabled participation in the real world, this, it would appear, is not always the case. However, perhaps the reification, support and encouragement experienced within virtual communities such as Facebook for those who are inadvertently marginalised, such as those with CFS/ME, may have the potential to contribute towards the courage and strength required to participate in the real world that is known as hostile. Similarly, perhaps the treasured reality of such virtual communities could be shared with

primary care workers as to demonstrate how beneficial belief; support, is in the lived experience of CFS/ME.

Chapter summary

In an attempt to allow the positives of CFS/ME to surface, the current theme initially considered coping in CFS/ME through acceptance and adjustment as letting go of the past and looking to a future in which one is different appeared to be an attitude that was essential to coping in CFS/ME. Finding a new way to be in the world, a new way to participate moreover appeared to contribute towards both coping and QoL in CFS/ME through the experience of purpose and meaning for participants as participants were able to be more than their chronic illness when they were able to participate. However, such participation although undoubtedly positive was not free from the burden of struggle and as such, struggle was indicative of the challenge of living well with CFS/ME for participants; limited positives. The chapter then returned to a discussion from C7 regarding the questioned lack of positives in the current work. Reflection was given to the reality of insiders and outsiders in interpretive work which foregrounded the role of community membership in analysis. An overarching aim of the current research being to give the CFS/ME community voice, was also given further consideration. As such, it was concluded here that although there was an alternative, more positive way to interpret the data, that the lack of positives in the current work was reasonable and knowing. However, although participants appeared to find new ways to be in the world through various forms of participation which engendered feelings of purpose and meaning; identity, it was on discussing their virtual connection to others that participants expressed a transparent positivity. On living in a world that silences, marginalises, and discriminates to existing virtually in a world which prides itself on acceptance, support, purpose and meaning, participants were no longer isolated or silent as through reification and legitimisation of CFS/ME, they experienced a cathartic and inclusive sense of belonging and identification in a virtual world that for many was akin to a lifeline and a way to be in CFS/ME.

CHAPTER ELEVEN (C11)

CONCLUSION

Broadly speaking, the current research endeavoured to explore the lived experience of identity in chronic illness: CFS/ME from a perspective that would allow for the consideration of historical and contextual factors, whilst also enabling the application of a re-conceptualisation of Wenger's (1998) CoP theory in an attempt to make sense of the issues of identity which appear central to the lived experience of chronic illness. Although the unpicking of the struggle of identity in CFS/ME was a driving force, the current research also wanted to be able to show how people with CFS/ME can renegotiate a life and self despite their lived experience of chronic illness. Exploration of the jeopardised identity in CFS/ME and the renegotiated identity in CFS/ME aligned with an emancipatory framework as the desire to provide a guiding light was an overarching aim of the current research. I will begin the conclusion by reflecting upon the extent to which the research aims as discussed in C5, were met:

- Explore the shifting social identity of those living with Chronic Fatigue Syndrome (CFS/ME) and the subsequent impact such shifts have on the sense of 'self' and identity of those living with CFS/ME;
- Explore the utility of Wenger's (1998) 'Communities of Practice' theory in understanding identity in chronic illness.

The wealth of cfsid data was underpinned by the above research aims, and as such the research aims were met, but some less so than others. The shifting social identity of participants was illuminated within the analysis, as was the re-conceptualisation of CoP. However, on reflection, although I have attempted to interweave and demonstrate the application of CoP concepts within the analysis, had I been more explicitly driven by specific CoP concepts during the period of data collection as opposed to the overarching 'identity is participation' CoP concept, perhaps the potential of the re-conceptualisation to provide a way to understand the lived experience of identity in chronic illness: CFS/ME could have been even more transparent.

- Widen the knowledge about CFS/ME; and by extension contribute to the chronic illness literature in general, how it (CFS/ME) is experienced, how the person interacts with the illness and the context of the person and the illness.

As rehearsed throughout, although the current research is CFS/ME focussed, the current research also endeavoured to transcend CFS/ME to other chronic illnesses; an endeavour which I believe was achieved by the consideration given to the parallels between the lived experience of CFS/ME and the lived experience of chronic illness in general. However, although the history of CFS/ME was foregrounded to demonstrate the role of context in the lived experience of CFS/ME, in hindsight, for this role to have been more explicitly substantiated, a greater focus on the context of other chronic illnesses and the relationship between the context of other chronic illness and the lived experience of other chronic illnesses would have been useful here.

- Provide an insight into CFS/ME for those who live with CFS/ME who may be unaware of the ramifications of the social construction of CFS/ME but who may be in a position to challenge and negotiate any associated oppression and marginalisation.

As the overarching aim of the current research was to provide a guiding light for those affected by chronic illness: CFS/ME, the above research aim emerged as a primary research aim. The commitment to provide an insight into the history of ME and the construction of CFS/ME, for both insiders and outsiders was compounded by a commitment to enlighten. Enlightenment cannot change the physical reality of CFS/ME, but feelings of stigma and shame, experiences of hostility etc. can serve to exacerbate the lived experience of CFS/ME. If the injustices surrounding CFS/ME are laid bare, I believe there is the potential for building blocks of emancipation. Although the current research was unable to test the relationship between enlightenment and emancipation, future work will endeavour to do so.

- Explore the mediating effect of social media support in chronic illness: CFS/ME.

The emergence of QoL through Facebook was unexpected, and as such was not a primary research aim, but one that evolved during the period of data collection. Therefore, the data pertaining to this particular research aim was more limited than the data pertaining to other research aims. However, the limited exploration of the mediating effect of social media support did provide a fascinating insight into the coping and pragmatism of those with CFS/ME who fought for a sense of community as to counter their problematic participation in real world communities.

Silencing in the group; dominant cfsid voices

Although cfsid provided a wealth of data, a well educated verbal group soon took the reins. On joining cfsid many participants provided voluntary introductions (main cfsid homepage), however, it was a subset of participants who contributed the most and a subset that was both knowledgeable and confident. During the period of data collection, I worried about the potential reality of some cfsid participants being silenced by others. I wanted people with CFS/ME to have a voice, all people, not only those who were well educated and verbal. As such, although the data that was emerging in cfsid was wonderful data, I was troubled by the fact that the data was perhaps unrepresentative of the broad spectrum of people with CFS/ME as the majority of the data was reflective of the lived experience of the dominant subset. However, I subsequently considered the fact that even if *all* participants had contributed richly; I would not have been able to claim that the data was representative of the experience of *all* people with CFS/ME. I did not want any participants to be silenced, but were they silenced or were they just less invested in the research, more unwell or busier than other participants etc.? Unless I return to cfsid to ask this question, my silencing theory will remain unsubstantiated. The last thing I wanted was for anyone with CFS/ME to be silenced in cfsid, and so if some people were, I feel both a sense of responsibility and regret. I wanted to allow a community to emerge and so the conversations and the open sharing of stories and activities in cfsid was central to the potential for the emergence of a community, but in hindsight, had I communicated

privately with all participants as opposed to predominantly communicating via the main cfsid homepage, perhaps a broader spectrum of cfsid participants would have been better enabled to engage with the research.

Despite the above critique, I do believe that social media enabled my research, and as such I would most definitely consider using social media in future work. I believe the familiarity and ease of use for participants, and the relationship that was able to develop between myself and participants to be fundamental strengths of the current research. Furthermore, on analysing the data, the fact that I was able to return to participants to address any gaps and/or inconsistencies was an undeniable privilege. I wanted to gain an insight into the lived experience of CFS/ME and through Facebook: cfsid I was able to gain this insight. I am not claiming this insight (analysis) as fact, but I do claim that the analysis reflects the subjective experience of some participants which makes transparent the reality of identity and coping in CFS/ME and by extension, the reality of identity and coping in chronic illness.

