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EXPLORING THE CONTESTED DIAGNOSIS OF CHRONIC FATIGUE SYNDROME/MYALGIC ENCEPHALOMYELITIS

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Declaration

I, the author, confirm that the Thesis is my own work. I am aware of the University's Guidance on the Use of Unfair Means (www.sheffield.ac.uk/ssid/unfair-means). This work has not been previously been presented for an award at this, or any other, university.

Abstract

This thesis explores the controversial diagnosis of chronic fatigue syndrome / myalgic encephalomyelitis (CFS/ME), which is arguably one of the most contested illnesses. What is particularly striking about CFS/ME is how much is unknown or uncertain about it; including its aetiology, its pathology and even its name. The diagnosis of CFS/ME is a fruitful area for sociological study, yet it remains an understudied area within the sociology of diagnosis. I offer an original insight into CFS/ME and diagnosis by incorporating a historical analysis which frames the contemporary exploration of how people diagnosed with CFS/ME experience their diagnostic journey. There are, I argue, distinct continuities between the historical and contemporary interpretations of fatigue dominated illness.

This study explores how CFS/ME has been historically framed through archival research of two fatigue dominated illnesses: neurasthenia and the Royal Free Disease. It also investigates the social framing of CFS/ME by drawing on 42 semi-structured, in-depth, interviews with people who have received a clinical CFS/ME diagnosis. The focus of which was the participants' clinical interactions and everyday experiences of living with CFS/ME. By combining these two forms of investigation this thesis seeks to provide an exploration of how people interpret and experience illness and diagnoses, both from a historical and contemporary perspective.

The analysis highlights certain key themes that arise from the research data. These include: psychologising, responsibility and legitimacy. These themes feed into the contested nature of CFS/ME and represent continuities between the historical antecedents and contemporary experiences of CFS/ME. I consider the epistemic and ethical implications of having a CFS/ME diagnosis withheld. The research also reveals participants' feelings of loneliness, stigma and invisibility and it is the first study to explicitly focus upon the loneliness and social isolation experienced by people with CFS/ME. I show how loneliness and social isolation can be conceptually distinct yet similarly experienced, through the idea of 'necessitated loneliness'. This thesis offers a greater understanding of the participants' own interpretations of their experiences, bodies and identities.

This thesis contributes to the existing literature on the sociology of diagnosis by identifying how the diagnosis of CFS/ME is experienced as a label and a process which has significant social consequences, including stigma, (in)validation and partial access to the sick role. I will demonstrate the crucial role of labelling in determining how people experience contemporary CFS/ME, and how the historical framing of fatigue dominated illnesses has affected that experience.

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Contents

Abbreviations

- CBT: Cognitive Behavioural Therapy
- CFS: Chronic Fatigue Syndrome
- DSD: Disorders of Sex Development
- GET: Graded Exercise Therapy
- GP: General Practitioner
- MCS: Multiple Chemical Sensitivity
- ME: Myalgic Encephalomyelitis
- MRI: Magnetic resonance imaging
- MUS: Multiple Unexplained Symptoms
- MS: Multiple Sclerosis
- OHEG: Oxford Health Experiences Group
- PTSD: Post Traumatic Stress Disorder
- NHS: National Health Service
- NICE: National Institute for Health and Care Excellence
- OHEG: Oxford Health Experiences Group
- OSOP: One Side of Paper
- VSC: Virtual Symbolic Community
- WHO: World Health Organisation

Chapter 1

Introduction

1.1 Overview of the Thesis

The aim of this chapter is to introduce the background, structure, and intellectual basis for the remainder of the thesis. This research offers a sociological and historical analysis of the contested diagnosis of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). The aim of the study is to reveal the ways in which CFS/ME is experienced as a contested diagnosis. The thesis will be underpinned by a sociology of diagnosis framework. It attempts to illuminate how the CFS/ME diagnosis is experienced as a label and a process which has significant social consequences (Jutel and Nettleton, 2011). Accordingly, the research questions guiding the thesis ask:

- RQ1: How do people with CFS/ME interpret and make sense of their diagnosis?
- RQ2: What is the diagnostic process for someone who has been clinically diagnosed with CFS/ME?
- RQ3: How does CFS/ME impact on the lives of those who have been diagnosed?
- RQ4: How have the fatigue dominated illnesses, neurasthenia and the Royal Free Disease, been historically framed?

By drawing from 42 in-depth semi-structured interviews with people who have been clinically diagnosed with CFS/ME, this research aims to offer insights into how patients experience their diagnostic journey. The study reveals how the patients experienced the onset of symptoms, the "diagnostic utterance" (Fleischman, 1999, p.10), treatments and broader diagnostic experiences. The thesis seeks to situate the diagnostic experience within the wider context of the illness experience and life course of CFS/ME patients.[1] By doing so, the research highlights how the social impact of diagnosis extends beyond the clinic to pervade the personal aspects of the patients' social lives. Further to this, the thesis draws from archival research conducted at the Wellcome Trust library and archives and the London Metropolitan archives. Here, the study provides a sociological analysis of two historical fatigue dominated illnesses, neurasthenia (1869-1930) and the Royal Free Disease (1955 onwards). By exploring how neurasthenia and the Royal Free Disease have been socially and historically framed, the

[1] The thesis refers to the participants as patients because the sample of the interview participants all have a clinical diagnosis of CFS/ME. All the participants were still under the care of their general practice even if they rarely visited the surgery.

thesis offers an insight into the social and historical framings of fatigue dominated diagnoses. A group of symptoms which are dominated by fatigue appear to recur historically. An historical analysis shows how the potential antecedent diagnoses, neurasthenia and the Royal Free Disease, emerge and subsequently ebb away from medical classification[2] and common usage. In the conclusion to the thesis, I argue that there are distinct continuities between the historical and contemporary interpretations of fatigue dominated illnesses.

The intention of the thesis is to offer an original contribution to the sociology of diagnosis, a key subdiscipline in the field of the sociology of health and illness. By combining historical archival research with contemporary empirical research, the thesis also aspires to provide a methodological contribution has seldom been used within the sociology of health and illness. To my knowledge, this is the first study to use a sociology of diagnosis framework to explore how people with CFS/ME experience their clinical diagnosis. This thesis also aims to break new ground within the sociology of health and illness by explicitly addressing the loneliness suffered by people with CFS/ME. The remainder of this introduction will focus on defining CFS/ME and it will provide some background information on the condition. The chapter will then detail the contents of the thesis and provide an outline of some of the key sociological themes with which the research engages.

1.2 Defining CFS/ME

The UK All-Parliamentary Group for ME/CFS[3] (2010) recognises CFS/ME as a long-term neurological condition and the World Health Organisation (ICD-10, Code G93.3) identified CFS as a somatic neuro-immunological condition.[4] The National Institute for Health and Care Excellence (2007) has suggested that the physical symptoms of CFS/ME can be as disabling and impactful as multiple sclerosis and systemic lupus erythematosus. One of the multiple issues involved with defining CFS/ME is that there is a lack of epidemiological data on the condition, but it is a relatively common health disorder, affecting 0.2-0.4% of the population in the United Kingdom[5] (NICE, 2007). While CFS/ME has the potential to affect anyone of any class, gender or ethnicity (Bhui *et al*., 2011), it is generally regarded as an illness

[2] Neurasthenia is listed in ICD-10 but it is rarely used in Western societies. However, neurasthenia is a diagnosis which is still in use in Japan and China.

[3] UK All-Parliamentary Group for ME/CFS (2010) published a report on National Health Service provision of CFS/ME services. It can be accessed here: APPG-Report-v3.pdf

[4] The ICD-11 has now been approved and will be put into effect on 1st January 2022. It lists CFS/ME as a neurological disease in 'other disorders of the nervous system', section 8E49.

[5] The estimate is based on extrapolated data from other countries (NICE, 2007).

which afflicts women, with estimates suggesting that CFS/ME is twice as common in women as it is in men.[6]

The definition of chronic fatigue syndrome and myalgic encephalomyelitis (also known as CFS or ME) has been the subject of debate and contestation (Spandler and Allen, 2017). Scholars (Grue, 2014; Wojcik, Armstrong and Kanaan, 2011) have pointed to how CFS and ME are separate diagnostic categories which have different historical trajectories and differing diagnostic criteria despite the two labels being used simultaneously. Yet, the diagnostic criteria are particularly complex with over 20 different diagnostic criteria for ME, CFS, PVFS (post viral fatigue syndrome) or CFS/ME.[7] In the absence of a consensus and an agreed alternative, this thesis uses both CFS and ME, CFS/ME to denote the same diagnosis. However, the data chapters in the thesis refer to CFS/ME as ME because the research underlying the thesis found that ME was the term favoured by the interview participants. The reasons for this preference will be discussed in chapter four. Although, the Fukuda *et al*. (1994) definition[8] is the most widely cited definition (Lim and Son, 2021; Lim *et al*., 2020), this thesis uses the information detailed in the National Institute for Health and Care Excellence[9] (NICE, 2007) guidelines because NICE informs NHS diagnosis and management of CFS/ME within England and Wales. NICE (2007) treats CFS and ME as being the same diagnosis. The guidelines were expected to be updated and published in 2020 but the update was delayed by the outbreak of Covid-19. There has been a subsequent delay because the committee is struggling to reach a consensus on the best approach to CFS/ME.[10]

CFS/ME is an unexplained illness (NICE, 2007) with an unknown aetiology and pathology. Current theories about the cause of CFS/ME include mental health problems, the longer-term result of a virus

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[6] In 1998 the All-Parliamentary Group for CFS/ME set out to consider how the NHS might best provide care for people of all ages who have this complex illness. The report can be viewed here: CMO-Report-2002.pdf (meassociation.org.uk)

[7] The ME Association is a leading UK charity, and the Chief Medical Officer has been involved in the recent updates to the NICE guidelines. Click here for the charity's description of CFS/ME. URL: What is ME/CFS? | The ME Association

[8] The Fukuda definition is from the Centre for Disease Control and Prevention (CDC). The definition suggests that chronic fatigue is the result of ongoing exertion which is not substantially alleviated by rest or sleep.

[9] For further information on the diagnosis and management, click here for the NICE (2007) Guideline for CFS/ME (2007) URL: Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management (nice.org.uk)

[10] NICE announces delay to the anticipated CFS/ME guideline, August 2021: Click here. URL: NICE pauses publication of updated guideline on diagnosis and management of ME/CFS | News and features | News | NICE

or infection, inherited genetics, and hormonal imbalances.[11] Symptoms include persistent and/or recurrent fatigue which is new or had a specific onset, has resulted in being less active and the fatigue is characterised by post-exertional malaise.[12] In addition to fatigue, the symptoms can include difficulty sleeping, joint and muscle ache without indications of inflammation, sore throat, painful lymph nodes without an alteration in size, cognitive dysfunctions, flu-like symptoms, headaches, dizziness, nausea, palpitations with no known cardiac pathology. Symptoms can fluctuate in severity, alter over time, and vary from person to person. The symptoms encompass far more than fatigue and the condition is multisystemic. The prognosis for patients is uncertain with some patients recovering, improving, or relapsing. The severity of the condition can vary and patients with severe CFS/ME can be housebound while others can have mild symptoms of the condition.

The symptoms of CFS/ME can be similar to other conditions (such as rheumatoid arthritis) and the NHS suggests that people experiencing CFS/ME symptoms should consult their general practitioner (GP) (NHS, 2021). The diagnostic process is one of exclusion because there are currently no biological markers or tests to biomedically identify the condition. The initial diagnosis usually happens in consultation with a GP. The NICE (2007) guidelines recommend tests which should be considered when ruling out other conditions. The NICE (2007) guidelines also suggest that referral to specialist CFS/ME care should be offered to patients within at least six months. However, secondary care referrals are only encouraged if the patient and doctor can agree that it might be beneficial. The referral to an CFS/ME specialist includes confirmation of the CFS/ME diagnosis and then the patient either uses general management techniques for the condition or they embark on a treatment plan which can include graded exercise therapy (GET), cognitive behavioural therapy and/or activity management programmes. Two things are particularly unclear from the guidelines and that is, firstly, which aspects of care and treatment occur in primary care or secondary. Secondly, CFS/ME is not a branch of medicine and the NICE (2007) guidelines do not specify within which specialism a CFS/ME specialist can be found.[13]

NICE's proposed treatments for CFS/ME have been controversial, especially concerning graded exercise therapy (GET). Patients have found GET to be more harmful than helpful and NICE (2021) has suggested that GET will be addressed in the forthcoming update to the NICE guidelines. There is no known cure for CFS/ME but NICE (2007) recommends clinicians treat the symptoms of the

[11] Click here for the NHS description of CFS/ME. URL: https://www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/

[12] Post exertional malaise is experienced within an unspecific period after activity and it can take days to recover (NICE, 2007).

[13] NICE (2007) suggests that if an ME clinic is available to patients the team should interdisciplinary, but the lead specialism is unspecified.

condition, which leaves some room for clinical interpretation. However, there are no specific pharmaceutical drugs targeted at treating CFS/ME although low doses of tricyclic antidepressants (particularly amitriptyline) can be prescribed for people with CFS/ME who have poor sleep and/or pain (NICE, 2007). The suggestions for the general management on CFS/ME include clinicians advising patients on sleep management, rest periods, relaxation techniques, healthy eating, and pacing.[14] This section has sought to offer a description of CFS/ME drawing on a range of resources from respected health organisations (e.g. NICE, NHS and the ME Association). Despite the wealth of information provided by these official organisations, there remains, however, a lack of research and data on the condition, as will be further discussed in the following section.

1.3 Background to the Research

The societal need to investigate CFS/ME is elicited in the NICE (2007, p. 5) guidelines where it is stated that "CFS/ME places a substantial burden on people with the condition, their families and carers, and hence on society". CFS/ME also imposes substantial economic costs on society, mainly in the form of informal care and lost employment (Collins *et al*., 2011; Jason *et al*., 2008). The absence of an agreed upon universal definition of CFS/ME means that research often lacks comparability and standardisation. Medical research into CFS/ME struggles to receive government or medical funding. The biomedical research conducted by the ME Observatory has relied on funding by patients and charities, such as the National Lottery Fund (Pheby *et al.*, 2011). CFS/ME ranks lowly within the medical hierarchy of disease classification because it is contested and currently medically unverifiable. Not only is CFS/ME medically marginalised but those diagnosed with condition find themselves subjected to dismissiveness and intolerance from healthcare professionals (Prior and Banks, 2011) and those within their social networks (Asbring and Narvanen, 2002; Clarke and James, 2003).

The current delay to the updated NICE guidelines for CFS/ME is, however, indicative that more research is needed into the diagnostic process of CFS/ME. On the 17th August 2021, NICE (2021) issued a statement highlighting that there was a need to further consult healthcare professionals and patients so that the guidelines could be passed because a consensus had not yet been reached. Moreover, the update from NICE (2021) suggests that ME/CFS is a complex, multi-system, chronic medical condition for which there is no singular approach to managing symptoms. The update further suggests that because little is known about CFS/ME, there are strong views on the condition. NICE (2021) refers website users from the CFS/ME page to the long-Covid pages within the NICE website. The two

[14] In the NICE (2007) guideline for CFS/ME, pacing is defined as energy management, with the aim of maximising cognitive and physical activity, while avoiding setbacks/relapses due to overexertion.

conditions have also been linked within the popular and medical press. Both illnesses have similar multisystemic symptoms and they both have the potential to be chronic conditions. While we know the cause of long Covid, it is not yet known why some people who have had Covid-19 experience long-covid and others do not. The prognosis for CFS/ME and longCovid is uncertain, and more research needs to be undertaken to understand the conditions.

The starting point to the thesis, defining CFS/ME, was challenging and complicated. Perhaps the one area for agreement on the health condition is that the illness encompasses contestation. CFS/ME is a relatively common condition about which little is known. Literature on the condition exists within sociology but it has often been combined with other contested illnesses or subsumed by research on illness experiences. However, the personal cost of CFS/ME can be significant. As existing qualitative research on illness experiences have shown, living with CFS/ME can be both stigmatising and delegitimating (Asbring and Narvanen, 2002; Dickson, Knussen and Flowers, 2007; Ware, 1992). Roberts (*et al*., 2016) found that people with CFS/ME are six times more likely to commit suicide than the general population. Sufferers have also reported clinical and social interactions where they were accused of imagining the illness, malingering or being mentally ill (Anderson *et al*., 2012). Most of the research on CFS/ME has been conducted within the field of psychology, which has focused on the alleged psychosomatic elements of the illness or the biomedical aspects of CFS/ME.

There is often an underlying assumption in psychological research that CFS/ME is a mental illness or that the condition is indicative of a lack of mental health. Sociological research has shown how the psychologising of CFS/ME is refuted and rejected by patients and CFS/ME activists (Spandler and Allen, 2017), especially within online communities (Dumit, 2006; Lian and Nettleton, 2015). Although there are potentially psychological elements to most chronic illnesses, there appears to be no conclusive medical evidence to suggest that CFS/ME is a psychological disorder or a psychogenic illness. Yet, as some studies have sought to show, CFS/ME can appear to be more stigmatised and psychologised than other contested illness (such as fibromyalgia and irritable bowel syndrome) which also encompass medically unexplained symptoms (Looper and Kirmayer, 2004). Brown (1990; 1995), a key figure within the sociology of diagnosis, has suggested that by exploring conflicted diagnosis and the social imprints of diagnosis we can better understand the underlying and broader mechanisms of diagnosis. One of the key arguments that this thesis seeks to make is that by exploring historical interpretations of fatigue dominated illness, we might better understand how CFS/ME is experienced contemporaneously.