Implications; contribution to knowledge

The CFS/ME story

Having immersed myself in the CFS/ME literature and on claiming a lack of depth and context in the reviewed CFS/ME literature which I argued gave only a provisional insight into the CFS/ME story, the current research has subsequently provided a thorough insight into the history of ME and the construction of CFS/ME. This thorough insight has illuminated not only the foundation of the scepticism surrounding CFS/ME, but has also provided an opportunity to understand more clearly the reality of the lived experience of CFS/ME. Drawing upon CoP; the reconceptualisation, it became apparent that within the lived experience of CFS/ME there was the potential for both enabling and disabling communities. Considering an emancipatory framework, only when a light is shone on the foundation of prejudice and discrimination does the potential for change have the potential to be realised, and if the reality of disabling communities is to become historical, such communities need to acknowledge their prejudices if they are to shift and become enabling communities.

Foregrounded re-conceptualisation of CoP

As acknowledged in C2, as far as I am aware, this is the first time that CoP has been used within chronic illness research. As such, applying CoP to the lived experience of chronic illness provided a novel way to unpick the lived experience of identity in chronic illness as, unlike the identity theories reviewed in C2, CoP makes explicit the mechanism of identity; identity is participation. An explicit mechanism and therefore a theoretical foundation such as this has provided a clear and concise opportunity to understand the crisis of identity in CFS/ME and in so doing a transparent framework within which to understand the potential for the renegotiation of identity in chronic illness: CFS/ME, through a commitment to renewed and possible forms of participation. Although CoP is constructed as a social theory of learning, the current research has shown that a re-conceptualisation of CoP can transcend transition to the lived experience of chronic illness which provides an opportunity to explore the reality of chronic illness trajectories. When one's life and self have been decimated by chronic

illness, an insight into the crisis of identity, coping and the renegotiation of life and self in chronic illness could light the way for those who are immersed within the darkness of grief; a life and self lost in CFS/ME. It takes time to come to terms with the reality of CFS/ME, and the current research would suggest that there are not really any shortcuts. With the passage of time, one learns how to live with CFS/ME and how to 'be' alongside CFS/ME. However, as knowledge is power, knowledge as enabled by the re-conceptualisation of CoP could better enable the CFS/ME journey for those who are currently reliant on the passage of time, and limited investment of a disabling community; primary care.

Innovativeness of method of data collection; cfsid

As discussed in C5, I claim cfsid aligns most successfully with the notion of a virtual quasi ethnography due to the fact that cfsid occurred online and was not a life space in exacting ethnographic terms. This claim is not unique to the current research and therefore cfsid would not necessarily be considered innovative. However, as existing literature explores, for example, the relationship between social media and the management of chronic disease (Merolli, Gray & Martin-Sanchez, 2013), and how social media can raise awareness of chronic diseases such as lupus (ScienceDaily, 2013), there appears to be a paucity of research exploring the role of social media in chronic illness research. cfsid enabled people living with chronic illness: CFS/ME to participate in the current research. It was a medium through which participants were able to negotiate their participation as they were able to participate as and when they were able to do so. I have claimed the importance of CFS/ME voices throughout, and I do not underestimate the role cfsid played in the enabling of such voices. I believe the reality of cfsid in the current research is one defined by inclusivity, and as such, the current research provides a powerful insight into how people living with chronic illness can be enabled in chronic illness research which is arguably beholden to the layered lived experiences of people living with chronic illness.

An additional originality claim may also be made regarding the insight gained into the role Facebook played in the lived experience of CFS/ME for participants. As discussed in C10, Facebook appeared to be a lifeline for many participants who were moreover unable to participate meaningfully in the 'real' world. The renegotiation of life and self through a 'virtual' connection to others, and the mediating effect of social media support as presented in the current research provided a provisional insight into participants' negotiation of identity and QoL in their lived experience of chronic illness: CFS/ME. This provisional insight has the potential to provide a platform upon which to consider further the seemingly uncharted virtual negotiation of identity and QoL in the lived experience of chronic illness.

Consideration of literature cited; longitudinal data

The analysis revealed a layered insight into participants' lived experience of CFS/ME, a lived experience that would not have been illuminated by a one off interview study; a snapshot. Having critiqued the CFS/ME and identity research in C3, I have argued for longitudinal data in C4, and the current data and analysis reaffirms the value of longitudinal data in qualitative studies. The current

data and analysis reflects a comprehensive insight into participants' lived experience of a crisis of identity in chronic illness: CFS/ME, which lays bare the reality of participants' jeopardised identities. This multifaceted perspective would not have been enabled by a snapshot and as such the current research has shown that if a comprehensive understanding of the lived experience of chronic illness and chronic illness trajectories is to be both enabled and claimed, chronic illness research, such as the current research, is better served by a framework that allows for necessary depth and nuance; a longitudinal framework, which is not limiting. For example, having allowed participants to share their CFS/ME stories and having invested time exploring the multiple losses expressed by participants, the current data and analysis also revealed the foundation of coping in chronic illness: CFS/ME, and as such what is possible for both life and self in chronic illness. Such possibilities did not however emerge immediately but over time within a wealth of multilayered cfsid interactions.

Insider perspective

The generous contribution of participants was enabled by their trust of me, an '*insider*' and the rapport nurtured within the safety of cfsid. My lived experience of CFS/ME privileged me with an insight and insider knowledge that was transparent to participants throughout the period of data collection. I shared both my CFS/ME story and lived experiences with them, which reaffirmed that I understood them as people, and their lived experience of chronic illness. Participants' commitment to the current research rested on the trust that my insider status engendered. Had I not been an insider, but an outsider; a researcher, as in the case of those driving the CFS/ME and identity literature reviewed in C3, I suspect the emerging data would have been constrained by participants' awareness of the limited insight of an outsider.

However, it is necessary to reflect upon the alleged subjectivity of an insider perspective and interpretivism as discussed in C4, C5, and C. I have argued that my insider perspective has ultimately enabled the current research, whilst also being aware that I had to be mindful of the potential blurring of lines between participants' experiences and my own during the period of data collection and analysis. I can confirm that despite concerns, the current research is representative of participants lived experience of CFS/ME, and although there are parallels between their lived experience of CFS/ME and my own, it is indeed their stories that are central to the current research. Having acknowledged the relationship between participation and positives in CFS/ME in C10, and in so doing, having illuminated that all is not lost with a diagnosis of CFS/ME, I can also confirm that my interpretation of the data reflects my total subjective understanding of the illness. I was able to see through participants' experience of participation in CFS/ME, to the reality of their participation often being one defined by struggle.

Where next?

There is a need for further research into the relationship between the context of chronic illnesses and the lived experience of the illness if the context theory as outlined in the current research is to be substantiated. Would the journey of CFS/ME be an easier journey if the context of the illness was not

one defined by, for example, scepticism, hostility, and discrimination? Only future research into a variety of chronic illnesses could answer this question. Similarly, as the current research only offered a preliminary insight into the relationship between identity and QoL in chronic illness: CFS/ME, and the mediating effect of social media support, despite believing in the originality claim, further research is required. Such research could substantiate and make explicit the relationship between social media and QoL in the lived experience of chronic illness. As such, in consideration of the current analysis, if people living with chronic illness could learn how to negotiate not only their identities but also their lived experience of QoL through participation; real world or virtual, the positives in their life with chronic illness could perhaps begin to counter the often overwhelming negatives.

On arguing for the possible relationship between enlightenment and emancipation, and as above that knowledge of the crisis of identity in CFS/ME, of coping, and the renegotiation of life and self in CFS/ME is akin to a power de force in the lived experience of this chronic illness, if CFS/ME journeys are to become less problematic, people with CFS/ME do need more than enlightenment and knowledge. The current research has demonstrated that the stigmatising of an illness is in no way trivial as it becomes a long lasting scar on the people suffering the illness. The lived experience of CFS/ME is underpinned by a millennia of meaning, much of which aligns with the scepticism surrounding the illness. If the lived experience of CFS/ME is to become less problematic, the history and construction of CFS/ME need to be laid to rest as the lived experience of CFS/ME for sufferers needs to be a lived experience that is privileged with respect; belief. If respect was to overcome the scepticism and doubt which underpins many CFS/ME stories, the lived experience of the illness could be one within which support and empathy evolve as central tenets, as in the case of other chronic illness such as MS, which were once shrouded in scepticism and doubt, but are now privileged with legitimisation.

The current research has shown what changes need to occur; there is a need for the medical and psychological profession(s) to re-evaluate the widespread pre-conceptions of CFS/ME and in so doing subsequently re-engage with CFS/ME and people with CFS/ME. Such re-engagement could put an end to the hostility which currently governs primary care interactions and could also open the door to necessary investment, both financial and emotional. If such radical change is to be realised, there needs to be a commitment from all involved. Both the literature review (C3), and analysis revealed that once a medic has personal experience of CFS/ME, knows someone with CFS/ME, their perception of the illness shifts as their mind opens up to the reality of CFS/ME. Perhaps there is a need for people with CFS/ME, and the CFS/ME community to have the opportunity to expose primary care workers to the lived experience of CFS/ME and in so doing, provide an education that would supersede both medical training for CFS/ME as it currently stands, and the understanding and knowledge of CFS/ME as provided by the media. An exposure such as this could enable changes to practice, as the CFS/ME community could foreground the potential relationship between primary care workers and coping. Biomedical research is needed, but the positive management of CFS/ME is dependent upon legitimacy and, as above, financial and emotional investment. As such, aside from

biomedical research, what is needed here is a commitment to the management of CFS/ME. There needs to be a new voice within primary care consultations:

I believe you are ill; I am going to help you to adjust to your new life with CFS/ME, and central to this adjustment is participation. When you find new ways to participate, your new life with CFS/ME has the potential to be a good life. It will take time, but you can do this, and I am here to support you.

The treatments discussed in C1 (p. 23) need revision. There needs to be an opportunity for people with CFS/ME to learn how to live well with CFS/ME, particularly as the consequences of trying to live well with CFS/ME continue to burden. Consideration of how best to do this is required, but provisionally, an occupational therapy programme could be designed for people with CFS/ME. An initial exploration of CFS/ME; a lost life and self, would be followed by a positive focus on the ways in which such losses can be negotiated. A new way to be in CFS/ME would be illuminated by the light and power of participation in the lived experience of chronic illness, and the role of communities of practice. If there was a shift in the understanding, knowledge, and management of CFS/ME, the CoP of family and friends for example, could have the potential to evolve as enabling communities for those with CFS/ME as the analysis revealed that when a community is enabling, participation, identity and QoL are also enabled. As such, part of the occupational therapy programme would benefit from the involvement of significant others to educate them in the ways in which they can be supportive; how to enable participation. Thus, the analysis revealed that when members of communities shifted alongside participants in response to their lived experience of chronic illness, participants were able to be more than their CFS/ME as they were able to participate in both life and self. However, although I have framed the exposing of primary care workers for example, to the reality of the lived experience of CFS/ME to be an 'opportunity', taking on a responsibility such as this would obviously be difficult if not impossible for those residing at the severe end of the CFS/ME spectrum. Perhaps hope rests upon those who do not reside at the severe end of the spectrum, those who no longer reside at the severe end of the spectrum, and insider researchers in the field of CFS/ME, as the current research confirms that medicine is not something that should merely be 'done' to people, but that there is a need for a shift in patriarchal medicine which would allow treatment to become a collaboration. Just as CFS/ME voices need to be heard, so too do patient voices. However, if such 'real life' exposure fails, a commitment to virtual CFS/ME communities by outsiders including primary care workers, and the friends and family of people with CFS/ME, is a commitment that could provide the knowledge and understanding necessary to enable the emancipation of both insiders and outsiders; in CFS/ME, ignorance is destructive.

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APPENDICES

Appendix 1: Reference index of papers published on epidemics of ME 1934-1980 (collected by Dr J. Gordon Parish) [online] Available at: www.meresearch.org.uk [Accessed 4 February 2013].

EPIDEMIC	Authors	Reference
1934 EPIDEMIC 1 Los Angeles City and California State, USA	Gilliam AG	Epidemiological study of an epidemic diagnosed as poliomyelitis occurring among the personnel of the Los Angeles County General Hospital during the summer of 1934. Public Health Bulletin No. 240, April 1938.
	Wilson JC, Walker PJ	Acute anterior poliomyelitis: Orthopedic aspects of California epidemic of 1934. Arch Int Med 1936; 54: 477–91.
	Dunshee JD, Stephens IM	Previous history of poliomyelitis in California. AJPH 1934; 24: 1197–200.
	Leake JP et al.	Epidemiology of poliomyelitis in California. AJPH 1934; 24: 1204–6.
	Van Wart R, Courville C, Hall EM	Epidemic of poliomyelitis in Los Angeles. Preliminary report on the pathological changes in the nervous system. AJPH 1934; 24: 1207–9.
	Bower AG et al.	Clinical features of poliomyelitis in Los Angeles. AJPH 1934; 24: 1210–12.
	Stephens GM	Epidemic of poliomyelitis in South California. AJPH 1934; 24: 1213–14.
	Kessel JF, Hoyt AS, Fisk RT	Use of serum and routine and experimental laboratory findings in 1934 poliomyelitis epidemic. AJPH 1934; 24: 1215–23.
	Hart TM, Luck JV	Orthopedic aspects of Los Angeles County 1934 poliomyelitis epidemic. AJPH 1934; 24: 1224–8.
	Shaw EB, Thelander HE	Poliomyelitis in San Francisco. AJPH 1934; 24: 1229–33.
	Kessel JF, Van Wart R, Fisk RT, Stimpert FD	Observations on the virus recovered from 1934–35 poliomyelitis epidemic in Los Angeles. Proc Soc Exp Biol Med 1936; 35: 326–9.
	Marinacci AA, Von Hagen KO	The value of the electromyogram in the diagnosis of Iceland Disease. Electromyogr 1965; 5: 241–51, duplicated in Bull Los Angeles Neurol Soc 1965; 30: 161–8. (Electromyography: describes findings of chronic cases from 1934 epidemic examined between 1948–52).
1936 EPIDEMIC 2 Fond-du-Lac, Wisconsin, USA	Armstrong G	Report to the Surgeon General, US Public Health Service of the investigation of an outbreak of “Encephalitis” in the St. Agnes Convent, Fond-du-Lac, Wisconsin, 1936.