Further to this, the thesis suggests that an in-depth interrogation into the diagnosis of CFS/ME is much needed. By utilising a sociology of diagnosis framework, it is possible to elucidate not only the experience of the CFS/ME diagnosis, but the broader workings of diagnosis. Diagnosis can and does illuminate issues central to the sociology of health and illness, such as medical authority and resource

allocation. Through attempting to understand the diagnostic experience of CFS/ME as a label and a process which has social consequences, a thorough investigation of patient experience can ensue. Moreover, there is a gap within the existing literature which suggests that sociological research into the clinical diagnosis of CFS/ME is needed.

1.4 Thesis Presentation

The introduction has, thus far, given an outline of what CFS/ME is and it has offered a rationale for the study. The introduction will now provide a summary for each chapter, of which there are eight. Following on from this introduction to the thesis, is the literature review which critically engages with the relevant literature pertaining to the study of both CFS/ME and diagnosis. Chapter two begins by suggesting that the study of diagnosis and CFS/ME can benefit from combining an historical and sociological perspective, which includes both empirical and archival research. The review of the literature includes an overview of the sociology of diagnosis, highlighting how the study benefits from a sociology of diagnosis framework. The diagnosis of CFS/ME is then situated within the wider literature on illness experiences with particular attention paid to research relating to CFS/ME and chronic illness. Positioning this study within the broader illness experience is an attempt to capture the experience of diagnosis as a process. In addition to this, the diagnostic experiences of people with CFS/ME have too frequently been subsumed within illness experience literature.

Chapter two positions CFS/ME as a contested illness and the condition is situated within the hierarchy of medical classification. The chapter suggests that CFS/ME is especially contested because it has been more psychologised than other contested conditions with multiple unexplained symptoms. Accordingly, CFS/ME warrants further study as a standalone illness rather than being grouped with other conditions. Literature within the sociology of health and illness has explored stigmatised health conditions and medically unexplained symptoms but the clinical diagnosis of CFS/ME has not recently been an explicit research focus.[15] Patients with contested conditions are often marginalised and there is a need to push forward the patients' perspective on CFS/ME. To my knowledge, there are currently no sociological studies which explicitly focus upon the clinical diagnostic experience of CFS/ME from the patient's perspective. The review of the literature is concluded by establishing how there are few examples of combining historical and empirical sociological research within the sociology of diagnosis. Further to this, the literature review ascertains that there is a gap in the sociology of diagnosis literature which has not given enough attention to the contested condition, CFS/ME.

[15] Clarke and James (2003) have conducted research which includes both clinically diagnosed and self-diagnosed sufferers' experiences of the CFS/ME diagnosis. However, this study focuses only on people who have been clinically diagnosed with CFS/ME.

Chapter three begins by discussing how the chosen methodological tools compliment the combined contemporary and historical exploration of how CFS/ME is a contested diagnosis. The chapter reflects on how the different strands of qualitative research, and the underlying methodologies, weave together to gain an insight into how people with CFS/ME experience their diagnosis both historically and contemporaneously. The second part of the chapter provides a rationale for studying the diagnoses - neurasthenia and the Royal Free Disease. The data collection and analysis are subsequently mapped and the section culminates in detailing how the data analysis formed narratives of neurasthenia and the Royal Free Disease. The third part of the methods chapter suggests the benefits of conducting in-depth semi-structured interviews with people who have been clinically diagnosed with CFS/ME. Crucially, the chapter reflects on my own researcher position and the potential limitations of the research along with areas that might be improved.

The structuring of the data focussed chapters, four to six, reflects how the sociology of diagnosis underpins this thesis. Chapter four pertains to understanding the diagnosis of CFS/ME as a label, chapter five relates to how diagnosis can be conceived as a process and chapter six explores the social consequences of diagnosis which focuses on experiences of loneliness and social isolation. However, the three lenses of labelling, processes and consequences are not mutually exclusive. Instead, they intertwine and overlap within each chapter. Chapter four uses the lens of labelling to explore how the interview participants understood and experienced the social significance of their diagnosis. The chapter demonstrates how the participants preferred ME over CFS in addition to the reasons why.

Chapter four then moves onto consider how the patient experience of CFS/ME clashes with the way it is medically classified and interpreted. Underlining the chapter is an illustration of the asymmetrical power dynamics between clinician and patient (Nettleton, 2013). Reflecting on Parsons' (1951) concept of the sick role, the structural differences between patient and clinician are illuminated. Furthermore, chapter four utilises Fricker's (2007) concept of testimonial injustice to elucidate the limited accordance given to the participants' narratives within clinical encounters. The social consequences of diagnosis are especially highlighted when some participants experienced a CFS/ME diagnosis being withheld. In the absence of a diagnosis the social significance of diagnosis is particularly striking. The epistemic privileges and positions of both clinician and patient are discussed and it is argued that labelling and classifying have very real and tangible social consequences for people diagnosed with CFS/ME.

Chapter five utilises the lens of diagnostic process to understand how people with CFS/ME experienced their diagnostic journey. The chapter largely concentrates on how the interview participants experienced the psychological framing of their diagnosis throughout the process of being diagnosed. Commencing the chapter is a reflection on depression. The interview participants experienced the damaging insistence

that CFS/ME was a mental illness, tantamount to depression or the symptoms being imagined. The participants also experienced the treatments of CFS/ME being framed by psychology/psychiatry despite feeling the illness was somatic. Psychologising the condition negatively impacted on the participants' mental health when they felt unsupported and discredited. A mental health approach to CFS/ME is made evident when the interview participants experienced treatments which focussed upon coping and behaviour. The consideration of behaviour prompts a discussion about patient morality and responsibility within the chapter. The final section of chapter five identifies how those diagnosed CFS/ME manage information about themselves in order to avoid being regarded as a stereotypical CFS/ME patient and being stigmatised with accusations of malingering, hysteria, and mental illness. The work of Goffman (1963) is incorporated into this chapter to highlight stigma, but this study attempts to move beyond identifying stigma by trying to understand the structural mechanisms involved in the stigma experienced by CFS/ME patients.

Chapter six explores the social consequences of the CFS/ME diagnosis by conceptualising loneliness and social isolation. The chapter begins by reflecting on the substantive literature on loneliness and social isolation that relates to living with a chronic illness. Here, I refer to the novel concept of "necessitated loneliness" which is when social withdrawal is an unwanted but necessary part of living with CFS/ME. The reasons for socially withdrawing are two-fold. The symptoms of CFS/ME mean that patients often need rest without stimulation. The second reason is that social withdrawal is a form of self-preservation when people with CFS/ME wish to socially withdraw to avoid the stigma and negativity of others. Friends and family members often sever ties, particularly as the illness worsens or fluctuates. Chapter six highlights how CFS/ME transforms the structuring of time and space for the participants. The concepts of "boundedness" (Little *et al*., 1998, p. 1486), "communicative alienation" (Little *et al*., p.1486), and "liminality" (Little *et al*., 1998, p. 1486) are used to elucidate how loneliness and social isolation permeates the lives of those diagnosed with CFS/ME.

Chapter seven examines the historical biographies of neurasthenia, followed by the Royal Free Disease. The fatigue dominated illnesses are not the same as contemporary CFS/ME, but they do bear some of the same characteristics, such as fatigue being a dominating feature. Neurasthenia and the Royal Free Disease can be regarded as potential antecedents of CFS/ME or ancestors of contemporary CFS/ME. A key figure within the sociology of diagnosis, Brown (1995), suggested that controversial diagnoses can illuminate how diagnostic categories emerge. The chapters prior to chapter seven have argued that CFS/ME is one such controversial and contested illness. Drawing from an analysis of archival data at the Wellcome Trust, the chapter focuses upon the theme of legitimacy. Neurasthenia is introduced to the reader, and it is argued that neurasthenia rose to become a popular diagnosis because it had a social function. Beard (1869), whose work is a focus within the chapter, framed the nervous disorder as a legitimate and organic disease which was associated with elitism, wealth and intellectualism. The

nuances of gender and class demonstrate how different intersections of people were either more or less likely to be diagnosed with neurasthenia at various points in time, as it gained in popularity and subsequently faded from prominence. The possible reasons for the decline of neurasthenia are then subjected to interrogation before moving onto the Royal Free Disease and the outbreak in the Royal Free Hospital in 1955. After introducing the Royal Free Disease, the argument is made that the Royal Free Disease was framed as being viral by the prevailing risk of poliomyelitis. The emergence and decline of the Royal Free Disease are then discussed. Chapter seven demonstrates how neurasthenia and the Royal Free Disease emerge as legitimate organic illnesses and decline in credibility while being linked with mental illness. The historical and social framings of neurasthenia and the Royal Free Disease are therefore elucidated and contextualised through a sociological lens.

The conclusion reflects on the overall study and the research process. Chapter eight considers why it has been important to study CFS/ME and it highlights the importance of using a sociology of diagnosis framework. The conclusion deliberates on the research questions, which are subsequently answered within summaries of the findings from each data chapter (four to seven). I elucidate how the framings of historical antecedents to CFS/ME, neurasthenia, and the Royal Free Disease, contribute to how CFS/ME is experienced contemporaneously. Continuities between the potential antecedent diagnoses and CFS/ME are therefore discussed and expanded upon. The cross-cutting themes of mental illness/psychologising, legitimacy and responsibility emerge historically and contemporaneously within the experiences of the interview participants. It is hoped that the thesis offers an original substantive contribution into how we might theorise CFS/ME and diagnosis. The conclusion will show how the study has attempted to fill the gap within the existing literature on theorising contested illness and diagnosis while enhancing our understanding of the lived experience of the CFS/ME diagnosis. Finally, I offer reflections on the broader applications of the research, as well as the limitations of the study. The conclusion finishes by reflecting on how the analytical insights can pragmatically inform future medical practice and how the revelations of the study can potentially be applied to long Covid.

Chapter 2

Literature Review

Bringing the Contested Diagnosis of CFS/ME into Focus

2.1 Introduction

This chapter critically engages with literature which facilitates and enrichens the study of CFS/ME. It combines a review of texts in the history of medicine with an analysis of more contemporary debates in the sociology of health and illness. The chapter begins, in the first section, by making a case for an historical analysis of diagnosis from a sociological perspective. The need for an historical interrogation of diagnoses is supported by key figures within the sociology of diagnosis, Brown (1995) and Blaxter (1978) and Jutel (2009), who have underlined how diagnoses are historically and socially contingent. The chapter will seek to show how an historical lens can elucidate the workings of medical classification and diagnosis, furthering our understanding of patient experiences of CFS/ME. The historical element of this chapter concludes by arguing that through combining historical research with contemporary empirical research, we are better able to gain an insight into how people with CFS/ME experience their diagnosis.

The subsequent section draws attention to the sociology of diagnosis, which underpins the overall thesis. Sociologists of health and illness have suggested that diagnosis warrants more sociological focus than it has previously garnered (Blaxter, 1978; Brown, 1990; 1995; Jutel, 2009; Jutel and Nettleton, 2011; McGann and Hutson, 2011). However, it is only within the last decade that the sociology of diagnosis has rapidly gained momentum. The topic of diagnosis had not previously been ignored but, rather, subsumed by dominating themes such as medicalisation, the sociology of technology and the history of disease (Jutel and Nettleton, 2011). The sociology of diagnosis is now a prominent subfield within the sociology of health and illness, providing a nascent body of literature. However, CFS/ME is largely absent from this subfield, failing to gain significant traction within the broader discipline of the sociology of health and illness. Much of our understanding of CFS/ME comes from the field of psychology and this chapter argues for a deepened sociological perspective on the illness, especially as the psychologisation of CFS/ME is both controversial and contested.

The remainder of the chapter is then divided into understanding diagnosis as a label and a process which has social consequences. Structuring the chapter in this way reflects how the overall thesis is influenced by a framework pertaining to the sociology of diagnosis. Jutel and Nettleton (2011) have suggested that

diagnosis can be understood in these three interrelated ways (labelling, processing and consequences). The chapter then explores the significance of the "diagnostic utterance" (Fleischman, 1999, p. 10) and situates the diagnostic label within the broader experience of the diagnostic process, both inside and outside the clinic. It argues for the need to explore the human significance of diagnosis by investigating how people with CFS/ME understand and attach meaning to their diagnostic label. Continuing with the theme of labelling, the chapter moves onto consider how diagnoses are categorised and labelled. Through a review of the relevant literature, it is shown how there are incongruities in how CFS/ME is medically categorised and how CFS/ME is treated. At the time of writing, no study has specifically focussed upon the clinical diagnostic process of CFS/ME. Through the review of the literature, it will be shown that there is considerable social significance attributed to how we label, classify and categorise. It is therefore proposed that there is a need to further explore how patients understand and interpret their diagnosis of CFS/ME, in order to explicate the diagnostic label and process.

The chapter then moves on to make the case for analysing diagnosis as a process. It begins by positioning CFS/ME within the hierarchy of the medical classification system by highlighting the plight of contested illnesses. It is necessary to situate the experience of the CFS/ME diagnosis within the broader context of contested illnesses. Brown (1995) has suggested that contested illnesses should be a focus for the sociology of diagnosis because they highlight wider power dynamics within medicine. Literature relating to the politics of contested illnesses points to the need to bring forward the marginalised voices and viewpoints of patients diagnosed with CFS/ME. This section of the chapter also notes that it is unclear why CFS/ME is more psychologised and stigmatised that other contested illnesses with multiple unexplained symptoms. It is therefore suggested that CFS/ME needs to be specifically focused upon as a standalone illness with its own historical lineage. The importance of the patient's voice is highlighted within this section and research on the epistemological stances of patients and clinicians are discussed. The section on diagnostic process concludes with epistemic injustice and how scholars have applied to the concept to CFS/ME.

The final section of the chapter reflects on understanding the CFS/ME diagnosis and its social consequences. The literature on diagnostic uncertainty is relevant to the many ambiguities related to CFS/ME. I draw upon the literature of medically unexplained symptoms (MUS) to demonstrate the impact of feeling ill and living with different types of uncertainty (epistemic, embodied and social). However, this discussion is followed by showing how a diagnosis can have significant ramifications for patients and that the impact of CFS/ME needs to be understood within the broader life course. I reflect on the literature detailing the illness experiences of people with CFS/ME, and find that delegitimation, mental illness and invisibility are interwoven and contribute to stigma. The work of Goffman (1963) is discussed to illuminate the discussion on stigma, but it is not an integral focus. Finally, the chapter moves onto consider the implications of holding a diagnosis of CFS/ME and how this related to the sick

role (Parsons, 1951). This thesis identifies the sick role (Parsons, 1951) as a way of understanding the de(legitimation) of a diagnosis. Overall, the chapter seeks to highlight the ways in which CFS/ME has been under researched within the sociology of health and illness. CFS/ME is a contested condition which would benefit from being both informed by the historical understanding of disease and approached within a framework underpinned by the sociology of diagnosis.

2.2 Historical Interpretations of Diagnosis, Disease and CFS/ME

2.2.1 The Historical Framing of Diagnosis

The introduction has indicated how this thesis is underpinned by a sociology of diagnosis framework. Key figures **(**Blaxter, 1978; Brown, 1995; Jutel, 2009) within the sociology of diagnosis have emphasised how diagnoses are historically and socially contingent, thereby highlighting the importance of an historical analysis to the study of diagnosis. Studying the emergence of diagnostic categories/disease is well established within the history of medicine (Porter, 1987; Rosenberg, 1992; Gilman, 2010). Aronowitz (2001; 2008) and Rosenberg (1992), for example, have shown how diagnoses result from social framing mechanisms. Within the sociology of diagnosis, Brown (1995) has been concerned with how a range of stakeholders play a role in disease discovery. Jutel's (2006; 2010a; 2011a; 2016) research has often incorporated an historical analysis to her work on diagnosis. However, it is surprising that there has not been more attention paid the history of disease within the sociology of diagnosis.

Blaxter (1978, p. 10), who was the first to draw attention to the need to focus more precisely upon diagnosis, explains that diagnosis is "a museum of past and present concepts of the nature of disease", which suggests that a diagnosis is an amalgamation of the historical and contemporary. Similarly, Jutel (2011a) claims that contemporary classification systems contain imprints of many prior conceptions of disease whose inscriptions are etched in the classificatory system, even if they are not in overt use today. This point is echoed by Armstrong (2011, p. 806-7):

> When classificatory systems and explanatory frameworks are in flux there is no Archimedean point from which to see things as they really are: neither causes nor reasons can have epistemological priority. Moreover, in that the classification defines identity it is difficult to say the new classification was 'chosen'... Better then to see medical classification as a fossil trace of an identity that is in part lost and an identity that is in part gained.

Historical diagnoses are therefore not the same as contemporary diagnoses, but they do bear some of the same characteristics. Aronowitz (1992, p. 173) has referred to historical diagnoses as "borderland antecedents", which alludes to the shared features of contemporary diagnostic categories while not

being identical. As the introduction to this thesis has stated, the research explores the diagnosis of neurasthenia and the Royal Free Disease which are treated as potential "borderland antecedents" (Aronowitz, 1992, p. 173) that are not the same as CFS/ME but they share some of the same characteristics. A clearer rationale for choosing neurasthenia and the Royal Free Disease is presented within chapter seven.