1937 EPIDEMIC 3 Erstfeld, Switzerland	Stahel H	Die Poliomyelitis — Epidemic bei Stab Geb. IR 37 and Geb Sch Bat II, Erstfeld, 18–30 July, 1937. Die Abortiv — Poliomyelitis. Schweiz Med Wochenschr 1938; 68: 86–91.
	Gsell O	Abortive Poliomyelitis. Verlag Thieme, Leipzig 1938; 20–1.
1937 EPIDEMIC 4 Frohburg Hospital, St. Gallen, Switzerland	Gsell O	Abortive Poliomyelitis. Verlag Thieme, Leipzig 1938; 13–18. (The three Swiss epidemics 3, 4 and 6 are summarised in review articles by Gsell O (1958) and Parish JG (1978).
	Houghton LE, Jones EI	Persistent myalgia following sore throat. Lancet 1939; 1: 196–8.
EPIDEMIC 5 Degersheim, St. Gallen, Switzerland	Gsell O	Abortive Poliomyelitis. Helv Medica Acta 1949; 16: 170–2
1946–47 EPIDEMIC 6 Iceland	Sigurjonsson J	Poliomyelitis and Akureyri Disease. Mixed epidemics of poliomyelitis and a disease resembling poliomyelitis with the character of the Akureyri Disease. Nord Med 1959; 61: 174–82.
1948–49 EPIDEMIC 7 North Coast Towns, Iceland, Akureyri Nov/Dec 1948, Saudakrokur Dec 1948/Jan 1949, Isafordur Jan/April 1949	Sigurdsson B et al.	A disease epidemic in Iceland simulating Poliomyelitis. Am J Hyg 1950; 52: 222–38.
	Sigurdsson B, Gudmundsson KR	Clinical findings six years after outbreak of Akureyri Disease. Lancet 1956; 1: 766–7.
	Sigurdsson B, Gudnadottir M, Petursson G	Response to poliomyelitis vaccination. Lancet 1958; 1: 370–1.
1949–51 EPIDEMIC 8 Adelaide, South Australia	Pellow RAA	A clinical description of a disease resembling poliomyelitis seen in Adelaide, 1949–51 Med J Aust 1951; 1: 944–6.
	Jackson JF	14th Annual General Report South Australia Institute of Medical and Veterinary Science, July 1951 – June 1952; 17.
	Pellow RAA, Miles JAR	Further investigations on a disease resembling poliomyelitis seen in Adelaide. Med J Aust 1955; 42: 480–2.
	Pappenheimer AM, Bailey OT, Cheever FS, Daniels JB	Experimental polyradiculitis in monkeys. J Neuropath Clin Neurol 1951; 1: 48–62.
1950 EPIDEMIC 9 St. Joseph Infirmary, Louisville,	Steigman AJ	An outbreak of an unidentified illness in the Nurses Training School of St. Joseph Infirmary, Louisville, in Kentucky in October 1950. Report to the National Foundation of Infantile Paralysis, 1951. (Data summarised by Henderson DA, Shelokov A, see

Kentucky, USA		Review article 2, 1959).
	Steigman AJ	Epidemic neuromyasthenia. N Engl J Med 1969; 281: 797.
1950 EPIDEMIC 10 New York State	White DN, Burtch RB.	Iceland Disease — a new infection simulating Acute Anterior Poliomyelitis. Neurology 1954; 4: 506–16.
1952 EPIDEMIC 11 Middlesex Hospital Nurses Home, London, England	Acheson ED	Encephalomyelitis associated with Poliomyelitis Virus. Lancet 1954; 2: 1044–8.
	Acheson ED	Outbreak at the Royal Free. Lancet 1955; 2: 395.
EPIDEMIC 12 Copenhagen, Denmark	Fog AT	Neuritis Vegetiva (Epidemica?). Ugeskr Laeger 1953; 115: 1244–51.
	Heidemann H	Opobet optraeden af myositer (epidemic myositis). Ugeskr Laeger 1952; 114: 1504.
	Krarup NB	Opobet optraeden af myositer: poliomyelitis? (Epidemic of myositis poliomyelitis?). Ugeskr Laeger 1952; 114: 1534.
EPIDEMIC 13 Lakeland, Florida, U.S.A.	Henderson DA, Shelokov A	Epidemic neuromyasthenia-clinical syndrome? N Engl J Med 1959; 260: 757-64.
1953 EPIDEMIC 14 Whitley Hospital, Coventry And Coventry District, England	Macrae AD, Galpine JF	An illness resembling Poliomyelitis observed in nurses. Lancet 1954; 2: 350–2.
1953 EPIDEMIC 15 Chestnut Lodge Hospital, Rockville, Maryland, USA	Shelokov A, Habel K, Verder E, Welsh W	Epidemic neuromyasthenia. An outbreak of poliomyelitis-like illness in Student Nurses. N Engl J Med 1957; 257: 345–55.
	Hardtke EF	Iceland disease in Indiana. J Indiana State Med Assoc 1955; 48: 245–50. (Case also described by Acheson ED, see Review article 1, 1959).
1953 EPIDEMIC 16 Jutland, Denmark	Pedersen EP	Epidemic encephalitis in Jutland. A clinical survey for the years 1952–54. Dan Med Bull 1956; 3: 65–75.
1954 EPIDEMIC 17 Tallahassee, Florida, USA	Bond JO	A new clinical entity? Lancet 1956; 2: 256.
1954 EPIDEMIC 18	Deisher JB	Benign myalgic encephalomyelitis (Iceland Disease)

Seward, Alaska		in Alaska. Northwest Med 1957; 56: 1451–6.
1954 EPIDEMIC 19 British Army, Berlin, Germany	Sumner DN	Further outbreak of a disease resembling poliomyelitis. Lancet 1956; 1: 764–6.
	Anon	Not poliomyelitis. Lancet 1954; 2: 1060–1. **
1954 EPIDEMIC 20 Liverpool, England		Comparative epidemiology: see Official Public Health report for Epidemic 24 (1955).
1955 EPIDEMIC 21 Dalston, Cumbria, England	Wallis AL	An unusual epidemic. Lancet 1955; 2: 290. (Further details in Letters, Lancet 1955; 2: 1091 and Lancet 1956; 2: 146)..
	Wallis AL	An investigation into an unusual disease seen in epidemic and sporadic form in a general practice in Cumberland in 1955 and subsequent years. MD Thesis. University of Edinburgh, 1957.
	Parish JG	Epidemic malaise. Br Med J 1970; 3: 47–8.
1955 EPIDEMIC 22 Royal Free Hospital, London, England	Anon	Infectious mononucleosis. Br Med J 1955; 2: 309–10.
	Anon	Outbreak at the Royal Free. Lancet 1955; 2: 351.
	Anon	Outbreak at Royal Free Hospital. Obscure nature of infection. Br Med J 1955; 2: 442–3.
	Compston ND	Epidemic at the Royal Free Hospital. Br Med J 1956; 2: 157.
	Anon	Report on the Ministry of Health for the year ended 31/12/55. Part II on the state of the Public Health: Being the Annual Report of the Chief Medical Officer for the year 1955. Her Majesty's Stationery Office; 71–4. Epidemics 13,16,22,24,27.
	Anon	The medical staff of the Royal Free Hospital. An outbreak of encephalomyelitis in the Royal Free Hospital Group, London, in 1955. Br Med J 1957; 2: 895–904.
	Compston ND	An outbreak of encephalomyelitis in the Royal Free Hospital Group, London, in 1955. Postgrad Med J 1978; 54: 722–4.
	Geffen D	An outbreak of encephalomyelitis in the Royal Free Hospital Group, 1955. Public Health 1957; 71: 13–24.
	Crowley N, Nelson M, Stovin S	Epidemiological aspects of an outbreak of encephalomyelitis at the Royal Free Hospital in the summer of 1955. J Hyg Camb 1957; 55: 102–22.

	Richardson AT	Some aspects of the Royal Free Hospital epidemic. <i>Ann Phys Med</i> 1956; 3: 81–9.
	Anon	Benign myalgic encephalomyelitis. <i>Lancet</i> 1957; 1: 1342. **
	McEvedy CP, Beard AW	Royal Free epidemic of 1955; a reconsideration. <i>Br Med J</i> 1970; 1: 7–11.
	Anon	Epidemic malaise. <i>Br Med J</i> 1970; 1: 1–2. <i>Correspondence: Br Med J</i> 1970; 1: 170–1. <i>Scott BD, Baines JHE, Judge B, Mayne DG; 299–300, Kelleher WH, Gill CH, Hare M, Kane S, Howells BK; 362–3, Compston ND, Dimsdale HE, Ramsay AM, Richardson AT, Acheson ED, Wray JR; 499–501, Gosling PH, Burke GJ, Hopkins EJ, Galpine JF. 1970; 2: 420–1, Poskanzer EC; Parish JG 3: 47–8,</i>
	Ramsay AM	Royal Free Disease. <i>The Royal Free Journal</i> 1970; 9–12.
	McEvedy CP, Beard AW	A controlled follow-up of cases involved in an epidemic of Benign Myalgic Encephalomyelitis. <i>Br J Psychiat</i> 1973; 122: 141–50. <i>Correspondence: Br J Psychiat</i> 1973; 122: 618, <i>Ramsay AM. 735, Parish JG.</i>
1955 EPIDEMIC 23 Perth, Western Australia	Steen AS	Virus epidemic in recurrent waves. <i>BMJ</i> 1956; 1: 235.
1955 EPIDEMIC 24 Gilfach, Geoh, Wales	Jones TD	Virus epidemic in recurrent waves. <i>BMJ</i> 1956; 1: 348.
1955 Sporadic Case: Boscombe, Hants, England	Jelinek JE	Benign encephalomyelitis. <i>Lancet</i> 1956; 2: 494–5.
1955 Sporadic Case: East Ham, London, England	Bonomini V, Montuschi E	Benign encephalomyelitis. <i>Lancet</i> 1956; 2: 629–30.
1955 EPIDEMIC 25 Addington Hospital, Durban and Durban City, South Africa	Hill RCJ	Memorandum on the outbreak amongst the nurses at Addington Hospital, Durban. <i>S Afr Med J</i> 1955; 29: 344–5.
	Association News	Report of the clinical meeting of the Natal Coastal Branch held on the 17th May 1955 at the Addington Hospital, Durban. The Durban “Mystery Disease”. <i>S Afr Med J</i> 1955; 29: 997–8.
	Alexander JS	Observations on neuromuscular dysfunction in the Addington outbreak. <i>S Afr Med J</i> 1956; 30: 88–90.
	Hill RCJ, Cheetham RWS,	Epidemic myalgic encephalomyelopathy — the

	Wallace HL	Durban outbreak Lancet 1959; 1: 689–93.
Sporadic cases: Johannesburg, South Africa, July 1954 – March 1955	Jackson AL, Jacobson S, Cooper B	A disease resembling poliomyelitis. Report of an outbreak in Johannesburg. S Afr Med J 1957; 31: 514–17.
1955–56 EPIDEMIC 26 Segbwema, Sierra Leone, Oct 1955 – Oct 1956	Rose JR	A new clinical entity? Lancet 1956; 2: 197.
	Rose JR	An outbreak of encephalomyelitis in Sierra Leone. Lancet 1957; 2: 914–16.
1955–56 EPIDEMIC 27 Patreksfordur and Thorshofn, Iceland, Oct 1955 – April 1956	Sigurdsson B, Gudnadottir M, Petursson G	Response to poliomyelitis vaccination. Lancet 1958; 1: 370–1.
April 1955 – Sept 1957 EPIDEMIC 29 NW London, England	Ramsay AM, O’Sullivan E	Encephalomyelitis simulating poliomyelitis. Lancet 1956; 1: 761–6.
May – June 1956, Royal Free Hospital, Nurses Preliminary Training School	Ramsay AM	Encephalomyelitis simulating poliomyelitis and hysteria. Lancet 1957; 2: 1196–200.
	Geffen D, Tracy SM	An outbreak of acute infective encephalomyelitis in a residential home for nurses in 1956. Br Med J 1957; 2: 904–6.
EPIDEMIC 29 Ridgefield, Connecticut, USA	Henderson DA, Shelokov A, Heller JH, Stafford T	Unpublished data, quoted by Henderson DA, Shelokov A. Epidemic neuromyasthenia N Engl J Med 1959; 260: 757–64.
1956 EPIDEMIC 30 Punta Gorda, Florida, USA	Poskanzer DC, Henderson DA, Kunkle BS, Kalter SS, Clement WB, Bond JO	Epidemic neuromyasthenia. An outbreak in Punta Gorda, Florida. N Engl J Med 1957; 257: 356–64.
1956 EPIDEMIC 31 Newton-le- Willows, Lancashire, England	Lyle WH	Lymphocytic meningo-encephalitis with myalgia and rash. Lancet 1956; 2: 1042–3.
	Lyle WH	An unfamiliar infectious disease: an account of an outbreak. MD Thesis, University of Manchester.

	Lyle WH	An outbreak of disease believed to have been caused by Echo 9 virus. <i>Ann Int Med</i> 1959; 51: 248–69.
1956 EPIDEMIC 32 Pittsfield, Williamstown, Massachusetts, USA	Deutaman W, Davis RK	(Unpublished - Data included in survey in Henderson and Shelokov. <i>N Eng J Med</i> 1959; 260: 757–64 and 814–18).
1956 Sporadic Cases, Hygiea, Sweden	Hook O	(Data summarised by Acheson ED. The clinical syndrome variously called Benign Myalgic Encephalomyelitis, Iceland Disease and Epidemic Neuromyasthenia. <i>Am J Med</i> 1959; 26 : 569–95).
	Anon	A new clinical entity. <i>Lancet</i> 1956; 1: 789–90. ** <i>Correspondence: Sigurdsson B, Lancet</i> 1956; 2: 298.
	Anon	Encephalitis, meningitis or poliomyelitis. <i>Lancet</i> 1956; 2: 1091. **
1956-57 EPIDEMIC 33 Coventry, England	Galpine JF, Brady C	Benign myalgic encephalomyelitis. <i>Lancet</i> 1957; 1: 757–8 and <i>Br Med J</i> 1957; 2: 645.
	Galpine JF	Benign myalgic encephalomyelitis. <i>Br J Clin Pract</i> 1958; 12: 186–90.
	Galpine JF	Epidemic malaise. <i>Br Med J</i> 1970; 1: 501.
1957 EPIDEMIC 34 Brighton, South Australia	Hicks DA	A new clinical entity. <i>Lancet</i> 1957; 1: 686.
	Anon	Virus meningitis and encephalomyelitis. <i>Br Med J</i> 1957; 1: 811–13. **
	Anon	Epidemic myalgic encephalomyelitis. <i>Br Med J</i> 1957; 2: 927–8. **
	Anon	Benign myalgic encephalomyelitis. <i>Lancet</i> 1957; 1: 1208–9.
	Acheson ED	Benign myalgic encephalomyelitis. <i>Lancet</i> 1957; 1: 834–5.
1958 EPIDEMIC 35 Athens, Greece	Daikos G, Paleologue A, Garzonis S, Bousvaros GA, Papadoyannakis N	<i>Arch Med Sci, Athens</i> 1958; 14: 617.
	Daikos GK, Garzonis S, Paleologue A, Bousvaros GA, Papadoyannakis N	Benign myalgic encephalomyelitis. An outbreak in a Nurse's School in Athens. <i>Lancet</i> 1959; 1: 693–6.
	Gsell O	Encephalomyelitis myalgia epidemica eine poliomyelitisahnliche Krankheit. <i>Schweiz Med Wochenschr</i> 1958; 88: 488–91. **
	Galpine GF	Benign myalgic encephalomyelitis. <i>Br J of Clin Pract</i> 1958; 12: 186–90. **
1958-9 Sporadic Cases, SW	Price JL	Myalgic encephalomyelitis. <i>Lancet</i> 1961; 1: 737–8.