As Brown (1995, p. 34) argues, diagnosis "serves as a pathway into the history of medical knowledge and practice" diagnostic categories can therefore be regarded as "sociomedical archives" (Brown, (1995, p 34) which contain "the history of action by all levels of the health care system" (Brown, 1995, p. 34). Brown (1995) suggests that tracing the history of diagnosis can elucidate historical medical knowledge. Yet, historical interpretations of diagnosis can also illuminate how we experience and understand contemporary diagnoses, such as CFS/ME. By looking to the past, we can answer contemporary questions, such as research question number one, "How do people with CFS/ME interpret and make sense of their diagnosis?" Jutel (2006; 2010a; 2011a; 2016) has utilised historical research for sociological purpose, but she has not yet combined contemporary empirical work with historical research. There is currently a a small body ofliterature within the sociology of health and illnesswhich synthesises contemporary empirical work with historical research.

Nevertheless, Jutel (2015) encourages researchers to look beyond the sociology of diagnosis to embrace interdisciplinary approaches to medicine because doing so can provide a deeper insight into how diagnoses operate and frame how we make sense of health and illness. Within her work, Jutel (2009, p. 280), has largely focused on "how diseases came to be part of western medicine, and how individual diseases emerge". Through an historical analysis of the two diseases, post-traumatic stress disorder and Alzheimer's disease, Jutel (2009, p. 280) shows how the "emergence of disease entities can be framed by, and in turn frame, social and cultural values." Jutel's (2010a, p. 1089) later work on the medicalisation of hypoactive sexual desire disorder highlights how:

> The process by which we construct diseases from symptoms provides insight into how we reflect upon the array of things which are before us: dysfunctional and otherwise. A collective cultural position determines which symptoms we will see, which we will brush off as insignificant, and how we make sense of what is there.

Rosenberg (1989, p. 2) also stresses the importance of consensus in the emergence of disease classifications when he states that "in our culture a disease does not exist as a social phenomenon until we agree that it does". However, my study is interested in the contest and conflict in arriving at a consensus (if at all) and the process by which we "brush off" (Jutel 2010, p. 1089) and make sense of disease construction. When undertaking contemporary research, our position as researchers is broadly

speaking, situated within the same contemporary context and culture as our subject of study (diagnosis). Historical research through a sociological lens can therefore help to deconstruct diagnosis and medical classification by providing contextual and historical distance.

The importance of historical distance is supported by Hacking (2001), who has been critical of how classification is seemingly natural and neutral, free from politics and ideology. Similarly, Bowker and Star (1999, p. 326) highlight the invisibility involved in classification where "seemingly purely technical issues like how to name things and store data in fact constitute much of human interaction and much of what we come to know as natural". Not only do Bowker and Star (1999) show how categorising and classifying are an integral part of human cognition/interaction, but their work demonstrates how categorising is central to medicine and science. For sociologists, diagnosis has the potential to offer an insight the history of medical knowledge and practice, as well as medical interaction with other social arenas and institutions (Zavestowski *et al.,* 2004). Combining sociological and historical research can critique diagnosis and illuminate the processes by which we come know a specific group of symptoms as being designated with a particular label. In light of the argument for studying diagnosis historically and contemporaneously, it is surprising, perhaps, that few studies have attempted to combine the two approaches within the sociology of diagnosis.

2.2.2 Historical Perspectives on CFS/ME

The previous section has detailed the argument for an historical and contemporary approach to investigating diagnosis. The current section narrows its focus to how historical perspectives on CFS/ME would benefit from a sociological study of the Royal Free Disease and neurasthenia. The Royal Free Disease and Neurasthenia have been connected to contemporary CFS/ME (Cohn, 1999; Aronowitz, 1998), but previous literature largely focuses upon one of these diagnostic categories rather than studying them in combination (Abbey and Garfinkel, 1991; Ramsay, 1986; Rosenberg, 1962; Shorter, 1992; 1997; Showalter, 1998 Wessely, 1990;). Previous attempts to trace the history of CFS/ME have claimed that the condition is a reincarnation of neurasthenia (Wessely, 1990), a modern form of hysteria (Showalter, 1998), a type of burnout, a culturally sanctioned illness (Abbey and Garfinkel, 1991), or a "trendy non-disease" (Shorter, 1997, p. 52). The history of CFS/ME is therefore itself contested and a historical perspective needs to be articulated and explored in more depth. Often underlining these histories is an attempt to explain what the nature of the condition is. However, this study seeks to engage with how CFS/ME is understood and how the health disorder and its potential antecedents (neurasthenia and the Royal Free Disease) have been interpreted. Armstrong (2003, p. 266) has suggested that an historical analysis of CFS/ME is an "easy picking" because the condition is particularly malleable to cultural and social changes. He also maintains that CFS/ME is more open to historical analysis because no one knows quite what it is**.** Yet, it is the unknown, contested and disputed aspects of CFS/ME which

makes the need for an historical analysis even more pressing.

Historical analyses of ME have not specifically focused upon the diagnosis itself, but Aronowitz (1998, p. 173) provides a sociological perspective on how the history of chronic fatigue syndromes and their "borderland antecedents" are contested. Aronowitz (1998) largely focuses on the outbreak of the Los Angeles Country General Hospital epidemic of 1934 and the chronic fatigue syndromes from the 1980s onwards. His history mainly draws from North American outbreaks and North American definitions of CFS/ME and he shows the process of agreeing a diagnostic label can be fraught with conflict. Aronowitz (1998) points to how medical professionals have historically indicated a belief that patients with CFS/ME are abusing the sick role (Parsons, 1951) by claiming the role without being regarded as being sufficiently ill. By exploring the past, Aronowitz (1998) also highlights the problems in lay and medical conceptualisations of disease legitimacy. Issues of legitimacy are common in the empirical research on the experiences of ME (Clarke, 1999; Ware, 1992). Although Aronowitz's (1998, p. 173) research focuses on the historical interpretations of the "borderland antecedents" to CFS/ME, his research provides context and insight into the research which has explored the contemporary experiences of CFS/ME. Within this thesis it is hoped that by combining historical and sociological research, continuities between the historical and contemporary interpretations of fatigue dominated illnesses can be elucidated, thereby deepening our understanding of CFS/ME. However, in broader terms, exploring contemporary and historical interpretations of CFS/ME has the potential to show how diagnoses are "contested, socially created, framed and/or enacted" and are influenced by wider "social, political, technological, cultural and economic forces." (Jutel and Nettleton, 2011, p. 793).

Lian and Bondevik (2015) have offered a sociological analysis of long-term fatigue illnesses, neurasthenia (1869-1930) and encephalitis (1970 onwards) by comparing medical texts from the respective time periods. Lian and Bondevik (2015, p. 920) show how "The historical controversies surrounding this medically contested condition (CFS/ME) neatly display the socially contingent factors that govern the social construction of medical knowledge". While they provide a contemporary and historical analysis of CFS/ME, there is currently no sociological research which combines historical research with contemporary empirical research into the diagnosis of CFS/ME.

However, a particularly notable historical study of CFS/ME is offered by Cohn (1999) who provides an anthropological and historical perspective on CFS/ME by drawing from interview data and historical biomedical literature. He compares CFS/ME with past illnesses which include global outbreaks of fatigue illnesses, including the Royal Free Hospital outbreak of 1955. Cohn (1999) highlights that from both the patients' viewpoint and the clinicians' perspective, the main concern has been one of legitimacy, which relates to whether CFS/ME was regarded as being a physical disease or a psychological disorder. Cohn's (1999) research is original in the way it combines historical research with contemporary empirical research. However, absent from the research literature is contemporary empirical research into the experiences of CFS/ME and historical research into the potential borderland antecedents, neurasthenia, and the Royal Free Disease. Moreover, what is needed is a sociological and historical analysis of ME, where diagnosis is both the analytical lens and the subject of the study.

2.3 A Sociology of Diagnosis Framework

The historical analysis of disease and diagnosis discussed in the previous section was advocated by scholars who contributed to the sociology of diagnosis. This section details how a sociology of diagnosis theoretical framework assists in the exploration of how the CFS/ME diagnosis is experienced. The sociology of diagnosis was becoming a prominent subfield within the sociology of health and illness when the research proposal for this study was being written. The sociology of diagnosis has therefore influenced how this thesis has been structured, analysed and positioned. Integral to the sociology of diagnosis is Blaxter's (1978) proposal that a diagnosis can be understood as being both a process and a category. The process is "the thing that the physician does: the conclusion reached, or the act of coming to that conclusion" (Blaxter, 1978, p. 9) whereas the category is the location within medical knowledge that a diagnosis is situated. While considering diagnosis as a category and a process provides a useful starting point, there have been significant changes within medicine since Blaxter (1978) wrote her paper on alcoholism being a social diagnosis. Jutel and Nettleton (2011, p. 793) suggested that "while diagnosis still forms the foundation of clinical practice, the day-to-day activity of diagnosing has become increasingly porous, permeated by commercial interests, consumerism and commodification".

My research focuses on labels (labelling) and process (processing) in the diagnosis of CFS/ME. In doing so, it uses a theoretical framework informed by the sociology of diagnosis. Brown (1995) highlighted the need to have a more robust theoretical framework for the sociology of diagnosis. However, despite increasing attention being paid to diagnosis, studies explicitly using a sociology of diagnosis theoretical framework have been somewhat sparse (see: Bell, 2014; Jovanovic, 2013; Madden and Sim, 2016; Morrison, 2019) since the special issue on diagnosis in the journal, Social Science and Medicine which was published in 2011. Swallow (2019) explicitly refers to the sociology of diagnosis in her study on Alzheimer's. She analyses the disease as a classification as well as diagnostic process, showing how

the Alzheimer's diagnosis is replete with uncertainty. Swallow (2019) highlights the ambiguous boundaries of classification when patients are given a pre-diagnosis. The boundaries of health and disease are further elucidated by showing how classification boundaries are negotiated.

Analytically separating diagnostic category from diagnostic process, yet being mindful of their interrelatedness, enriches her broader discussions around diagnosis. Through analytically separating category and process, Swallow (2019) was able to highlight the complex relationships and social structures involved in the diagnosis of Alzheimer's Disease. Although, the thesis separates chapters on labelling and process, it is done with an awareness that both labelling and processes are difficult to extrapolate when researching a diagnosis.

In addition to analysing diagnosis as a label and a process, the social consequences of diagnosis are an integral part of this study. Jutel and Nettleton (2011) have done much to the propel the sociology of diagnosis to become a sociological sub-discipline. In their Special Issue, Jutel and Nettleton (2011) added the 'third rubric' of consequences to Blaxter's (1978) category and process. Jutel and Dew (2014, p. 2) echo the importance of consequences because "both the classification and the process are framed by social and political forces and have social and political consequences". The consequences of diagnosis can be seen to work at both an individual and a social level, involving issues such as stigma, legitimacy, and identity politics. Being diagnosed also has consequences for how individuals are valued by society, such as acting as a gateway to care and social support (Morrison, 2019). This literature review will explore the social consequences of CS/ME in to the context of diagnostic uncertainty, the sick role (Parsons, 1951), stigma and legitimation. There is a gap within the research literature in that there is currently no research on CFS/ME which explicitly uses a sociology of diagnosis framework. However, diagnosis does emerge as a subtheme within studies which detail CFS/ME illness experiences (Broom and Woodward, 1996; Cooper, 1997; Woodward, Broom and Legge, 1995), CFS/ME clinical interactions and online communities formed around CFS/ME (Dumit, 2006; Lian and Nettleton, 2015). The subsequent section begins by reflecting on the diagnostic label and how it is conferred to patients.

2.4 Labelling

2.4.1 A Diagnostic Label: The 'Utterance'

When a patient approaches their general practitioner with a set of symptoms, it is the job of the clinician to arrange the seemingly disorganised set of symptoms into an organised diagnosis (Balint, 1964). The power instilled in doctors to diagnose and categorise, is exemplified by Freidson (1970) and Starr (2004), who show how the professional status of doctors provides doctors with the authority to diagnose but "for medical authority to exist, it must be characterised by both legitimacy and dependence" (Jenkins 2011, p. 106). Although patients are likely to self-diagnose before entering a clinical

consultation (Frankel, 2001), research has also shown how patients often feel a need to corroborate their self-diagnosis with clinicians, even when doing so is actively discouraged (Jutel and Banister, 2013). Through selecting participants who hold a clinical diagnosis of CFS/ME, the participants' interactions with healthcare professionals can be elicited. A sample of interview participants with a clinical diagnosis also helps to elucidate the structural ties and organisational aspects of medical classification, rather just an individual's personal classificatory process. The importance of exploring the classificatory process is especially pertinent for Jutel (2019), who suggests that diagnosis still makes and maintains the authority of doctors, differentiating their profession and knowledge from other healthcare professionals and laypeople. As she states: "putting a name to a disease remains transformative for the individual receiving a substantial diagnosis. Naming it, emerges from, and contributes to the authority of the medical profession in its historic traditions and in contemporary society." (Jutel 2019, p. 302). Through studying the labelling and process of a clinical diagnosis, the power relations and negotiations between clinicians and patient can be better elucidated.

However, the diagnostic process inevitably involves the naming of the diagnostic label. A diagnosis can be at once both "category and an event" (Kokanovic, Bendelow and Philip, 2013, p. 377), a classification and a diagnostic instance. Jutel (2014) suggests that the diagnostic moment, when the diagnostic label is first mentioned, can alter how life is perceived and experienced. The significance of the diagnostic moment is demonstrated by Fleischman (1999, p. 10) who refers to the diagnostic "utterance", marking a distinction between before diagnosis and after, suggesting life will never quite be the same again after the condition/disease has been named. However, the attention to the "human significance" (Peek, 2017, p. 35) of a diagnosis can sometimes be lost in diagnostic utterance, when the "chasm between 'lay' and 'expert' knowledge is at its deepest and the new 'patient' is at their most vulnerable" (Peek, 2017, p. 39).

Later in this chapter, I will seek to show how there can be an epistemological void between patient and doctor within clinical interactions regarding CFS/ME. However, Jutel (2014) encourages us to look beyond the moment when a diagnosis is first mentioned, to regard diagnosis as a process. My research therefore focuses on the diagnostic label as part of a longer diagnostic process which extends further than the clinical interaction between patient and doctor. This study accounts for the impact of the illness both before and after the diagnosis is named, both inside and outside the clinic. In doing so, the research aims to consider the wider social implications and the "human significance" (Peek, 2017, p. 35) of the CFS/ME diagnosis. Moreover, this study investigates how the diagnosis of CFS/ME impacted on the interview participants' lives.

The importance of being able to name an illness has been emphasised by Rosenberg (2002) and reiterated by Davis (2011, p. 158), the latter of whom claims that a "medical condition is only as real

as its definition". Davis shows how the reframing of intersex with the new term, disorders of sex development (DSD) terminology, allows clinicians to reclaim medical jurisdiction over the intersex body. Prior to changing the medical term for intersex to DSD, the medicalisation of intersexuality was successfully being contested by intersex activists who were framing intersexuality as a social rather than biological problem. Davis (2011) showed that the naming of a condition can encompasses a political stance, a territorial claim, and a particular viewpoint. The definition and label of CFS/ME has been contested and debated (Jason, 2007; Jason, Nicholson and Sunnquist, 2016) but ME has been preferred by patients because CFS emphasises fatigue, which undermines the seriousness of the condition and the multiple symptoms that CFS/ME can encompass. My research therefore questions whether the label CFS and/or ME is favoured and how people who have been diagnosed with the condition make sense of their label(s).

2.4.2 Classifying, Sorting, Categorising. Lumping and Splitting

The classificatory and organisational aspects of the CFS/ME label are particularly salient in light of the ambiguous categorisation of CFS/ME. The World Health Organisation classifies CFS/ME as a somatic neuro-immunological condition (ICD-10, code G93.3)[16] and, in the United Kingdom, the All-Parliamentary Group for ME/CFS (2010) also recognises CFS/ME as a long-term neurological condition. This is, however, incompatible with a survey (Wojcik, Armstrong and Kanaan, 2011) which asked members of the Association of British Neurologists whether they viewed chronic fatigue syndrome as being a neurological condition. 84% of respondents did not. At the heart of this inconsistency is the question of whether CFS/ME is a psychiatric illness or a somatic/organic one. Wojcik, Armstrong and Kanaan (2011) suggest, however, that organic and psychological are not mutually exclusive and that pitting psychological against organic denies advances in how medicine conceptualises illness and disease.

Further, "whilst the current classification may not accurately reflect professional consensus (at least in the UK), CFS/ME is in many ways an orphan illness, sitting on the border between medicine and psychiatry." (Wojkvic, Armstrong and Kanaan, 2011, p. 503). This orphan status is reflected in the current NICE (2007) guidelines where the proposed treatments for CFS/ME lie in the field of psychiatry with the controversial treatments of GET (Graded Exercise Therapy) and CBT (Cognitive Behavioural Therapy), connecting CFS/ME to psychiatry and mental illness. Further complexity is added by the fact that it is unclear whether CFS/ME should be categorised under the umbrella term MUS (multiple unexplained symptoms) or if CFS/ME might be regarded as an illness that is comprised of MUS (Picariello *et al*., 2015). Shepherd (2004), who is the Medical Adviser to the ME Association, has

[16] The ICD-11 has now been approved and will be put into effect on 1st January 2022. It lists CFS/ME as a neurological disease in 'other disorders of the nervous system', section 8E49.

denounced the heterogeneity of conditions which are diagnosed as CFS/ME. It is therefore possible to see how the categorisation of CFS/ME is ambiguous and seemingly misaligned with the proposed treatment options. The significance of this is striking when we consider how "classification systems both structure and constrain the world they describe: they act as the lens of perception, as the mediator of experience, as the conceptual framework through which medical reality is stabilised and maintained" (Armstrong, 2011, p. 80). It is therefore pertinent to explore how the diagnosis of CFS/ME mediates patient experience and whether the label reflects the medical/social reality of the people diagnosed with the condition.

Categorisations in clinical practice have been critiqued by Brown (1987), who highlights a misalignment between the definitions in the DSM-5 (Diagnostic Statistical Manual) and the applications of diagnostic categories at a clinical level. Blaxter (1978) has also drawn our attention to the inconsistency between classification systems and the clinical implications of diagnostic practice. She uses the example of alcoholism to demonstrate how the diagnostic process and the ICD classification are not aligned. Further, Blaxter (1978) claims that diagnostic categories fail to be useful to the patient or doctor when they were unaccompanied by an effective treatment. This is echoed in more recent research on fibromyalgia, when Boulton (2019) suggests that the diagnosis fails to offer a road map for living with and treating the illness.

Nevertheless, later studies reveal how treatments can precede a diagnosis (Goodwin, 2010) and dictate the aetiology. Consequently, diagnostic process does not always follow a linear trajectory whereby symptom presentation is followed by a diagnosis and subsequently trailed by treatment or care. The transformative power of diagnosis has the potential to be thrown into disarray when treatment does not require a firm diagnostic classification. The imperative to explore the diagnostic process of CFS/ME can therefore be seen where the aetiology and pathology are unknown, yet the treatments are psychiatric. Through their work on CFS/ME activism and mental health activism, Spandler and Allen (2018) have highlighted the need to pay closer attention to the psychiatric framing of CFS/ME.

However, the process by which we categorise, and sort has been addressed by Zerubavel (1996, p. 421) who suggests that it is human to "lump" together similar things and "split" (Zerubavel, 1996, p. 421) that which we perceive as being dissimilar. Jutel (2011a) further elaborates on lumping and splitting, to suggest that classification seeks to create meaningful juxtapositions or interfaces between groups of objects. Yet, grouping together the similar and separating that which is dissimilar can be a strength and hindrance in clinical practice as well as in everyday life. It can prevent us from thinking more widely across categories and ignore those which evade categorisation and boundaries. The relevance of categorisation to CFS/ME was shown by Horton-Salway (2007), who used the illustrative example of CFS/ME to demonstrate how the stigma of psychological illness is embedded in GPs' categorisations

of illnesses and patients, into genuine and bandwagon cases. How doctors categorise people with CFS/ME can have significant social and medical consequences, yet little is known about how CFS/ME patients interpret and experience the diagnostic process and labelling.

The conceptualisation of 'lumping' and 'splitting' has further implications for clinical practice and patient experience. In their research on autoimmune conditions, Joyce and Jeske (2020) found that broad diagnostic classifications of autoimmune disease helped doctors to support patients. It is common amongst those with autoimmune conditions to meet criteria for different autoimmune disorders or for the diagnosis to change to another autoimmune disease. Joyce and Jeske (2020) proposed that broad diagnostic categories can help to navigate uncertainty while providing clinical room for manoeuvre as well as legitimacy. This research offers original insights into understanding diagnosis as a category, through elucidating how patients lump together (broader category of autoimmune disease) and split (narrower labels e.g. multiple sclerosis) disease categories/classifications. Joyce and Jeske (2020) highlight the importance of gaining insights into how patients understand their diagnosis label and how they experience the diagnostic process. Altering categorisations within medical practice can therefore have tangible social consequences for people diagnosed with autoimmune diseases. As in the case of CFS/ME, those social consequences can encompass issues of uncertainty and legitimacy. The consequences of labelling highlights the need to further explore how and why people with CFS/ME prefer ME over CFS (Jason, Nicholson and Sunnquist, 2016) how patients interpret their diagnosis and how they experience the process of being diagnosed.

2.4.3 Defining the Ambiguous: Contested Illnesses

The previous section sought to show how ME transgresses the boundaries of disease and illness, and this ambiguity bears the signature of a contested illness. At the time of writing this thesis, the contested nature of CFS/ME is being highlighted by the recent delay to updating the NICE guidelines for CFS/ME, because the committee is struggling to reach a consensus on what those new guidelines should be (NICE, 2021). It is therefore necessary to situate CFS/ME within the literature on contested illness to demonstrate where and how CFS/ME is positioned in the hierarchy of disease classification. Canguilhem (1989) suggests that contested illnesses are accredited with a low status. This is echoed by Album (1991) who has shown how clinicians rank contested illnesses with low prestige (Album, Johannessen, and Rasmussen, 2017; Album and Westin, 2008). The experience of being diagnosed with a contested illness is therefore fraught with uncertainty and dispute. Contested illnesses are comprised of varying symptoms with unknown origins (Barker, 2008) that effect multiple body parts. They are, therefore, often regarded as less medically and socially legitimate than diseases with a biomedical aetiology and diagnostic framework (Lian and Robson, 2019).

CFS/ME is an illness which is difficult to diagnose, and it relies on a diagnosis of exclusion, whereby biomedically identifiable diseases are ruled out until the residual diagnosis of ME remains. There are no identifiable abnormalities, and the diagnosis depends upon the narrative of the patient. Moreover, CFS/ME is a chronic illness which is suffused with conflict, since there is no agreement on the name, the aetiology, prevalence, or the treatment (Banks and Prior 2001; Brown *et al.*, 2017; Horton-Salway 2002; 2004;). Brown (1990) was the first to specifically call for a "sociology of diagnosis" but in his later work, Brown (1995, p. 39) recommended exploring, "controversial and conflictual diagnoses", because they provide an insight into some of the most "pressing issues of power in medical diagnosis" (Brown, 1995, p. 39). CFS/ME therefore warrants further sociological investigation as a contested illness and a contested diagnosis. Although previous studies have identified that CFS/ME is contested (Millen, Peterson and Woodward, 1998), what is less clear are the social mechanisms and structures underlying how and why CFS/ME is particularly disputed.

Moss and Teghtsoonian (2008) edited a collection of essays spanning different areas of contestation, which largely focus upon the power dynamics of how ill and/or disabled bodies are understood, labelled, and defined. Diagnosis can be identified as a key theme which runs throughout the edited works, demonstrating the need to study the role that diagnosis plays within the experience of contested illnesses. Moss and Teghtsoonian (2008, p. 7) define contested illness as "illness that is defined as illegitimate, framed as 'difficult,' or even non-existent by – researchers, health practitioners and policy makers operating within conventional paradigms of knowledge". However, they also note how contestation can be found in "practices of critical engagement by researchers, by activist communities, by those who have been diagnosed with illness, or by those who experience themselves as ill – with both established and emerging understandings of the aetiology, diagnosis, symptomatology, and treatment of illness" (Moss and Teghtsoonian, 2008, p. 7). Moss and Teghtsoonian (2008) therefore suggest that there is the potential for any illness, disability, or disease to be contested or at least to have elements of contestability.

Drawing on his empirical anthropological research, Dumit (2006, p. 579) identifies five defining features of contested illness. Firstly, that contested illnesses are chronic rather than acute and they struggle to fit into the sick role (Parsons, 1951). Secondly, that the symptoms of contested illness are what he refers to as "biomental" (Dumit, 2006, p. 579) whereby it is unclear whether the symptoms or cause are in the body or the mind. Thirdly, the treatments are wide ranging, and they include medical and alternative therapies. Fourth, contested illnesses have blurred boundaries, meaning that they can be mistaken or linked to other illnesses with similar symptoms. Lastly, contested illnesses are "legally explosive" (Dumit, 2006, p. 579), particularly when patients try to gain disability status. Dumit (2006, p. 577) also draws attention to the difficulties in obtaining a diagnosis when an illness is contested, by stating that contested illnesses are "illnesses you have to fight to get". There is a significant body of

research highlighting delegitimising encounters that people with CFS/ME experience with medical professionals, which certainly indicates that the clinical experiences of CFS/ME encompass tensions, disputes and uncertainty (Asbring and Narvanen, 2002; 2003; Andersen *et al.*, 2012; Ax, Gregg and Jones, 1997; Broom and Woodward, 1996; Clarke, 1999; Clarke and James, 2003; Cooper, 1997; Deale and Wessely, 2001).

Dumit's (2006) characteristics of contested illnesses provides a useful springboard for identifying how CFS/ME is contested. However, Dumit's (2006) characteristics of a contested illness drew from his research on how an online forum was managed by people with CFS/ME and multiple chemical sensitivity (MCS). Similarly, Asbring and Narvanen (2002; 2004) have grouped their research on CFS/ME and fibromyalgia together and their later findings (Asbring and Narvanen, 2004) showed how CFS/ME was more psychologised than fibromyalgia. It can therefore be argued that CFS/ME warrants sociological investigation as a standalone illness rather than being grouped with other contested conditions. Moreover, CFS/ME has a specific group of symptoms, and as I have argued, CFS/ME has an historical trajectory which makes it distinct from other contested illnesses.

Further, CFS/ME has been found to be more stigmatised in the work of Looper and Kirmayer (2004), who compared patients with illnesses that entailed MUS (ME, fibromyalgia and irritable bowel syndrome) with comparable counterparts with a known pathology (multiple sclerosis, rheumatoid arthritis and irritable bowel disease). Perhaps unsurprisingly, the participants with MUS scored more highly on perceived stigma than the medically verified group. However, it was only CFS/ME which individually scored more highly in perceived stigma when compared to a similar disease of known pathology, multiple sclerosis. Looper and Kirmayer (2004) suggest that this is because there is no known cause for CFS/ME and the symptoms are therefore attributed to emotional disorders. Nonetheless, this does not fully explain why CFS/ME should result in higher perceived stigma when there is also no known cause for fibromyalgia. It is also unclear why an unknown cause should default to an emotional disorder when fibromyalgia or irritable bowel syndrome also have unknown causes. Further research is needed to explore what is particular to CFS/ME to make it more stigmatised than other contested conditions with medically unexplained symptoms. Much of the qualitative literature on CFS/ME details the threat of stigma that is experienced by people who have the condition (Asbring and Narvanen, 2002; Broughton *et al*., 2017; Travers and Lawler, 2003; Ware, 1992). However, by revealing the experience of the CFS/ME diagnosis and its potential historical antecedents, this thesis looks to move beyond identifying stigma to attempting to understand how stigma is enacted along with the possible reasons why.

2. 5 A Fraught Diagnostic Process

2.5.1 Micropolitics and Macropolitics of CFS/ME: The Patient's Voice

The majority of the literature on contested conditions has focused upon how lay/patient activism has contributed to the establishment and confirmation of contested diagnostic categories (Dumit, 2006; Kroll-Smith and Floyd, 1997; Moss and Teghtsoonian, 2008) such as miner's lung (Bloor, 2000), Lyme Disease (Aronowitz, 1991), Gulf War syndrome (Brown *et al*., 2001; Zavestoski *et al*., 2004), Repetitive Strain injury (Arksey and Sloper, 1998) and fibromyalgia (Barker, 2005; 2008). Less attention has been paid to how CFS/ME is politicised, but Prior and Banks (2001, p. 11) have shown how clinical consultations can often take on a form of:

> micro political struggle in which neurological symptoms can be re-framed as psychiatric symptoms, and psychiatric symptoms as neurological. In short, a contest in which the demarcation lines between mind and body are continually assessed and re-defined, and the tenets of 'biomedicine' are constantly challenged.

Mind-body dualism permeates the politics of CFS/ME (Spandler and Allen, 2018) as CFS/ME activists attempt to denounce the psychologisation of the condition. Contested illnesses such as CFS/ME do therefore entail a politicised form of illness experience and "even if that does not entail social movement organizations, it does entail politicized support groups that engage in struggle over the very label of the disease" (Zavestowski *et al*., 2004, p. 172).

Exploring diagnosis sociologically therefore offers a way of seeing how individuals function in a wider social context (Jutel and Dew, 2014). The importance of doing so is highlighted by McGann (2011), who suggests that the perceived normality of diagnoses in everyday life leads us to falsely believe that they are scientific entities free of cultural ties. McGann (2011) warns of the dangers of medical social control when the political aspects of diagnosis remain hidden. Nettleton and Lian (2015) illuminate the politics of the CFS/ME diagnosis in their finding that a VSC (virtual social community) was double edged in that it had the ability to empower but also restrain its members. Lian and Nettleton (2015) show how the micro social dynamics of the VSC have the potential to impact (or not) on the wider macro political relations involved in the legitimisation of CFS/ME, while indicating the broader socio-political relationships involved in contested illnesses. Through the VSC curtailing certain types of opinions on CFS/ME, they controlled how CFS/ME was defined within that space.

Conrad and Schneider (1992, p. 22) emphasise how diagnoses are the "politics of definition" and there is space for contest in reaching an agreement over what that demarcation might be. It is this area for contest which is focused upon within my study. There is a need to further explore the politics of how

CFS/ME is defined and understood from the perspective of those who have been diagnosed with the condition. In doing so, it is possible to deconstruct the 'normality' of diagnosis and reify the contested aspects of the condition. Bowker and Star (1999) claim that classifications highlight certain voices while suppressing others. Similarly, Jutel (2011a, p. 202) suggests that "classification engages some social perspectives and shuts down others, but once a classification is established it reproduces itself in an intuitive way that silences debate". People with CFS/ME have been marginalised and stigmatised, and this places a greater emphasis on the need to bring the patient voice/perspective forward, so that their social perspective is not "shut down" (Jutel, 2011a p. 202). The next section furthers the case for amplifying the patient voice by showing how patient experience is subverted by medical knowledge and authority.

2.5.2 Epistemological Tensions: Patient Experience and Medical Knowledge

A key theme which recurs within the literature on CFS/ME and other contested illnesses, is that of the tensions between patient experience and medical knowledge, subjective experience versus biomedical evidence. Heath (2007, p. 183) neatly summarises the role of a general practitioner (GP) where she remarks on being presented with more illness than disease, while noting that the job of the clinician is to maintain "the border between subjective illness and disease categories recognised by biomedical science; of confining people within those categories only when such labelling will be positively useful to them". However, the diagnostic work of the clinician is made more complicated when we consider that the CFS/ME diagnosis relies on the patient's subjective interpretation and personal narrative of their symptoms, because there are no objective means to test and identify the signs of CFS/ME. CFS/ME therefore challenges how we conceptualise illness and disease. My study approaches CFS/ME as a diagnosed illness, to denote how the illness has a diagnostic label yet lacks a biomedical explanation.

Dew and Jutel (2014) suggest that patients present their illness based on the presumption that they have a disease. They distinguish illness from disease by suggesting that it is disease which is diagnosed. Earlier scholars (Balint, 1964; Eisenberg, 1977; Kleinman, 1988) have differentiated between disease and illness. The concept of disease is often treated as the knowledge domain of scientists and medical experts, while illness refers to the lived experience of sufferers. Frank (1995, p. 16) proposes that the clinician's reinterpretation of a patient's story requires the patient to give in to "narrative surrender", whereby illness and symptoms are transformed into medical terms. McGann (2011) helpfully distinguishes between medical and social discourses, claiming that they have varying dominance during the diagnostic process. Medical discourse is concerned with the analysis of organic states within the body. Medical discourse therefore assumes that disease is present when objective biological markers are beyond normal limits. Social discourse of diagnosis draws on the individual's own experience, the relationship of the body to the outside world as well as the self with the social world. The diagnosis of CFS/ME therefore straddles illness and disease, often relying more on social discourse than medical

discourse within the diagnostic process. The reliance on social discourse within the diagnosis of CFS/ME makes it particularly amenable to sociological qualitative inquiry.

However, even the existence of CFS/ME as a diagnostic category requires doctors to put aside their undergraduate training in evidence-based medicine, which perceives the body and disease in biomedical terms. Classification and categorisation can be regarded as components of "professional vision" (Goodwin, 1994, p. 628) central to the social and cognitive organisation of a profession. Goodwin (1994, p. 628) argues that "through the construction and use of coding schemes, relevant classification systems are socially organized as professional and bureaucratic knowledge structures, entraining in fine detail the knowledge of those who administer them". He further suggests that one of the ways in which professional vision is created is through learning. Doctors are taught how to perceive (as well as how not to view) disease and bodies according to their medical training (Smith and Hemler, 2011). Ware (1999) points to how healthcare professionals are entrenched in biomedical training and often refuse to assign diagnostic labels to people with CFS/ME because there is no currently discernible aetiology. Larun and Malterud (2007) highlight how doctors struggle to maintain their professional medical authority because of the scientific uncertainty entangled with CFS/ME. Although the literature indicates that there can be a medical reluctance to diagnose CFS/ME, there are currently, to my knowledge, no studies which specifically explore the process of the clinical CFS/ME diagnosis from the patient's perspective.

So far, this section has suggested that patient and clinician are pitted against one another, but a diagnosis can also be an interpretive project, involving an exchange between lay patient and professional to find a mutually satisfactory explanation (Leder, 1990). Horton-Salway (2004) found that in a negotiation about the definition of contested disease categories, such as CFS/ME, it was important for patients to feel they could speak from their own experience and personal knowledge. However, doctors' interpretation of CFS/ME as being veiled depression, suppressed personal experience as a "fact-constructing device" (Horton-Salway, 2004, p. 367). This demonstrates how medical authority can dominate personal experience within the diagnostic process of CFS/ME.

Mishler (1984, p. 121) highlights how the "voices of the life world" (patients) and the "voice of medicine" (Mishler, 1984, p. 121) (doctors) contrast because both are entrenched in different epistemes and granted unequal authority. The patient's voice is given less status than medical authority, which makes the need for a patient perspective on CFS/ME even more pertinent.