London, England		
1959 EPIDEMIC 36 Newcastle upon Tyne, England	Pool JH, Walton JN, Brewis EG, Uldall PR, Wright AE, Gardner PS	Benign myalgic encephalomyelitis in Newcastle-upon-Tyne. <i>Lancet</i> 1961; 1: 733–7.
1959 Sporadic Cases, NW London, England	Goldwater S	Influenza-like illness. <i>Br Med J</i> 1960; 1: 962–3.
	Acheson ED	The clinical syndrome variously called Benign Myalgic Encephalomyelitis, Iceland Disease and Epidemic Neuromyasthenia. <i>Am J Med</i> 1959; 26 : 569–95. **
	Henderson DA, Shelokov A	Epidemic Neuromyasthenia - clinical syndrome? <i>N Engl J Med</i> 1959; 260: 757–64 and 814–18. **
1954 and 1961 Sporadic Cases, England	Kendall RE	The psychiatric sequelae of Benign Myalgic Encephalomyelitis. <i>Br J Psychiat</i> 1967; 113: 833–40.
1961 Sporadic Case, Basel, Switzerland	Gsell O	Encephalomyelitis myalgia benigna, epidemische Pseudoneurasthenie. <i>Schweiz Med Wochenschr</i> 1963; 93: 197–200 and 196: 1–2.
1961–62 EPIDEMIC 37 New York State	Albrecht RM, Oliver VL, Poskanzer EC	Epidemic neuromyasthenia. Outbreak in a convent in New York State. <i>JAMA</i> 1964; 187: 904–7.
1964–66 EPIDEMIC 38 NW London	Scott BD	Epidemic malaise. <i>Br Med J</i> 1970; 1: 170.
	Ramsay AM	Epidemic neuromyasthenia 1955–1978. <i>Postgrad Med J</i> 1978; 54: 718–21.
1965 School Hysteria Epidemic, Blackburn, England	Moss PD	Mysterious Illness at Girls School. <i>Br Med J</i> 1965; 2: 950. <i>Correspondence: Br Med J</i> 1965; 2: 1062, <i>Epidemic collapse, Lynch CF, Hysteria and “Royal Free Disease” Ramsay AM. Winter Vomiting and collapse Bull Med.</i>
	Moss PD, McEvedy CR.	An epidemic of overbreathing among schoolgirls. <i>Br Med J</i> 1966; 2: 1295–300.
	McEvedy CR, Griffith A, Hall T.	Two school epidemics. <i>Br Med J</i> 1966; 2: 1300–2.
	Anon	Epidemic hysteria. <i>Br Med J</i> 1966; 2: 1280. **
EPIDEMIC 39 Franklin, Kentucky, USA	Miller G, Chamberlin R, McCormack WM	An outbreak of neuromyasthenia in a Kentucky Factory — the possible role of a brief exposure to organic mercury. <i>Am J Epidemiol</i> 1967; 86: 756–64.
	Marinacci AA, Von Hagen KO	The value of the electromyogram in the diagnosis of Iceland Disease. <i>Electromyogr</i> 1965; 5: 241–51. **
1965–66 EPIDEMIC 40 Galveston	Johnson JM, Micks DW	Epidemic neuromyasthenia Variant? <i>Texas Reports on Biology and Medicine</i> 1967; 25: 484.

County, Texas		
	Leon-Sotomayor L	Epidemic diencephalomyelitis. A possible cause of neuropsychiatric, cardiovascular and endocrine disorders. New York Pageant Press, 1969.
1967–70 Sporadic Cases, Edinburgh, Scotland	Innes SGB	Encephalomyelitis resembling benign myalgic encephalomyelitis. <i>Lancet</i> 1970; 1: 969–71.
1968 EPIDEMIC 41 Fraidek, Lebanon	Mourad S, Chidiac J	Benign myalgic encephalomyelitis in Lebanon. <i>Leb Med J</i> 1969; 22: 735–40.
1969 EPIDEMIC 42 Medical Centre, State University of New York, USA	Damadian R	Unidentified symptom complex. <i>N Engl J Med</i> 1969; 280: 1131. <i>Correspondence: Trimble G. Epidemic Neuromyasthenia. N Engl J Med</i> 1969; 281: 105. <i>Fisher CM. On Damadian's Ache, 281: 106. Epidemic Neuromyasthenia, 281 : 797–8. Steigman AJ, Hart RH, Adamson JR</i>
1970 EPIDEMIC 43 Lackland Air Force Base, Texas, USA	Graybill JR, Silva J, O'Brian MS, Reinartz JA	Epidemic neuromyasthenia. A Syndrome or disease? <i>JAMA</i> 1972; 219: 1440–3.
Reanalysis	McEvedy CP, Beard AW	Royal Free epidemic of 1955; a reconsideration. <i>Br Med J</i> 1970; 1: 7–11.
	McEvedy CP, Beard AW	Concept of benign myalgic encephalomyelitis. <i>Br Med J</i> 1970; 1: 11–15. **
	Anon	Epidemic malaise. <i>Br Med J</i> 1970; 1: 1–2. <i>Correspondence: Br Med J</i> 1970; 1: 170–1, <i>Scott BD, et al. 299–300, Kelleher WH, et al. 362–3, Compston ND, et al. 499–501, Gosling PH, et al. 2: 420–1, Poskanzer DC. 3: 47–8, Parish JG.</i>
1970–71 EPIDEMIC 44 Hospital for Sick Children, Great Ormond Street, London, England	Dillon MJ, Marshall WC, Dudgeon JA, Steigman AJ	Epidemic neuromyasthenia: outbreak among nurses at a children's hospital. <i>Br Med J</i> 1974; 1: 301–5. <i>Correspondence: Br Med J</i> 1974; 1: 574–5, <i>Wallis GG, Perry FS. 2: 276, Parish JG. 559, Dillon MJ.</i>
	Dillon MJ	Epidemic neuromyasthenia at the Hospital for Sick Children, Great Ormond Street, London. <i>Postgrad Med J</i> 1978; 54: 725–30.
	Parish JG	Epidemic neuromyasthenia: a reappraisal. <i>IRCSJ International Research Communications, Medical Science</i> 1974; 2: 22–6. **
	Shelokov A	Epidemic neuromyasthenia. In: <i>Infectious Diseases. Hoeprich PH (ed). Harper and Rowe: Maryland 1972: 1297–9.</i>

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	Compston ND	An outbreak of Encephalomyelitis in the Royal Free Hospital Group, London in 1955. 722–4.
	Dillon MJ	'Epidemic neuromyasthenia' at the Hospital for Sick Children, Great Ormond Street, London. 725–30.
	Corridon JP	'Epidemic neuromyasthenia' in Southwest Ireland. 731–6 .
	Ball AP	Disease due to echovirus type 19 in Birmingham, England, 1975: relationship to 'epidemic neuromyasthenia'. 737–40.
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	Currie DM, Shelokov A	Repetitive stimulation abnormalities in 'epidemic neuromyasthenia'. 746.
	Sutton RNP	Ill defined neurological diseases of possible viral origin. 747–51.
	Papiglione G, Harris R, Kennedy J	Electroencephalograph investigation in so-called myalgic encephalomyelitis. 752–4.
	Behan PO	Post-infections encephalomyelitis: some aetiological