The need to understand the epistemological viewpoints of patients with contested conditions is illuminated by Barker (2005, p. 7) who coined the term "epistemological purgatory". When the patient arrives at epistemological purgatory, they confront the question, how do we know what we know? It is the aim of my study to find out how people with CFS/ME understand their diagnosis and make sense of it.

2.5.3 Epistemological injustice: Testimonial Injustice and Hermeneutical Injustice

Continuing the topic of epistemologies, several scholars have applied Fricker's (2007) concept of epistemic injustice to illness experience (Carel and Kidd, 2016; Crichton, Carel and Kidd, 2017; Spandler and Allen, 2018). However, Blease, Carel and Geraghty (2017) use Fricker's (2007) epistemic injustice to provide a deeper insight into the epistemological processes involved in diagnosis, by analysing the ethical consequences of the differing epistemological perspectives between CFS/ME patients and their clinicians. Fricker (2007) points to two types of epistemic injustice: testimonial injustice and hermeneutical injustice. Blease, Carel and Geraghty (2017) apply these two concepts of epistemic injustice to the case of CFS/ME by highlighting how they play a role in the discreditation of patients with CFS/ME. According to Fricker (2007) testimonial injustice occurs when a speaker is unfairly accorded a lower level of credibility because of prejudice. In such circumstances, a listener negatively stereotypes the speaker and believes the speaker has a reduced reliability to bear and convey knowledge. The result is that the speaker's contribution to the shared epistemic enterprise is unjustly excluded. Blease, Carel and Geraghty (2017) show how testimonial injustice occurs when the CFS/ME patient's perspective on the illness is ignored and discredited by clinicians.

The second type of epistemic injustice, hermeneutical injustice is defined by Fricker (2007) as being an injustice when there is a collective shortfall in our shared conceptual resources: in this way, she defines hermeneutical injustice as a structural problem. Blease, Carel and Geraghty (2017) show how people with CFS/ME suffer hermeneutical injustice where they are excluded from making sense of the CFS/ME diagnosis and prevented from contributing to how CFS/ME is medically understood. Blease, Carel and Geraghty (2017) effectively use Fricker's (2007) concepts to show how both hermeneutical and testimonial injustice may lead to marginalising a group, physically and/or epistemologically. They highlight how people with CFS/ME are stigmatised while being accorded little credibility as patients, which feeds into negative stereotyping of CFS/ME patients.

Although the previous section has shown how epistemic injustice is part of the diagnostic process of CFS/ME, epistemic injustice can also be a social consequence of the CFS/ME diagnosis. Spandler and Allen (2018) haven taken the concept of epistemic injustice one step further than Blease, Carel and Geraghty (2017). They identify how the epistemic injustice suffered by people with CFS/ME is exacerbated by the condition being framed as a psychiatric problem. Spandler and Allen (2018) point

to how patients' persistent attempts to gain acknowledgement for their condition (i.e., obtain a diagnosis) is treated as further evidence of their irrationality. The politics/politicisation of CFS/ME has previously been discussed within this chapter but Spandler and Allen (2018) argue that epistemic injustice is integral to understanding the discrimination and prejudice experienced by people with CFS/ME and mental health conditions. Both CFS/ME activists and mental health activists make demands for greater legitimation, recognition and justice. Understanding how epistemic injustice is enacted is therefore key to appreciating the delegitimation and stigma which scholars have identified in the illness experience of CFS/ME.

2.6 The Social Consequences and the Social Significance of Diagnosis

2.6.1 Palliating Uncertainty or Diagnostic Illusory? An Unsatisfactory Roadmap

The remaining discussion within the literature review will focus on exploring literature on the social consequences of diagnosis. The current section critically engages with research which has focused upon the un(certainty) embedded in medical diagnosis. Uncertainty is especially relevant to studying the diagnosis of CFS/ME when we consider that Blease, Carel and Geraghty (2017) suggest the ambiguity of CFS/ME is responsible for the epistemic injustice that people with CFS/ME experience within clinical encounters. In Woodward, Broom and Legge's (1995) research, the reluctance to diagnose CFS/ME was found to be partly due to medical uncertainty surrounding the condition. Even those who have recovered from CFS/ME find themselves living in a liminal and uncertain state, where they are never too far away from illness (Brown, Huszar and Chapman, 2017). Using specific diagnostic criteria doctors can try to eliminate some of the uncertainty in a diagnosis to provide continuity across practitioners and their patients (Timmermans and Berg, 2003). However, scholars have questioned the extent to which diagnosis creates more ambiguity.

Perhaps one of the most striking areas of diagnostic uncertainty pertains to medically unexplained symptoms (MUS). Nettleton (*et al.,* 2004; et al., 2005; 2006) has built a body of work relating to diagnostic un(certainty) and MUS, which is a group of symptoms that have no name and an unknown aetiology. While CFS/ME is a named illness/syndrome it is also an uncertain illness with an unknown organic explanation, and it is therefore useful to drawn from literature on MUS. Nettleton (2006, p. 1168) suggests that people with MUS experience "embodied doubt", which is reflective of life in late modernity that is replete with uncertainty and ambiguity. In the absence of a diagnostic label, Nettleton (2006, p. 1176) finds that "biomedical classifications are social constructions which have the symbolic effect of stabilising identity and restoring coherence. But they also generate ambivalence". In subsequent research, Nettleton, Kitzinger and Kitzinger (2014, p. 134) apply their concept, "diagnostic illusory" to "capture the ambiguities and nuanced complexities associated with the biomedical imperative to name and classify." They question whether diagnoses raise false hopes with the

expectation of certainty and intelligibility. Jutel (2016, p. 97) echoes this query where she states that "our desire to palliate uncertainty via diagnosis may lead to, rather than remedy, its powerful impact".

Studies on the contested condition fibromyalgia have pointed to how the diagnosis fails to be explanatory for patients, and leaves them feeling uncertain and unclear about their illness (Barker, 2005; Boulton, 2019). However, Nettleton (2006) has also demonstrated that holding a diagnosis is better than not having a diagnosis. Nettleton's (2006) finding is echoed in the diagnosis of CFS/ME, because the positive consequences of receiving a diagnosis have been shown to counterbalance the negative ones (Cooper, 1997). Asbring and Narvanen (2002) highlight how the diagnoses of CFS/ME and fibromyalgia encompassed "double significance" for their participants, on the basis that the diagnoses could be stigmatising, but to a lesser degree than not having any diagnostic label. It might be the case that "anxiety and mystery can be ordered, if not precisely allayed" (Rosenberg 2002, p. 256), but the research of Asbring and Narvanen is nearly twenty years old and it would be fruitful to revisit the significance of a CFS/ME diagnosis. The need to do so is pertinent when scholars (Hadler, 1997; Huibers and Wessely, 2006) have queried whether CFS/ME should be diagnosed at all. However, the next section addresses how the diagnosis of CFS/ME must be understood within the wider illness experience.

2.6.2 Illness Narratives: Contextualising Diagnosis

In trying to understand how a patient experiences their diagnosis it is necessary to contextualise the diagnosis within the wider illness experience. Before the proliferation of the sociology of diagnosis, the subject of diagnosis had been an embedded feature in research on illness experience (Jutel and Nettleton, 2011) rather than being a focal point. Since the early 1980s there has been an abundance of scholarly work on illness narratives (Frank, 1995; Hyden, 1997; Riessman, 2003), highlighting the importance of the patient voice within medicine and how people make sense of illness (Corbin and Strauss, 1988). Illness and diagnosis have been shown to be life changing and life altering. Charmaz (1983; 1991), for example, writes about the struggle for a new self that people often experience after living with a chronic illness. Williams (1984, p. 175) shows how ill people form a "narrative reconstruction" as they try to reconcile their past, present and self-identity within society. One of the research questions to this thesis asks, "How do people with CFS/ME interpret and make sense of their diagnosis?" This question lends itself to qualitative inquiry and the research question positions the study within the subfield of illness experience, which is well established within the sociology of health and illness.

There has been a significant body of literature on identity change in relation to CFS/ME (Asbring, 2001; Reynolds and Vivat, 2010; Travers and Lawler, 2008; Whitehead, 2006a; 2006b) which suggests that the CFS/ME can be life changing and identity altering. The impact of living with a contested illegitimate

illness has been highlighted sociologically. Part of the "human significance" (Peek, 2017, p. 35) incorporated into a diagnosis, lies in the power of diagnosis to provide people with a new identity of 'patient-with-a-diagnosis' (Frank, 1997, p. 33). The CFS/ME diagnosis has been shown to provide patients with closure in their search for an explanation for their symptoms (Hyden and Sachs, 1999). In their research, Arroll and Howard (2013) found that the CFS/ME diagnosis can transform patients' identities in four different ways. Firstly, the participants compare their old selves with their new selves. Secondly, during their time being socially isolated, participants reflected upon the behaviours of those around them. Thirdly, there was space to rethink their potential futures. Lastly, there was a desire to rebuild their lives, which the authors refer to as "post traumatic growth" (Arroll and Howard, 2013, p. 304).

Bury (1982, p. 168) describes chronic illness as a "biographical disruption" involving a division between life before the onset of illness and afterwards. This concept deviates from a focus on acute illness and the deviance implicated in Parson's sick role (Bury 1982). Such disruption occurs when the normal assumptions and behaviours can be no longer anticipated/ achieved. Asbring (2001) draws attention to the biographical disruption experienced by women with CFS and fibromyalgia. The participants experienced the paradox of work and social identity loss coupled with "illness gains" (Asbring, 2001, p. 315), such as space for contemplation and reprioritising. Frank (1993) further reinforces this, suggesting that diagnosis can offer an ill person an interval within which to reorganise their lives.

However, the application of biographical disruption warrants further attention, as Williams (2000) has been critical of research using biographical disruption without criticism or reflection. He suggests that disruptions occur in our lives, whether we are healthy or ill. Williams (2000) also proposes that biographical disruption does not occur with every chronic illness, and he favours a more sensitive approach to its usage. In a similar vein, Brown and Harris (1984, p. 234) observed the loss of "assumptive worlds" (1984, p. 234), which highlights the social causes of depression. They argue that losing the possibility of an assumptive world, or presupposed future, can be devastating for an individual and a potential factor in the onset of illness. They contextualise life disruptions within the wider life course, implying that illness does not occur within a social vacuum, even if it there are moments when illness is our sole focus. My research therefore contextualises the social consequences of CFS/ME by considering the participants' wider illness experience while being careful not to perpetuate social and psychological reasons for the illness. There is a need for sensitivity to social and psychological causes, because patients have refuted psychosomatic explanations for the illness and advocated physical and organic causes for CFS/ME (Spandler and Allen, 2018).

2.6.3 Delegitimating Experiences of CFS/ME: Stigma, Mental Illness and Invisibility

This section explores how the delegitimation of CFS/ME is connected to issues of stigma, invisibility and mental illness. Ware (1992, p. 347) defines delegitimation as "the experience of having one's perceptions of an illness systematically disconfirmed". While the previous section showed how sufferers often have their views discredited through testimonial injustice, this section seeks to focus specifically on the mechanisms and issues involved in the stigmatisation and delegitimation of CFS/ME.

Ware (1992) explains that people with CFS/ME experience stigma and shame because the illness is associated with mental illness. She found that people with CFS/ME have their symptoms trivialised, psychologised and delegitimated. Although Ware's (1992) research was nearly thirty years ago, subsequent research has supported Ware's research by showing how people with CFS/ME experience their illness being undermined, discredited and psychologised (Horton-Salway, 2001; Tucker, 2004). Incorporated within the literature on stigma and CFS/ME is the theme of the condition being a bodily problem that is biomedically invisible (Ware, 1992). There are no tests or signs for CFS/ME and this renders the condition undetectable to medical testing and the human eye (Dickson, Knussen and Flowers, 2007; Pilkington *et al*., 2020). The patients are inconspicuous in public life when they take time away from others to recuperate (Hannon *et al*., 2012; Lian and Rapport, 2016). Delays in diagnosis (Arroll and Senior, 2008) also add to the invisibility of CFS/ME, because patients are unable to identify their illness or have their symptoms medically verified. Previous studies on CFS/ME have highlighted how the invisibility of the illness is involved in the stigma of the condition (Chew-Graham *et al*., 2008; Edwards, 2007; Ware, 1992). The invisibility of CFS/ME and its sufferers present a case for specifically focusing on CFS/ME, to make both the condition and the experiences of its sufferers more discernible.

As CFS/ME is visually and medically imperceptible, the stigma attached to CFS/ME means that some people choose to conceal their illness (Pilkington *et al*., 2020). Goffman (1963, p. 42) might refer to concealing an illness as "passing" or "covering" (Goffman, 1963, p. 101). Goffman (1963, p. 130) argues that "the stigmatized individual is advised to accept himself as a normal person because of what others can gain in this way, and hence likely he himself, during face-to-face interaction". Moreover, concealing the discrediting feature makes others feel more at ease around the individual. Goffman (1963) also states that an individual can be discreditable, which involves having a "mark" that is not discernible. For these people, the issue of managing information presents a quandary as to whether they should choose to conceal or divulge their discrediting feature.

Stigma is a well-established subfield/topic within sociology and Goffman (1963) has made a significant contribution to the modern understanding of stigma being socially constructed (Kleinman and Hall-Clifford, 2009), with most sociological research on stigma drawing inspiration from Goffman's (1963) seminal text, "Stigma: Notes on the Management of Spoiled Identity" (Tyler and Slater, 2018). Goffman's (1963) work on stigma creates a background to this thesis because stigma does play a crucial

role in understanding the diagnostic experience of CFS/ME. Goffman's (1963) work has been explicitly used in the work of Asbring and Narvanen (2002) on CFS/ME and fibromyalgia. They found that patients used impression management to conceal their illness or withdraw from others. Asbring and Narvanen (2002) also discovered that the presentation of the participants was sometimes at odds with how their caregivers perceived them. For example, the participants refuted psychological explanations for CFS/ME while their caregivers psychologised their symptoms. Asbring and Narvanen (2002) provide an insight into how the status of CFS/ME is stigmatised and psychologised outside clinical interactions. How people with CFS/ME manage their illness information is reflected upon within the thesis, informed by Goffman's (1963) work on stigma.

Further, Kleinman and Hall-Clifford (2009) have emphasised the need to focus more on the social aspects of stigma rather than the psychological, which they claim has often failed to consider how social life and relationships are altered by stigma. The social setting and power dynamics of stigma are often overlooked, as is the question of who benefits and why (Tyler and Slater, 2018). Scambler (2006, p. 451) points to Goffman's interest in structural interaction and his neglect of social structure because "cultural norms of shame and blame and the labelling processes with which they are bound up never exist in a structural vacuum but invariably arise within a structural nexus". Scambler (2009) therefore asks that sociologists of health and illness look beyond Goffman (1963) and this thesis does so by highlighting the social context and structural inequalities involved in the stigma of the condition.

2.6.4 The Sick Role: Diagnosis as a Social and Legitimising Function

A diagnosis can perform a social function by validating an individual's claim to being sick (Telles and Pollack, 1981; Woodward, Broom and Legge, 1995) and when a diagnosis legitimises the illness experience, an individual can reach a social agreement about symptoms and re-establish a legitimate social role (Stewart and Sullivan, 1982). Within the wider literature on contested illnesses, patients struggle to gain the rights and privileges of the sick role (Parsons, 1951), such as legitimation (Hadler, 1996), welfare benefits (Lippel, 2008) and treatment (Brown *et al*., 2001). Despite the explanatory, legitimating and structuring power of diagnoses (Jutel, 2009), the process of a contested diagnosis does not necessarily give patients a satisfying explanation for their symptoms or access to resources and treatments.

The sick role (Parsons, 1951) is especially relevant in the patient experience of CFS/ME because the lack of medical legitimation makes it challenging for patients with CFS/ME to access resources, support or disability payments (Dumit, 2006). In addition to this, people with the condition struggle to secure a diagnosis, but without a diagnosis the sick role (Parsons, 1951) cannot be granted. By drawing from patient narratives and the views of physicians, Asbring and Narvanen (2003) were able to reveal how some people with CFS/ME and fibromyalgia struggle to access the legitimacy endowed by the sick role.

Patients often experience the symptoms of CFS/ME being trivialised and undermined by clinicians (Lian and Nettleton, 2015). With regards to accessing the resources of the sick role, Booth, Price and Walker (2018) found that the current British welfare system fails to account for fluctuating illnesses, such as systemic lupus and CFS/ME. Hammond (2002) maintains that the stigma of CFS/ME impacts on the assessment of patients trying to access benefits. Moreover, evidence for benefit claims is required and documentation is often haphazard for claimants with CFS/ME (Hammond, 2002).

In summary, Parsons (1951) asserts that being sick is a specific social role, which consists of four main parts. Validation constitutes the second part of the sick role, which is the obligation of the sick person to seek professional medical help. This relationship should be entered with an understanding that the patient will act on the advice of the doctor and comply with all the prescribed treatments to facilitate recovery. Lastly, if the previous conditions of the sick role are met, the fourth criteria can be achieved, which is the temporary status of the sick role and which will only last until the treatment is finished. It is assumed that the treatment will be successful and result in the patient returning to their normal social role.