		mechanisms. 755–9. **
	Cooke WT	The neurological manifestations of malabsorption. 760–2.
	Crow TJ	Viral causes of psychiatric disease. 763–7.
	Thomas M	Epidemiological approaches to 'epidemic neuromyasthenia': syndrome of unknown etiology (epidemic myalgic encephalomyelitis). 768–70.
	Rundle A	Raised lactic dehydrogenase and glutamic oxalo-acetic transaminase levels and normal creatinine phosphokinase.
	Wilkie D	Low oxygen uptake of lymphocytes, which are intolerant of chlorimipramine. 771.
	Others	772–4.
	Anon	Editorial epidemic myalgic encephalomyelitis. <i>Br Med J</i> 1978; 1: 1436–7. ** 1979 <i>Correspondence: Br Med J</i> 1978; 1: 969, Easton HG. 2: 202, Wookey C.
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1979 EPIDEMIC 47 Southampton, England	May PGR, Donnan SPB, Ashton JR, Ogilvie MM, Rolles CJ	Personality and medical perception in benign myalgic encephalomyelitis. <i>Lancet</i> 1980; 2: 1122–4. <i>Correspondence: Was it Benign Myalgic Encephalomyelitis? Lancet</i> 1980; 2: 1310, Ramsay AM. 1981; 1: 37–8, Geodwin GS. 221–2, Gosling PJH. 325, Ramsay AM. Myoglobinaemia in Benign Myalgic Encephalomyelitis. <i>Lancet</i> 1981; 1: 670, Layzer RB. Myalgic encephalomyelitis, 950–1, Parish JG
1979 Biochemistry	Ramsay AM, Rundle A	Clinical and biochemical findings in ten patients with benign myalgic encephalomyelitis. <i>Postgrad Med J</i> 1979; 55: 856–7.
1980 Review articles	Bishop J	Epidemic myalgic encephalomyelitis. <i>Med J Aust</i> 1980; 1: 585–6 and 609. **
	Behan PO	Epidemic myalgic encephalomyelitis. <i>Practitioner</i> 1980; 224: 805–7.
	Kale SA, Jones JV, Poskanzer DC	Icelandic disease or epidemic neuromyasthenia. (Questions and Answers). <i>JAMA</i> 1980; 244: 2666.
	Behan PO, Behan WMH	Epidemic myalgic encephalomyelitis. In: Rose R, ed. <i>Clinical neuroepidemiology</i> . Tunbridge Wells: Pitman Medical 1980, pp. 374–83.

Appendix 2: Information pinned to the cfsid page

The cfsid message, which was visible to non-members, read as follows:

Hello 😊

Thank you for coming to have a look at cfsid.

cfsid is a group primarily created for the purpose of research. I am a Human & Health Sciences researcher at the University of Huddersfield who is interested in the experiences of others with CFS/ME. MY fundamental aim is to raise awareness.

To learn more, please join the group and then read the 'My Current Research Project' document found in 'Files' above. On joining and learning more about what my research is about, if you don't want to take part or be a member of cfsid you can easily leave the group. I obviously hope you won't want to, but if you do it is an easy process.

Many thanks, Rebecca.

As above, the following information was found 'Files' in cfsid, which was purposefully easy to navigate for participants:

My Current Research Project *Apologies for there being quite a lot to read here, but I thought it would be easier for you if I put all the information into one document!*

Title of Research: Experiences of Social Identity Transition and Chronic Fatigue Syndrome (CFS/ME): A Qualitative Study

Whilst I was studying for my undergraduate degree, I decided to do a piece of research on the experiences of people with Chronic Fatigue Syndrome (CFS/ME). Having been a sufferer for many years myself, I was interested to learn more and to explore the experiences of others. I interviewed a number of people with CFS/ME and found that issues of identity were central to their experience of CFS/ME. I would now like to investigate this issue further by exploring the vulnerable sense of 'self' and identity of those living with chronic illness (CFS/ME). I am particularly interested in what happens to the identity of someone with CFS/ME when they first become ill and throughout their life with CFS/ME.

I have created the Facebook group 'cfsid' primarily for the purpose of my current research project. I anticipate the Facebook group will be active from November 2013 until September 2014. Although I will be able to offer advice on sources of support such as CFS/ME support groups, I will not be able to provide therapeutic support personally. As such, the Facebook group is not a support site, but links to support groups will be provided.

If you are interested in taking part, please read the 'Participant Criteria' below:

Participant Criteria

1. I am aged 18 years or over;
2. I have had CFS/ME for a minimum of 6 months;
3. I have been medically diagnosed with CFS/ME.

If you have answered **YES** to all of the above, please read the '**More Information**' below:

More Information

I would now like to tell you a little more about my research and about me...

As a participant:

- I would like you to interact and engage within the Facebook group 'cfsid' as much or as little as possible and able, but preferably at least once a week. I will begin various conversations about different topics (such as your diagnosis, your first few months of illness, family responses etc.) that I would then like you, as a participant, to talk about within the cfsid.
- I will also encourage you to share your diary experiences (for example, what social occasions you have missed out on that week/month etc.) which provide an insight into life with CFS/ME. I will also upload various articles and headlines to allow you to give your opinion on what is written about CFS/ME in the media.
- I will also upload various photos that I would like you to comment on and in turn I would encourage you to upload photos of what is, for example, important to you and photos which perhaps represent your old life in contrast to photos which reflect your current life with CFS/ME.
- To get the ball rolling, I have created a couple of preliminary activities which will enable me to 'get to know you'. The simple activities are designed to give me an insight into your personal experience of CFS/ME broadly and specific to identity. I will send the activities to you via private message.

It is important here to say that I don't expect everyone to do everything. In short, whatever contribution you can make to my research will be invaluable and therefore very much appreciated. I wanted to include various different types of activities such as the conversations I will begin, the articles I will upload and the photos etc as to make my research as interesting as possible for you. So please don't be overwhelmed by the variety of activities.

I would like an online community to develop which you, as a participant, would be a part of. I hope the online community will allow you to share your experiences of CFS/ME which will help me to gain an insight into your worlds. Some of those who take part online (6 – 10) will be asked if they would be willing to take part in one interview (lasting no more than 1 hour), which could take place either in person or via Skype.

On consenting to take part, I want to make it clear that you can withdraw at any time and can choose whether or not to withdraw previously supplied data (for example, conversations you have taken part in within the Facebook group). Furthermore, the nature of Facebook profiles means that anonymity within cfsid would only be enabled if you created a new FB account (with a false name) for the purpose of participating in my research. However, if anonymity within cfsid is not an issue to you, you can still decide how you want to be represented in the research (for example, you could ask me to use a false name for you when I write up my research).

On a personal note, having lived with CFS/ME myself for a number of years, I understand more than most the difficulties those with CFS/ME face on a daily basis. I am passionate about giving a voice to those with CFS/ME as, in my experience; CFS/ME can be extremely isolating and often misunderstood. During the worst years I was both bedbound and housebound and so I do understand chronic incapacity and isolation. When I was thinking about how to carry out my research, I was drawn to the internet as I hoped an online community would not only benefit me, but also my participants. Additionally, regarding the 6-10 participants I hope to interview, I assure you I intend to make the interviews as easy as possible for you. As such, to reiterate, I am open to using methods such as Skype and will be flexible regarding when the interviews take place and always understanding if they need to be rearranged, for obvious reasons.

If you are still interested in taking part, please read the '**Protocol**' below:

Protocol

By participating within the Facebook group:

- I will be respectful and contribute in an appropriate manner;
- I will be at all times considerate of others' feelings and as such respond with courtesy and sensitivity;
- I will not use offensive language or make comments which could be upsetting or hurtful to others.

I as the researcher will remove anyone from the Facebook group who does not comply with the above protocol. If you would like to take part, please open the '**Participant Consent Form**' document which can be found in '**Files**' on the cfsid page.

The 'Participant Consent Form' document:

PROJECT TITLE:

Experiences of Social Identity Transition and Chronic Fatigue Syndrome: A Qualitative Study.

Material gathered during this research will be treated as confidential and securely stored. Please answer each statement concerning the collection and use of the research data by making **BOLD** either YES or NO.

I have read and understood the information provided on the 'cfsid' blog.	YES/NO
I have been given the opportunity to ask questions about the study.	YES/NO
I have had my questions answered satisfactorily.	YES/NO
I understand that I can withdraw from the study at any time without having to give an explanation.	YES/NO
I understand that if I withdraw from the study I can choose whether or not to withdraw previously supplied data.	YES/NO
I understand that my identity will be protected and that all data will be anonymous within my written research (if desired).	YES/NO
I agree to notes and audiotapes of my interview (in line with conditions outlined above re anonymity) being securely stored.	YES/NO

I would like to see a copy of the data in which I feature.