Parsons' (1951) seminal work on the sick role (Parsons, 1951) has been especially influential within the sociology of health and illness, where we consider the relationships and structures between patient and doctor. Nevertheless, the sick role (Parsons, 1951) has been criticised for a number of reasons. Such reasons include the temporary nature of the sick role (Parsons, 1951) not accounting for chronic illness (Radley and Billig, 1996). The sick role (Parsons, 1951) fails to account for how CFS/ME is often a chronic, disabling and fluctuating illness with an uncertain prognosis. In an exploration of CFS/ME patients' narratives about recovery, Cheshire *et al*. (2021) reports how patients express a desire to leave the sick role because of the stigma they experience from occupying that role. Cheshire *et al*. (2021) also suggests that the participants did not regard recovery as being free of symptoms. Instead, returning to 'normal' social roles was the epitome of recovery. This is an unusual finding because literature around contested conditions points to the difficulties in obtaining the sick role rather than the desire to leave it. The study also highlights the importance of social functioning from the patients' point of view. The reintegrating effect/function of the sick role was evident despite the participants remaining unwell.

Further criticisms of the sick role have included how the concept is only applicable to western protestant societies (Shilling, 2002). The sick role (Parsons, 1951) has also been criticised for being outdated (Turner, 1986) and somewhat naïve in the claim that the doctors act in the common good, especially since healthcare has become increasingly commercialised (Crossley, 1998). Medical practice and diagnosis have also become increasingly complex with the rise of patient empowerment (Salmon and Hall, 2003; Andreassen and Tronsden, 2010), the proliferation of the internet (Broom, 2005; Hardey,

1999) and the development of new medical technologies (Blaxter, 2009; Martin *et al*., 2020). Frank (2016) therefore casts aside the sick role and contends that the ill person is a subjective narrative. Yet, Frank (2016, p. 15) also concedes that "institutional medicine still trades on relationship norms that recall Parsons' sick role", while highlighting that now institutional medicine also incorporates illness experience. This suggests that the asymmetrical power dynamics, which are integral to the sick role (Parsons, 1951), remain unequally weighted towards the clinician.

Nevertheless, the sick role does demonstrate how diagnosis can be integral to social functioning by validating an individual's claim to be sick (Telles and Pollack 1981; Woodward *et al*., 1995). Without such professional classification, welfare benefits and prescribed treatments may not occur (Arksey and Sloper, 1999; Rosenberg, 2002). Diagnoses can also legitimate the illness experience, allowing an individual to a reintegrate into society and re-establish a credible social role (Stewart and Sullivan 1982; Williams, 2005). Williams (2005) provides an extensive review of Parsons' work on health, illness, and medicine. He suggests that despite Parsons' assumptions about the patient consenting to the sick role, "Parsons speaks forcefully and compellingly to the asymmetrical nature of doctor–patient relations, given the expertise of the former and the needs of the latter" (Williams, 2005, p. 140). In his response to criticisms of the sick role, Parsons (1975) counters that although there is some room for negotiation in clinical interactions, the doctor remains in a position of authority over the patient.

Crossley (1998) captures the relevance of the sick role in his exploration of patients living with HIV and AIDS. He uses Parsons' sick role theory to challenge patient empowerment discourse around HIV and AIDS, which had seemed to overlook the structural and functional aspects elucidated by the sick role. At the same time, Crossley (1998) highlights how HIV and AIDs patients also reject some of the obligations and responsibilities of the sick role. By using the sick role as the basis for his analysis, Crossley (1998) provides a more current and pragmatic perspective on the functionality of the doctor-patient relationship.

The emphasis on obligations and responsibilities has been highlighted in the case of CFS/ME and fibromyalgia, when patients are expected to meet the conditions of the sick role (Parsons, 1951) through being compliant if wish/need to access the resources and legitimacy that the sick role (Parsons, 1951) engenders. While HIV and AIDs are biomedically verifiable, CFS/ME is not and this has the potential to emphasise the need to conform to being perceived as being a good patient. This has been demonstrated by CFS/ME and fibromyalgia patients being met with negative sanctions when challenging their clinicians (Asbring and Narvanen, 2004). Asbring and Narvanen (2004) interpreted the negative sanctions as ways in which clinicians attempted to normalise unwanted patient behaviour. Parsons (1951, p. 243) insistence on treating illness as a form of social deviance took the sick role into a "moral realm". While treating sickness as a form of deviance is problematic (Twaddle, 1973), the

morality of diagnostic classification "provides a cultural expression of what society is prepared to accept as normal and what it feels should be treated" (Jutel, 2009, p. 279). Doctors can in this way be seen as "moral entrepreneurs" (Becker, 1963, p. 147) because they legitimise and label sickness. Further, diagnostic labels have been imposed on individuals who demonstrate a physical or social condition which violates what is socially acceptable (Conrad and Schneider, 1992; De Swaan, 1989; Freidson, 1970).

However, Grue (2016) finds the issue of compliance challenging for people with CFS/ME and those with other chronic illnesses. Grue suggests that illness is work because patients are expected to monitor their condition and take responsibility for their illness. While 'illness work' (Grue, 2016, p. 410) can be empowering it can also be oppressive because:

> While the classical sick role may be problematic for its association with stigma and suspicion, the active sick role, the onus of building an illness career, may place people with chronic illness, when they are at their most vulnerable and have the least resources, in a double bind. (Grue, 2016, p. 410)

Parsons' (1951) sick role is an example of how legitimacy, authority and dependency intertwine (Jenkins, 2011). It has been shown how the act and receipt of a diagnosis can structure medical practice, provide social approval for particular sickness roles, and legitimate bureaucratic relationships (Rosenberg, 2002). The sick role therefore provides a foundation upon which we can ask, how do structural and functional relationships interact in the experience of CFS/ME?

2.7 Conclusion

The intention of this chapter has been to review the substantive literature relating to diagnosis and illness experience and reflect on how they contribute to studying CFS/ME. In addition to this, the chapter has also considered relevant conceptualisations and theorisations within the sociology of health and illness while discussing how they assist with investigating CFS/ME. The chapter began by making the case for the historical analysis of diagnosis from a sociological perspective. It identified a gap in the historical research and interpretations of CFS/ME, where studies are sparse. I suggest that by looking to the past, we can better understand how CFS/ME is experienced contemporaneously. There is little research within the sociology of health and illness which combines contemporary and historical research while focussing on diagnosis. By conducting archival research and semi-structured contemporary interviews, the thesis aims to contribute a deeper understanding of the CFS/ME diagnosis.

Jutel and Nettleton (2011, p. 799) proposed that diagnosis "provides not only a category and process

but a neat analytic tool that serves as a prism that reflects and casts light on a multiplicity of issues in health, illness and medicine". Within my research, diagnosis acts a lens through which we can understand broader issues, such as the power dynamics between clinicians and patients, the intrinsic uncertainty encompassed by contested conditions and how historical diagnoses emerge and ebb away. The literature review has also indicated how diagnosis can "explore the way classifications and labels are constructed, framed and enacted" (Jutel and Nettleton, 2011, p. 798). However, diagnosis is also the subject and focal point of the study, situated within the experience of patients who live within the condition and have experienced the diagnostic process. The argument has been made that the sociology of diagnosis can provide a useful framework for understanding the diagnosis of CFS/ME as a label and a process with social consequences. There are currently no studies on CFS/ME which specifically focus upon how the diagnosis is experienced by patients, nor are there any that are underpinned by a sociology of diagnosis framework.

The chapter has shown how CFS/ME is a contested condition which is undermined, stigmatised and delegitimated. CFS/ME is situated within the literature on contested illness by demonstrating how CFS/ME is categorised at the bottom of the medical hierarchy. The CFS/ME diagnosis appears to evade categorisation and continues to provoke and create uncertainty for those diagnosed with the condition. CFS/ME also occupies a liminal status between illness and disease and eludes the boundaries between the psychological and somatic. Yet it is precisely the ambiguity and dispute encapsulated by CFS/ME which warrants further sociological analysis, particularly within the sociology of diagnosis.

Most of the qualitative studies on CFS/ME are in the field of psychology and they point to the stigma of CFS/ME, but the psychologising of CFS/ME has been refuted and questioned by activists and patients (Spandler and Allen, 2018). Often underpinning psychological research on the condition is the assumption that patients' CFS/ME is either caused by a lack of mental health or tantamount to mental illness. The study of CFS/ME would therefore benefit from a sociological investigation into the condition by studying how it is experienced and understood, rather than what the condition is. Goffman's (1963) work on stigma has been signposted because the concepts of "covering" and "passing" highlight the ways in which people seek to avoid or reduce stigma. This thesis also attempts to understand more about the mechanisms of stigma by considering the how epistemic injustices are experienced by people with CFS/ME.

The need to bring the patient experiences of CFS/ME forward has been a recurring theme throughout this chapter. I have indicated the ways in which medical classification can silence and amplify the patient's voice. The chapter has also addressed the potentially competing epistemologies between doctor and patient. By positioning CFS/ME within the literature on medical classification and medical epistemology, attention has been drawn to how the experiences of people with CFS/ME are

marginalised and maligned. However, the diagnostic experience also needs to be considered in relation to the literature on illness experience. In this respect, it was suggested that investigating the CFS/ME diagnosis requires contextualisation, whereby the diagnosis can be understood within an individual's life course and illness experience. By doing so, it is possible to elucidate the social power, significance, and social consequences of diagnosis and, moreover, how people with CFS/ME make sense of their uncertain and contested diagnosis.

Finally, I explored the social consequences of diagnosis by reviewing the relevant literature on the sick role (Parsons, 1951). The sick role (Parsons, 1951) is especially salient in the case of CFS/ME because patients are often denied the sick role or even a partial form of it. The final section suggests that the sick role (Parsons, 1951) is not without limitations. Yet the sick role can provide a conceptual springboard for an analysis of the social structures mediating the relationships involved in the diagnosis of CFS/ME. Ultimately, this chapter has underlined how diagnosis is social; as an act, a process, a label, an experience and an endeavour. CFS/ME is a condition which has been under-researched within the sociology of health and illness. It warrants analysis that is underpinned by a sociology of diagnosis framework while investigating CFS/ME as a standalone condition.

Chapter 3
Methodology

3.1 Introduction

In this chapter, I provide an explanatory and reflective discussion on how this study explored the experience of the CFS/ME diagnosis. This chapter identifies how the chosen methodological tools compliment the contemporary and historical exploration of the contested diagnosis of CFS/ME. Structured into four parts, this chapter begins with the rationale for choosing to conduct qualitative research and I consider the congruity of the methods with a broadly interpretative viewpoint. Within this section I explain how the combination of historical archival research and contemporary interviews complement one another, showing how they are methodologically aligned.

The second part of this chapter moves on to discuss the archival research of two diagnoses; neurasthenia (Wessely, 1990; Shorter, 1992; Showalter, 1998) and the Royal Free Disease (Ramsay, 1986; Cohn, 1999), which have been connected to contemporary CFS/ME. The reasons for choosing neurasthenia and the Royal Free Disease are set out and followed by a mapping of the data collection conducted within the Wellcome Trust Library and archives. The approach to the archival data focuses on building a corpus which is rich for data analysis (Silverman, 2019). The thematic and holistic data analysis of the archival materials, which enabled me to construct a narrative around the emergence of both neurasthenia and the Royal Free Disease, is also discussed.

The third section of the chapter will focus on providing information about the qualitative interviews conducted with 42 people who had received a clinical ME diagnosis from a doctor. Semi-structured interviews were chosen because they allow for the flexible and reflexive exploration of illness experience (Mason, 2002). The study takes a thematic approach to data analysis, drawing on the approach developed by the Medical Sociology and Health Experiences Research Group at Oxford University. The thematic analysis of the interviews is illustrated in a step-by-step account, revealing a systematic approach to the data.

The chapter then moves on to reflect on my position as a researcher and an inside/outsider in the research process. The ethical considerations involved in the study are discussed with particular attention paid to the ethical challenges which arose during data collection. The limitations of the methods used in the study are then reflected upon, along with proposals for how the research could be further improved.

Finally, the conclusion summarises the chapter, providing an overview of how the various strands of the qualitative research, and its underlying methodologies, weave together.

3.2 Qualitative Research: Rationale and Methodological Viewpoint

The existing literature informed the research questions guiding the thesis, as well as the selection of the methods, analysis and analytical framework (Galletta and Cross, 2013). The research questions are compatible with qualitative methods and Tolley (2016, p. 24) suggests that such methods:

> generate knowledge of social events and processes by understanding what they mean to people, exploring and documenting how people interact with the world around them. It also seeks to elucidate patterns of shared understanding and variability in those patterns

One of the research questions asks, how do people with CFS/ME interpret and make sense of their diagnosis? The juxtaposition of two perspectives on fatigue related diagnosis – one historical and the other contemporary – helps to bring histories into the present and illuminate contemporary experiences of CFS/ME. By exploring how neurasthenia and the Royal Free Disease have been socially and culturally framed, it is possible to identify continuities with more contemporary experiences of CFS/ME. Consequently, "by opening windows on cultural understandings of health and disease, methods of qualitative research can help us comprehend some…new problems in old ways" (Tolley *et al.,* 2016, p. 21).

Within social research methods, there is often a link between the theoretical perspective and the research methods. While social scientists might align themselves with a particular world view (Pope and Mays, 2006), my own methodological perspective has been driven by the research questions (Brannen, 2004), which revolve around exploring experience. However, the theoretical viewpoint underlining this research might be broadly referred to as grounded within the interpretivist tradition. This asks the social researcher to "grasp the subjective meaning of social action" (Bryman, 2016, p. 26). One way of gaining interpretative understanding is through phenomenological epistemology, which is concerned with how we make sense of the world. This approach is largely epistemologically congruous with how I wanted to understand the experience of the CFS/ME diagnosis, as a diagnostic process and a label which has social consequences.

As Nettleton and Watson (1998) have argued, phenomenology can privilege the experiential aspects of the body; it understands human perception and knowledge to be embodied. Moreover, I "assume that that action and lived experience may be grasped from the vantage point of the actor who is invariably embodied" (Nettleton and Watson, 1998, p. 4). In asking people with CFS/ME how they experienced

their diagnosis, I was also exploring how they understood their bodies, their illness, and their identity. It was important that a sociological focus on the diagnosis of ME did not overlook the physicality of the illness experience. The emphasis on embodiment is particularly salient when considering patient opposition to psychosocial explanations for ME (Asbring and Narvanen, 2002; Spandler and Allen, 2018). Such explanations have been said to undermine the physical symptoms and suffering involved in living with the condition.

So far, I have shown how the historical and contemporary research interconnects and complements one another. The archival research and qualitative interviews might initially seem misaligned and incongruous in their methodologies. However, historical research has traditionally been influenced by positivism (Sweeney, 2015) and I draw broadly from an interpretative approach to the archival research. According to this analytic viewpoint, "documents are valuable sources of information, not about 'facts', but about 'subjective' experience, the ways in which people attribute meanings to their experiences, and the perspectives they develop in ordering and seeing patterns in their experiences" (Drew, Raymond and Weinberg, 2006, p. 66).

The study therefore offers an historical analysis of neurasthenia and the Royal Free Disease which is one possible interpretation of how fatigue dominated illness have been framed and, in turn, frame societal and cultural attitudes. Rosenberg's (1989; 1992) approach to the history of medicine suggests that framing can aptly describe the fashioning of explanatory and classificatory schemes of specific diseases. Further to this, the biological and embodied aspects of disease and illnesses are not overlooked by framing. Rosenberg (1992) suggests that biology shapes the variety of choices available to societies in framing conceptual and institutional responses to disease. Consequently, the archival research and the interviews are both underpinned by a broadly interpretivist approach and an attempt to incorporate the embodied experience of illness.

3.3 Archival Research

3.3.1 Archival Research: Research Approach

Scholars (Abbey and Garfinkel, 1991; Wessely, 1990;) have made connections between ME and neurasthenia by questioning whether ME was a contemporary reincarnation of neurasthenia. I also chose to study neurasthenia as part of my PhD research because it is identified as the first instance of medicalised exhaustion (Lian and Bondevik, 2015). Previous literature (Cohn, 1999; Ramsay, 1986) had also made links between ME and the Royal Free Disease, identifying the Royal Free Disease as the first instance of what we now know as CFS and/or ME. In addition to this, much like CFS/ME, neurasthenia and the Royal Free Disease are both multisystemic illnesses which encompassed a wide range of sporadic symptoms dominated by persistent fatigue. When I first undertook the historical

research, my intention was to use this research to contextualise the interview data. However, the archives proved to be such a rich source of data, which told their own story about fatigue dominated illnesses and how they had been historically and culturally framed that I also used them as a source of data. In the following sections, I will provide an overview of the approach taken to this archival research.

3.3.2 Archival Research Process: Journeying Through The Pages

Documents remain an essential source of social data in almost any area of sociological research, "which is just as significant a record of certain social realities as do the data generated by other more familiar methodologies" (Drew, Raymond and Weinberg, 2006, p. 73). My archival research began with an exploratory scoping of the archives at the British Library, The Wellcome Trust, and the London Metropolitan Archives. The scope of the research project had to be narrowed due to time constraints and the final data analysis focused on materials held at the Wellcome Trust library and archives, which are based in London, Euston. One of the advantages of the Wellcome Trust is that the library and archives are well organised and catalogued. The collection also specialises in the history of health and medicine. While the London Metropolitan Archives were particularly fruitful for contextualising the outbreak of the Royal Free Disease, the data analysis from the materials was too detailed to be included within this thesis. At the Wellcome Trust I focused upon the two fatigue dominated illnesses, neurasthenia (1869-1930) and the Royal Free Disease (1955 onwards), within their respective periods. Neurasthenia was restricted to 1868-1930 in order to capture the year preceding Beard's first publication on neurasthenia and on the basis that secondary data had suggested that neurasthenia had almost disappeared by the 1930s (Straus, 1991). The Royal Free Disease catalogue search was constrained by the dates 1954 onwards to ensure that the year before the outbreak was captured, as well as any retrospective analysis. There was no upper limit on the date for the Royal Free Disease as it is unclear how and when the Royal Free Disease ebbed away.

The archival data research continued until saturation point. In this case, saturation meant finding nothing which related to the main topic, but it would have also meant stopping once more of the same was found (Mautner, 2008). Saturation is "taken to indicate that, on the basis of the data that have been collected or analysed hitherto, further data collection and/or analysis are unnecessary" (Saunders *et al*., 2018, p. 1893). A key word search was undertaken, and alternative key words were used for both diseases/illnesses (see table 1). The alternative words were derived from a review of the literature pertaining to both diagnoses, but further key words also emerged from the searches. The following key words were used in the catalogue search and the results were further filtered by the dates:

Table 1: Key word searches at the Wellcome Trust Library and Archives

Neurasthenia	Royal Free Disease
• Myalgic Encephalomyelitis • Chronic Fatigue Syndrome • Benign Polio Myelitis • Benign Poliomyelitis • Benign Myalgic Encephalomyelitis • Epidemic Neuromyasthenia • Neuromyasthenia	• Myalgic Encephalomyelitis • Chronic Fatigue Syndrome • Benign Polio Myelitis • Benign Poliomyelitis • Benign Myalgic Encephalomyelitis • Royal Free Hospital epidemic • Strand Hospital Epidemic • Royal Free Illness • Icelandic Disease • Akuyeri Disease • Yuppie Flu

It should be noted that the keyword searches were limited as they did not include a search for poliomyelitis, which was a prevalent contagious virus in England in the 1950s (Snell, 1991). The significance of poliomyelitis was that the Royal Free illness and other similar epidemics were confused with it (See chapter 7). Poliomyelitis was excluded from the search because of the huge amount of search results yielded, and the scope of this project was already extensive. It would not have been possible for me to retrospectively distinguish between mistaken cases and actual cases of poliomyelitis. The words "Benign poliomyelitis/ Benign polio myelitis" were therefore used as a single search term within speech marks to limit the search of poliomyelitis to benign cases. I built a corpus of primary data and the key words emerged from the research, such as Icelandic disease and Akuyeri disease. The selected materials were restricted to printed text in the following forms tabulated below.

Table 2: Types of materials included in the database search Wellcome Trust Library and Archives.

Included Wellcome Trust Materials	Excluded Wellcome Trust Materials
• Medical Journals • Medical Texts • Patient Biographies • Public Health Records • Meeting Minutes • Cartoons with Text	• Website Stills • Audio Recordings • Photographs • Films

The reasons for excluding website stills, images, photographs, audio recordings, and films were partly because they were not textual materials. For the sake of continuity, the same type of data analysis was used to approach the archival research and the contemporary research. Thematic analysis was used to analyse both the interview transcripts and the textual materials from the archives. As Bryman (2008, p. 538) states, "One of the main difficulties with qualitative research is that it rapidly generates a large, cumbersome database because of its reliance on prose in the form of…interview transcripts and documents." The archival research therefore focused on textual materials to also provide manageable parameters to the study.

A random sampling of materials did not seem appropriate because the size and quality of the materials were unknown before commencing the research. The sample of materials relied on selecting a relevant corpus, which was achieved with key word searches. Once each key word search yielded no new results, the iterative process continued until the key words had been exhausted. Not all of the key words were identified prior to the research, since further key words emerged from the investigative process within the archives. An example of this was that I had been unaware that the Royal Free Hospital was known as the Strand Hospital, despite being located on Theobald's Road in Holborn, and after this the Strand Hospital was also used as a search term. The class marks and references of the documents were added to any notes regarding each material (Bauer and Aarts, 2000) and kept in Microsoft Word files. Any notes were typed up after leaving the reading rooms as computers were not always available. In addition to this, hard copies of the references and class marks were kept on flash cards and organised alphabetically.

Francis (2013) has pointed to how historical researchers have a duty to familiarise themselves with the social and cultural context of the day. It can be argued that this is especially important when analysing

historical data through a sociological lens, given the social nature of the inquiry. The context surrounding neurasthenia and the Royal Free Disease was established through a review of secondary data sources on the two diagnoses. The review of the secondary data sources was conducted by searching the University of Sheffield Library Catalogue using key word searches for both the Royal Free Disease and neurasthenia. After initially inputting the key words from the Wellcome Trust searches, the results were too large and had to be filtered down to a basic key word search to make the data manageable within the time constraints. The secondary sources were useful for beginning and contextualising the study. They provided insights and clues into data sources and interpretations that might not have been otherwise considered (Lewenson, 2011). The current section has elucidated the research process involved in the archival research. The next section moves on to discuss the analysis and finding the story within the data on fatigue dominated illnesses.

3.3.3 Archival Data Analysis: Unearthing the Story

The analysis of historical data is an interpretation of obtainable materials to piece together a story that informs contemporary understanding (Taylor and Francis, 2013). In doing history, researchers do not develop new data, but rearrange existing data (Danto, 2008). In addition to a holistic reading of each material, my analysis was also informed by the question, "How have the fatigue dominated illnesses, neurasthenia and the Royal Free Disease, been historically framed?" However, this question needed to be broken down into smaller and more specific questions, which included:

- How did neurasthenia and the Royal Free Disease emerge?
- What were the dominating theories on the cause of these diseases/ illness?
- What were the treatments for neurasthenia and the Royal Free Disease?
- What type of people (class, gender…) were treated for neurasthenia and the Royal Free Disease?
- What are the continuities between neurasthenia, the Royal Free Disease and CFS/ME, if any?

Further to the research questions the documents themselves had to be assessed for veracity, context, provenance, purpose and usefulness (See appendix A for my checklist on evaluating historical resources). I used a checklist to ensure that I was reflecting upon these issues as I researched the historical data. The interview research and the archival research were conducted in parallel. This meant that the themes which arose in the interview data could be cross referenced with the archival findings. However, it was important to avoid cherry picking the data to suit emerging theories and themes (Mautner, 2008) which had already arisen from the interview data. Reflexivity was integral to the process of reading the materials and reflecting on why I was including them in my research. The need for reflexivity is informed by the perspective that the researcher is a research instrument which has

influence in how the data is recorded and analysed (Tolley *et al*., 2016). Keeping an open mind and letting the data speak for itself therefore aids the rigour of the historical analysis (Taylor and Francis, 2013).

In order to be able to substantiate any claims, flash cards were used to document the investigative trail which was used support my own interpretation of the data. Each source was summarised on one flashcard and the key themes were written at the bottom of each card. I also took photographs of some of the archival materials so that I could study them in more detail and quote directly from the texts. Using quotations enables some transparency, so that the reader can view the data for themselves. The selected texts were rich sources of data making explicit the linguistic means through which the representations of a reality and social relationships are enacted (Mautner, 2008). The archival data was analysed thematically, but in a way that more holistic than the interview data and this was due to the volume of data and the time constraints on the project. There are, however, continuities between the archival research and the interview research in that the data from both methods was approached with a thematic analysis. The current section has mapped the steps of the data analysis, showing how I crafted a story which demonstrates how fatigue dominated illness have been culturally and historically framed. The next section focuses upon the in-depth semi-structured interviews which elucidated the contemporary experiences of the CFS/ME diagnosis. I now turn to the rationale for specifically choosing to undertake in-depth semi-structured interviews.

3.4 Qualitative Health and Illness Research: In-Depth Semi-Structured Interviews

3.4.1 Research Approach: Insights into Contemporary Experiences of Illness

This study sought to explore the experience of the CFS/ME diagnosis and the exploratory nature of this research required the flexibility to investigate views and experiences. Conducting in-depth semi-structured interviews was therefore appropriate because they are adaptable and seek to establish the views of the participants (Bryman, 2016). This style of interview has been described as a guided conversation (Rubin and Rubin, 2005) and I found there was room for participants to provide additional views/concerns and this facilitated insight into what the respondent saw as relevant and important. Equally, if some questions/specific topics had already been addressed by the participants referring to the interview guide enabled a smooth transition onto another area for discussion.

One of the research questions underlining this thesis concerned the diagnostic process/journey of the participants, and it asked, “What is the diagnostic process for someone who has been clinically diagnosed with CFS/ME?” The adaptable interview guide meant that I was able to ask questions which clarified the chronology and details within the respondents’ answers. One of the advantages of semi-structured interviews is that the researcher can seek clarification and elaboration on the information

given by the participant (May, 2013). The flexibility of the interview is also useful in cases where the researcher has little information about the participants before meeting them (Dimond, 2015). For instance, I sometimes knew the age and gender of a person but not much more other than that they had been diagnosed with ME. The semi-structured nature of the interview meant that I was able to ask key questions of all the participants to gain an insight into the demographics of the sample. At the same time, the interview style enabled the research to be concerned with the aspects of diagnosis which were deemed important by the interview participants.

The interview guide was divided into three parts (see appendix B). The first part of the interview guide focused upon the participants' medical story, such as when and where they experienced the onset of the symptoms. In contrast, the second part of the interview guide focused on participant emotions, relationships and identity. The rationale behind taking this approach drew from previous health and illness research (Cornwell, 1984; Morse, 2016; Radley and Billig, 1996) which has shown how, in qualitative interviews, respondents will only move onto the emotional side of illness once they feel comfortable. Therefore, the interview guide moved from questions which were aimed to be relatively straightforward onto questions that were more probing. In addition to this, the participants may never have had the space to tell th+eir story before and, because of this, often find that "they reveal to themselves as much as they do to the interviewer" (Morse, 2012, p. 20). It therefore seemed appropriate to begin with more basic questions and build up to increasingly complex and personal queries.

Within the archives of the Wellcome Trust, I found a patient questionnaire from 1976 (see appendix C) and the notes accompanying the questionnaire state that the document was sent to patients diagnosed with Icelandic Disease.[17] The recipients of the questionnaire included some patients who had been affected by the Royal Free Disease. The Patients Association had composed the questionnaire which had sought to better understand what it referred to as "Icelandic Disease". The notes accompanying the questionnaire state that "Icelandic Disease is also known as the Royal Free Disease following an outbreak in 1955 which attracted wide publicity", so it is evident that the author regarded Icelandic Disease and the Royal Free Disease as being same illness under different names. The accompanying notes summarised how the questionnaire was part of a larger initiative to identify sufferers and to further research into the condition. The Patients Association wanted to make a leaflet for patients reassuring them that they had an "organic" illness. The results for the patient questionnaire (1976) are under embargo until 2078, so it is not possible to do a cross-comparison of the results, but the meeting minutes and summaries provided data which corresponded with the questionnaire. The questions from the

[17] Icelandic Disease and Akureyri Disease are alternative names for CFS/ME. Icelandic Disease/Akureyri Disease originates from an epidemic simulating poliomyelitis, which took place in the town of Akureyri in Northern Iceland in the winter of 1948–1949.

questionnaire were used to inform the interview guide, and this meant that I was able to address some of the issues that had concerned the researchers investigating the patient experience of Icelandic Disease/ Royal Free Disease. The patient questionnaire not only provided a link between the historical research and the contemporary research, but it also enabled me to build some continuity between the two. The Patients Association had broadcasted their research on the radio and found themselves overwhelmed with the number of responses. In the following section I will focus on outlining issues of access and recruitment.

3.4.2 Access and Recruitment

The recruitment of interview respondents was done through three channels, which included snowball sampling, social media recruitment and local ME patient groups (who met in person). The initial snowball sampling was done through word of mouth and elicited six interview respondents. The next stage of the participant recruitment involved the local ME Groups which were found on the website of the ME Association. While the local ME groups were listed on the website of the ME Association they were not managed by the charity. Some groups were eliminated from the sample if they had a niche focus, for example if they had a religious element. I targeted the ME patient groups based on where they were geographically located and these locations included: a northern industrial city, a rural town, a southern medieval city and London and outer-London. Further, each of these locations was managed by a different healthcare trust. My research found that the diagnostic process and patient pathway were different for each of these locations. For example, participants from a rural town struggled to access their local CFS/ME clinic because it involved a one-and-a-half-hour car journey for them. Instead of meeting healthcare professionals face-to-face, they were regularly consulted via telephone call during their diagnosis of CFS/ME. The leaders of the local groups forwarded my introduction letter to their members and information sheets and consent forms were sent to those who expressed an interest in my research.

The final stage of recruitment was done through the assistance of the ME Association. The ME Association was chosen because I had already built a relationship with them before beginning the PhD. The Medical Advisor at the ME Association, Dr Charles Shepherd, vetted me by speaking with me on the phone to discuss and approve the study. Dr Shepherd kindly mentioned my research when he spoke to an ME group in a Northern city, and he put me in touch with the Communications Officer via email. I created recruitment messages for Facebook, Twitter and the newsletter (electronic and paper), which were fed by the ME Association. My adverts were then forwarded on to blogs, over which I had no control. The study was also shared via Facebook and retweeted by those who had seen the original advert. I received more than 500 responses to the call for participants and I had received over one hundred emails in 24 hours with people willing to participate in the research. The number of participants who volunteered for the study perhaps reflects the significance of the diagnostic experience for people

with CFS/ME. The organisation of the responses required multiple inbox folders based on geography, confirmation, and interview type. I received interest from potential participants from areas which had not been stated in the recruitment drive with some offering to travel and conduct interviews over Skype. Whilst my intention was to do the interviews face to face, a more flexible approach was needed after reflecting that some people would be too ill to be interviewed in person. The majority of the participants were not in paid employment, and seldom left their homes. Some participants rarely left their bedrooms. This meant that scheduling interviews was largely contingent on the participants' health status and self-care routines. The difficulties in scheduling the interviews reflects how CFS/ME pervades the daily lives of those living with the condition and how they can find it difficult to plan due to the fluctuations in the illness.

It was, however, important to capture a range of perspectives, to reflect the experience of living with CFS/ME, and this included interviewing participants experiencing differing levels of severity in the illness. I adapted to the needs of the research participants by doing Skype interviews or interviewing in multiple time chunks and I rescheduled interviews when participants were too ill to speak. The mean average length of the interviews was one hour and a half, but the face-to-face interviews tended to be longer and averaged at two and a half hours. The shortest recorded time was forty minutes and the longest was nearly four hours (inclusive of comfort breaks). In the case of 13 interviews, the time was split into chunks over a period of days or weeks because the respondent had wished to spend longer talking about their experiences, but they had not felt physically able to do so. The interview time being divided in this way meant that the participants would sometimes readdress previously addressed topics in the interview because they had time to reflect on their answers. The duration of the interviews was also dependent on the availability/routines of the participants, such as what time of day they felt the most well and when they slept/rested.

With regards to the format of the interviews, 21 interviews were face-to-face and in person, 8 were via Skype video conferencing (face-to-face) and 13 were conducted over the telephone. The majority of the face-to-face interviews were done in the homes of the participants. This was often easier for the participants because travelling often proved to be physically difficult. Conducting interviews in the home also provided a natural setting, which can help to build a rapport between the participant and the researcher. Interviewing face-to-face has the advantage of the researcher being able pick-up clues involving non-verbal signs, such as nodding (Walliman, 2006). Most of the face interviews took place in the participants' homes. Five of the face-to face interviews were conducted in cafes, one in a library and another interview was done at the participant's workplace.

3.4.3 The Sample and Demographics

To explore how people with CFS/ME experienced their diagnosis, I interviewed 42 people who had been clinically diagnosed with the condition. The DipEx (now Healthtalk) studies, which explore illness experiences found that between 40 and 50 interviews provide a sufficiently wide range of experiences (Ziebland and McPherson, 2005). The qualitative data collection and analysis were done in tandem to achieve data saturation, but there is no consensus on a formula to indicate when saturation is achieved. It was clear when the data was not saturated when the analysis seemed thin despite the richness and length of the interviews.

In order to meet the aims of the study it was essential that all the participants had been diagnosed with CFS/ME in the UK by a doctor within a secondary care setting. I had recruited people who had been diagnosed recently, as well as those who had lived with their condition for many years. The mean average time that it took to receive a diagnosis was 2 and a half years. The shortest amount of time it took for a respondent to be diagnosed was 3 months and the longest time it took to receive a diagnosis was 15 years. The ages of the respondents ranged from age 18 to 60, with a mean average of 40 years old.

With regards to gender ratios, there has been evidence to suggest that female sex is the only demographic risk factor in CFS/ME, with the relative risk being between 1.3 and 1.7 depending on the diagnostic criteria used (Reid *et al*., 2000). A sampling frame was not chosen because the United Kingdom demographics for CFS/ME are estimates based on figures extrapolated from other countries (NICE, 2007). In total, 6 men were interviewed out of a total of 42 people, and there is currently a gap in the literature with regards to male experiences of living with CFS/ME. The interview participants also consisted of 39 people who identified themselves as white, two women who stated that they were white Irish and one woman who preferred not to say. In terms of nationality, all of the respondents were British except for one person but she had been diagnosed in England. Their class was not easily discernible because of the significant changes to their occupational status and income.

3.4.4 Transcription and Analysis of Interview Data

The interviews were audio-recorded and transcribed to produce a written record for analysis. The transcripts included intonations and interruptions such as laughter, pauses, crying and tearfulness. Pets also interrupted the interviews and they needed attention during conversations with the participants. The sounds and interactions with animals became part of the data because it was clear that pets were an integral part of the respondents' lives. Once the recorder was turned off, some participants continued talking. As a point of ethics, the extra data was not incorporated because it was unclear whether the participant would want those extra conversations included. The interview transcriptions were typed soon after the interview and this was useful in being able to identify emerging patterns and anomalies.