YES/NO

I agree that the contents from the Facebook group and interview can be used for research purposes unless I withdraw.

YES/NO

Name (printed) _____

Signature _____ **Date** _____

Feel free to contact me if you have any further questions:

Rebecca Murray – rebecca.murray@hud.ac.uk

On completing the participant consent form, please email a copy to me at: rebecca.murray@hud.ac.uk and send a signed hard copy to:

R. Murray

Human & Health School Research Office

University of Huddersfield

Queensgate

Huddersfield

HD1 3DH.

Appendix 3: Participants' biographical data; duration of illness

Anna Marie: 18 years

Annie: 22 years

Catriona: 6 years

Chloe: 16 years

Dan: 34 years

Dark Knight: 6 years

Eleanor: 35 years

Fiona: 5 years

Jessica: 15 years

Julia: 6 years

Kate: 3 years

Katie: 9 years

Laura: 23 years

Louisa: 20 years

Margaret: 32 years

Mary: 22 years

Michelle: 15 years

Netty: 19 years

Olivia: 19 years

Rachel: 4 years

Ros: 13 years

Tessa: 16 years

Appendix 4: University of Huddersfield ethics application

THE UNIVERSITY OF HUDDERSFIELD

School of Human and Health Sciences – School Research Ethics Panel

OUTLINE OF PROPOSAL

Please complete and return via email to:

Kirsty Thomson SREP Administrator: hhs_srep@hud.ac.uk

Name of applicant: Rebecca Elizabeth Murray

Title of study: Experiences of Social Identity Transition and Chronic Fatigue Syndrome: A Qualitative Study

Department: Behavioural Sciences

Date sent: 11/01/13

Issue	Please provide sufficient detail for SREP to assess strategies used to address ethical issues in the research proposal
Researcher(s) details	Rebecca Elizabeth Murray – Human & Health Sciences PhD Studentship
Supervisor details	Dr Jane Tobbell – Director of Studies Dr Abigail Locke – Second Supervisor
Aim / objectives	<p>Having recently completed my dissertation which explored issues of identity and Chronic Fatigue Syndrome (CFS), it became apparent that one's social identity is fundamental to one's sense of 'self' and identity. Therefore, the current research endeavours to:</p> <ul style="list-style-type: none">• Explore the shifting social identity of those living with CFS and the subsequent impact such shifts have on the sense of 'self' and identity of those living with CFS.• Enable further insight into the complexity of the jeopardised sense of 'self' and identity of those living with chronic illness (CFS), an area which has received little attention.• Widen the knowledge about Chronic Fatigue Syndrome; and by extension contribute to the chronic illness literature in general, how it is experienced, how the person interacts with the illness and the context of the person and the illness.• Have the potential to inform school, NHS, workplace and governmental policy.• Contribute to theory by using Wenger's (1999) Communities of Practice theory in a new way and thus extending our understanding of it and perhaps widening the power of that theory.
Brief overview of research methodology	<p>Literature Review: Conduct a literature review to enable a theoretical and practical framework to inform data collection and analysis.</p> <p>Media Analysis: Conduct a media analysis to establish how ME/CFS has been positioned in the media. The media analysis will be my 1st data chapter.</p> <p>Participants: Create an online discussion board from which to collect</p>

	<p>data. Go to existing ME/CFS sites and invite people to join and contribute to the said discussion board. Also create a Twitter account from which to recruit participants. The discussion board will be open to anyone who wants to join, but it will be made clear that for the purpose of my research I am interested in people who have been medically diagnosed and have thus had ME for a minimum of 6 months. Participants will be asked to provide a brief narrative to introduce themselves.</p> <p>Relevant Data: Research objectives will be paramount and therefore it will be made clear that I am interested in the negotiation of one's identity at the onset and throughout the course of life with ME/CFS.</p> <p>Protocol (Attached): There will be a protocol for the discussion board and it will be clear, in participating; participants are abiding by the protocol. I will remove any offensive comments etc. and will be aware of potential vulnerability of participants.</p> <p>Participant Support: The discussion board will provide information sheets which make it clear the discussion board is not a support site and that the data I wish to collect from the discussion board is for research. Additionally, there will be a link to consent forms (Attached) which I will ask participants, when completed, to return to me via email. There will however, be links to support groups on the discussion board (Attached).</p> <p>Risk Assessment (Attached).</p> <p>Pluralist Data Collection:</p> <ul style="list-style-type: none"> • Online discussion board: Will provide daily interaction and focussed discussion (For example, diagnosis, first months, professional shifts, family responses etc.) – I will say I am interested in diary experiences which capture the lived experience of ME/CFS (For example, what social occasions participants have missed out on that week etc.) • Interviews 1 hour x 6-10: Over a one year period 6-10 of those participants from the discussion board will be interviewed 3 times as to allow further insight into their worlds as the discussion board equates to interrupted narratives. <p>Interview 1: Timeline</p> <p>Interview 2: Photos</p> <p>Interview 3: Aspirations/Futures</p> <p>Aware of potential upset; I will stop recording, ask if they are OK to continue etc.</p> <ul style="list-style-type: none"> • Photo Elicitation The 6-10 participants who are interviewed will be asked to take photos of what, is for example, important to them. <p>Data Analysis:</p> <p>All data will be analysed using a theoretical thematic analysis (Braun & Clarke, 2006).</p>
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Study Start & End Date	Start Date: 1 st October 2012 2015 End Date: 1 st Oct
Permissions for study	Participants have not yet been identified, but, permission will be requested to recruit participants from established online communities.
Access to participants	Participants as recruited through online communities and personal contacts, will have a minimum age of 18 years.
Confidentiality	All electronic data will be preserved in password protected files. Any handwritten data will be transferred to electronic form promptly with the handwritten data being subsequently shredded. The discussion board/forum is not a one to one facility and as such all who take part will have access to all posts. However, participants will be asked how they want to be represented in the research. Thus, participants can manage their own confidentiality/anonymity requirements.
Anonymity	All participant names will be changed. All information which identifies a participant will be omitted or altered to preserve anonymity.
Psychological support for participants	To reiterate, interviews will be stopped if a participant becomes upset and will only resume upon the participants instruction. Links to support groups will be provided on the discussion board. Participants will be made aware participation is voluntary and can be terminated at any time and despite having given consent to take part, their data can be withdrawn at any point upon their request.
Researcher safety / support (attach complete University Risk Analysis and Management form)	Risk assessment attached.
Identify any potential conflicts of interest	None expected.
Please supply copies of all relevant supporting documentation electronically. If this is not available electronically, please provide explanation and supply hard copy	
Information sheet	Attached
Consent form	Attached. Consent forms will be emailed or sent through the post, and will be signed and returned (hard copy) before the data collection begins.
Letters	N/A

Questionnaire	N/A
Interview guide	Attached: 1) Timeline 2) Photos (of things which are important to participants which will guide the 2 nd interview) 3) Aspirations/Futures
Dissemination of results	Relevant conferences and journal papers.
Other issues	
Where application is to be made to NHS Research Ethics Committee / External Agencies	N/A
All documentation has been read by supervisor (where applicable)	Please confirm. This proposal will not be considered unless the supervisor has submitted a report confirming that (s)he has read all documents and supports their submission to SREP

All documentation must be submitted to the SREP administrator. All proposals will be reviewed by two members of SREP.

If you have any queries relating to the completion of this form or any other queries relating to SREP's consideration of this proposal, please contact the SREP administrator (Kirsty Thomson) in the first instance – hhs_srep@hud.ac.uk