During each interview I took brief notes in case the audio recordings failed or if I need to jot a reminder to explore something the participant had mentioned. After each interview it was important to take time to write down my reflections as a researcher, including what might be done better or differently. This is a reflexive practice which May (2013) suggests is essential to qualitative research to ensure rigour and awareness of the researcher's position within the study. The diary also helped me to deconstruct how I had felt about the interviews, as it was not possible to confide in anyone due to the restrictions of confidentiality.

The analytical process began early in the research collection, and it was informed, to an extent, by the literature review and a return to the literature. Early interviews raised issues that were not anticipated based on the literature, and I was able to amend the interview guide accordingly. An example of this was how the unanticipated themes of loneliness and social isolation unexpectedly emerged. My analytical approach is borrowed from the Oxford Health Experiences Group (OHEG) who conduct research into patients' experiences of a range of illnesses, such as autism and cardiovascular disease. Their work attempts to illuminate the broader effects of illness on patients' lives and highlight how patients perceive their care. In a similar way, my research attempts to understand how people with CFS/ME experience their diagnosis. The thesis situates the diagnostic experience of CFS/ME within the participants' broader illness experiences and life course. One of the reasons for choosing the OHEG approach to analysis is that they offered a step-by-step approach to undertaking thematic analysis which has been specifically adapted to explore health and illness experiences.

The OHEG use thematic analysis (Ziebland and McPherson 2006; Ziebland *et al*., 2013) in their research which "offers a toolkit for researchers who want to do robust and even sophisticated analyses of qualitative data" (Braun and Clarke, 2013, p. 2). One of the drawbacks to the thematic analysis was where the participant's overall story was being lost through coding. However, a benefit of the OHEG approach is that they use OSOP (one side of paper) to detail the patient's story (see appendix D). The thematic analytical process that I undertook is detailed in the steps in the flow chart on the next page.

Flowchart: The Analytical Process of the Semi-Structured Interviews

While previous research has focussed on the narratives of people with CFS/ME (Bulow, 2008; Cheshire *et al*., 2021) some of the narrative can be lost within a thematic analysis. This was counterbalanced by producing one-page summaries for each participant detailing the chronology and key themes/details of their experiences. The analysis of the interviews was conducted in tandem with the archival research, and this helped to identify emerging themes. The themes within the historical framings of fatigue dominated illnesses and the themes within the contemporary experiences of CFS/ME were compared

and contrasted. In so doing, I was able to highlight the continuities between the historical archival data and the interview participants contemporaneous experiences of CFS/ME.

3.5 Researcher Position and Reflections

I reflected on my position as a researcher throughout the research process, evaluating the potential effects this might have on the analysis and writing-up. My own personal experience of a misdiagnosis led me to consider the possibility of researching the diagnosis of CFS/ME. The review of the existing literature on the topic of study can be influenced by the researcher's experience, autobiography and their understanding of the research context (Galletta and Cross, 2013). The significance of this pertains to two key issues which arose during the process of data collection. The first relates to recruiting for interview participants and the second is connected to my position as a researcher.

As to the first, one of the avenues of participants recruitment was through the patient charity, The ME Association. After a phone conversation and email exchanges with the ME Association, they kindly agreed to advertise my research call for participants on their social media outlets. However, in addition to the agreed text, information was added by the ME Association that I have been misdiagnosed with CFS/ME and I had a family member living with ME at the time of the study. This raised the ethical dilemma where information about my family was put in the public domain without their consent. However, my relative was comfortable with the advertisement because they were unnamed, and they hoped the disclosure might encourage more people to come forward as participants. The next section relates to the issue of researcher membership and how this impacted on the research.

The subject of researcher position in relation to those studied is relevant to all approaches of qualitative methodology because the researcher plays a direct and intimate role in data collection and analysis (Dwyer and Buckle, 2009). The majority of the interview participants did acknowledge my experience of CFS/ME, as someone who had a personal insight into the diagnostic process, and I was seen as a partial insider. This seemed to help to elicit confidence and trust in me as an interviewer. In addition to this, 17 of the respondents wanted to know more about my own patient narrative during the interview. I was more comfortable doing this during the interviews than I was through email because the exchange felt more reciprocal. Whilst this thesis is far from an autobiographical account, I recognise that my past clinical and diagnostic encounters enter the research experience. Life experiences can bias research and they can also enrich it. I view myself as a co-constructor of the data that I represent in this thesis, which is part of the interpretative research process. The analysis attempted to be methodical and logical but my own schema and ways of "lumping" and "splitting" (Zerubavel, 1996, p. 421) have been imposed on the research data and, to an extent, it can be argued that all research involves some subjectivity.

However, it is important to counterbalance subjectivity with reflexivity which is essential in maintaining rigour by attending to my thought processes and position as a researcher (Galletta and Cross, 2013). This can improve the reliability and credibility of the data presented by the researcher (Arber, 2006). However, it is a balance between being "acutely tuned-in to the experiences and meaning systems of others…and at the same time to be aware of how one's own biases and preconceptions may be influencing what one is trying to understand" (Maykut and Morehouse, 1994, p. 123). Considering my position as a researcher is also tied to the ethics of the study, and within the next section I reflect upon the professional and personal ethics involved in the design and execution of the research.

3.6 Ethics

The ethical considerations concentrate on the interviews and focus around four key areas: informed consent, confidentiality, anonymity and the wellness of the interview participants. The scope of this research was such that it had the potential to request sensitive information from participants due the focus on illness experience. Data collection on illness experience can involve "asking about intimate, embarrassing and terrifying aspects of this changed life that the participant sometimes does not want to think about, let alone discuss" (Holloway, 2005, p. xv). It was therefore vital that personal information and research data were treated confidentially and that the participants were assured of anonymity. The research was designed to address these issues as well as ensuring informed consent and sensitivity to the needs of people who have a chronic illness.

The consent form (see appendix E) and an information sheet (see appendix F) were designed to be understandable to those being interviewed and checked by people outside the fields of sociology and medicine. The ethics committee in the sociology department at the University of Sheffield provided ethical approval and no concerns were raised. The information sheet and consent form were sent to the participants via email/ post ahead of the research for their signature. I also took hard copies of the forms along to the face-to-face interviews and all participants provided informed consent. To further ensure informed consent the respondents were asked whether they had any questions about the research, both at the beginning of the interview and once the interview had ended. Participants were informed that the study was voluntary and that they could withdraw at any time and without any reason (Thomas and Hodges, 2010).

The proposal for the study was checked by the Chief Medical Officer at the ME Association who suggested that the interviews should not last longer than an hour because of the impact on the participants. It was also important that the participants were well enough to take part, and this was stated in the information sheet. As previously mentioned, the interview respondents were asked at frequent intervals (approximately 15 minutes) during the interview whether they were okay to continue to speak.

During the interviews, every possible effort was made to detect nonverbal signs of inconvenience or any indication of a wish to withdraw from the interviews (Mazaheri *et al*., 2013). For some participants, their interviews were conducted in 15-minute intervals and they returned for subsequent interviews to finish their story.

With regards to confidentiality and anonymity, all of the personal details, data and transcripts were password protected on my own personal desktop. Any hard copies were stored securely, and they will be cross-cut shredded upon submission of this study. In the interview transcripts, the names of the participants were removed and replaced with a pseudonym of the same gender. I transcribed and analysed the interviews myself which also ensured confidentiality. The tendency of researchers to choose locations near to their research institutions can undermine anonymity (Pope and Mays, 2006) but this study was completed in three different geographical locations. Wengraf (2001) suggests that a test of confidentiality is where certain identifying details are changed sufficiently so that, friends and family would not recognise the person. The narratives of the participants were kept intact but any distinguishing features have been altered or eliminated from the discussion and writing up of the research. So far, the ethics of the study have been discussed, with particular attention paid to sensitivity, confidentiality and anonymity. The next section highlights the limitations of the research design and process.

3.7 Limitations of the Research Design and Process

This study has tried to ensure that the qualitative research has been rigorous and systematic while resonating with external validity. However, the first reflection on the limitations of the research concerns the data analysis. With the benefit of hindsight, I would have used Nvivo or a similar software package to aid my analysis of the data. There was a huge amount of filing, paper and organisation which might have otherwise been streamlined. Within this study, I investigated how people and diagnoses are labelled and qualitative research largely measures social phenomenon by classifying and taxonomy (Pope and Mays, 2006). However, the interpretation and coding and analysis of the data could have been enriched and improved through respondent feedback or collaborating with experienced academics.

In addition to this, the transcripts and thesis could have been checked by the participants so that they could clarify, amend or retract their interviews. Participant checking would also have helped to validate whether my interpretation of their experiences held true for them. In terms of critically appraising this qualitative study, it is suggested that instead of conceptualising validity as it applies to the natural sciences it is more relevant to consider alternative criteria and rethink validity in the context of social and qualitative research (Richardson and St Pierre, 2005). It was therefore important to ask the questions:

- What is the "face validity" (Ruane, 2016, p. 119) of the research? Does it ring true?
- How comprehensible would this explanation be to a thoughtful participant in the setting?
- How well does the explanation cohere to what is already known?
- What is the negative evidence or what are the outliers? The OSOP methods allows a researcher to identify deviant cases that do not fit with the emerging story and that warrant particular attention.

The validity of this research is tied to being a reflexive researcher, continually reflecting and self-checking. I do feel confident that the thick description drawn from the interviews helps to demonstrate from where my analysis originated. A further limitation of the study is that it does not represent people of different ethnicities because 41 of the 42 transcribed interviews were with people who identified as white. The study represents a range of experiences of the CFS/ME diagnosis but there are grounds to suspect that people from different ethnicities may have different health and social experiences (Byrne *et al*., 2020), in which case the study may be limited by their exclusion. These limitations do not invalidate the findings from the existing participants in the same way that an incomplete sample might affect the applicability of results that rely on a numerically representative sample.

3.8 Conclusion

The chapter has sought to show how qualitative methods were chosen to best explore the experiences of people living with CFS/ME, from both a contemporary and a historical perspective. One of the key contributions of the overall research is where the thesis combines archival historical research with contemporary semi-structured interviews. The mixture of two different but complimentary perspectives on fatigue related diagnosis – one historical and the other contemporary – helps bring histories into the present and illuminate contemporary experiences of CFS/ME.

Taking a seldom used approach to the research methods has made it particularly important to provide a detailed and transparent description of how the research was undertaken. Chapter three has therefore mapped the practical elements of the data collection, from recruiting the interview participants to how both the historical and contemporary research were analysed. The chapter shows how thematic analysis has been used in both the historical archival research and the contemporary semi-structured interviews. One of the criticisms of thematic analysis is that is has not been well-defined (Bryman, 2016) but this chapter has offered the specific steps which were taken during the data analysis.

The interviews were conducted in a way that would accommodate the needs and self-care routines of the interview participants. The adaptations to the research process were responsive to some of the challenges of living with CFS/ME. Measures to adapt to the requirements of the participants included Skype calls and home visits. Further steps included dividing the interviews into chunks of time so as not to exhaust or drain the participants. Memory and concentration difficulties can be symptoms of CFS/ME. One of the advantages of taking notes during the interviews was being able to remind the participants of their train of thought when they asked to be reminded. Therefore, the process of researching what can be a fluctuating, chronic and disabling illness itself provides an insight into the illness experiences of the interview participants.

Patient experiences of the CFS/ME diagnosis is placed at the heart of this research. Semi-structured in-depth interviews were undertaken to give space to people with CFS/ME to tell their stories. Chapter two showed how people with CFS/ME have often been marginalised and had their illness experience undermined. The participants commented that the interviews had provided them with an unusual opportunity to reflect on their illness and how their condition had affected them. They found that having the time to talk about their CFS/ME experiences had been helpful and cathartic. One participant commented on how they were unable to access counselling services, but they had felt a need to discuss how they were feeling. Whilst the research was not intended to be therapeutic, the impact of the interviews on the participants might indicate that there is a lack of support for CFS/ME patients. The stigma attached to the condition might also prevent open conversations about CFS/ME with people within the CFS/ME patients' social networks. The negativity that people with the condition experience may also prevent patients from seeking additional help from healthcare professionals. The positive research experiences of the participants indicate the value of conducting social research into the diagnosis of CFS/ME.

Chapter 4
Labelling ME: Epistemic Injustice and Diagnostic Uncertainty

Georgia: I mentioned ME to my doctor and he basically said 'well it doesn't really exist, some people like to give a name to a collection of symptoms they can find no reason for. It's going to be really hard for someone to point to that and say that's what you've got.

4.1 Introduction

The definition and usage of CFS and/or ME has been contested and debated (Jason, 2007; Jason, Nicholson and Sunnquist, 2016). In the absence of conclusive biomedical evidence underpinning either CFS or ME, the labels and the illness have been particularly open to different interpretations. Medical classification systems and diagnoses are often naturalised, opaque and taken for granted. By exploring a diagnostic label which is contested, it is possible to "render visible" (Jutel 2019, p. 3) the influence of a diagnosis (Brown, 1995) and how it has been interpreted. It is also important to understand how people with ME attach meaning(s) to their diagnosis because they live with the illness day-to-day. ME patients appear to have a particular type of epistemic privilege, due to their embodied experience of the condition. While doctors are highly trained in expert medical knowledge, presently there appears to be no conclusive biomedical explanation for ME. This suggests, perhaps, that much can be learned from patient experience. This chapter seeks, therefore, to explore the participants' experiences of diagnostic labelling and ME by considering the wider context of their illness experience. By exploring the ways in which patients experience the labels of ME and CFS, the chapter seeks to offer an original contribution to the sociology of diagnosis.

The chapter draws on two key concepts to illuminate the data and elucidate the its main arguments. These concepts are "epistemic injustice" (Fricker, 2007, p. 1) and the sick role (Parsons, 1951). Using the concept of epistemic injustice, the current chapter highlights the manifestations of stigma which the participants experienced within clinical interactions. The chapter also discusses the issue of legitimacy in relation to the sick role (Parsons, 1951) and the argument will be made that the sick role is still relevant within the experience of the ME diagnosis. The sick role, despite its limitations, is able to show the social consequences of having a diagnosis withheld and/or delegitimised. One of the benefits of the sick role (Parsons, 1951) concept is how it demonstrates the structuring and bureaucratic role of diagnosis. In addition, the asymmetrical power dynamics between patient and doctor are elucidated by employing the sick role (Parsons, 1951) within this chapter.

The communicative value of the ME diagnosis will be illuminated in the chapter, because being able to attach a name to a group of symptoms allows patients to confer the illness to themselves and to discuss it with others. The importance of naming is especially salient where a diagnosis withheld, and the chapter will demonstrate how the uncertainty of "diagnostic limbo" (Corbin and Strauss, 1988, p. 22) is experienced in the period between first feeling the symptoms and eventually receiving a diagnosis. Naming the condition will be shown to be integral for the participants to be able to attempt to form a coherent illness narrative and make lifestyle adjustments. The classificatory work of patients is also highlighted, especially in the absence of a diagnosis, when the participants considered and ranked diseases according to whether they feared them more or less than ME. Consequently, the chapter interrogates the issue of (un)certainty within the ME diagnosis and whether it alleviates or propagates ambiguity.

With regards to the structure of the chapter, the first section begins by exploring the meanings that the participants attached to both ME and CFS, as well as the reasons for their preferred diagnostic label. Both labels are replete with ambiguity, but as will be shown, ME was the term often favoured by the participants. The first section will discuss the participants' reasons for preferring ME over CFS, which relate to the functional and political aspects of the diagnosis. While ME is an inaccurate and imperfect diagnostic label, it does offer the best available shorthand to denote the symptoms of the condition. There is hope that patients with ME will experience more certainty and legitimacy in the future through further research effecting positive change in societal attitudes towards ME. Moreover, the participants perceived the ME diagnosis to be socially and historically located.

The second section explores the significance of receiving an ME diagnosis. The participants' expectations of receiving an ME diagnosis were frequently disappointed, as they had often anticipated certainty and an unambiguous prognosis. The discussion in the second section shows how receiving a clinical ME diagnosis did not readily grant access to the resources and the legitimacy of the sick role. It will demonstrate how ME challenges the ways in which we might traditionally conceptualise diagnosis, whereby diagnosis is expected to provide a "roadmap" (Boulton, 2019**,** p. 809) to treatment and prognosis. Participants appeared to experience "epistemological purgatory" (Barker, 2005, p. 7), even after a clinical diagnosis, when biomedicine was unable to validate their subjective understandings of their bodies. Consequently, "diagnostic limbo" (Corbin and Strauss, 1988, p. 22) can still occur after a diagnosis has been given because some participants continued with their search for an alternative label for their symptoms.

The chapter then discusses the ethical implications of having a diagnosis withheld while considering the social consequences of experiencing the suspension of, or delay to, an ME diagnosis. Through experiencing the ME diagnosis being suspended or withheld, the participants were deprived of knowledge of themselves, and their bodies. The participants were also denied access to the structuring and functional roles of diagnosis, by being prevented from trying to obtain the sick role. The harmful social consequences of having a diagnosis withheld are considered and reflected upon by drawing from Fricker's (2007) work on epistemic injustice. However, the chapter begins by introducing how the participant's interpreted both CFS and ME.

4.2 CFS or ME? The Best Available Shorthand

During every interview, each participant was asked how they referred to their illness and the reasons for their preference. The interview participants provided an insight into why they showed a preference for either CFS or ME. Here, favouring a particular diagnostic label is political and functional. The responses from the interview participants showed more than a mere predilection for a name. Their preferred diagnostic label reflected how they understood their illness and what the terms CFS and ME meant to them.

Lucy had been diagnosed with ME 22 years prior to the interview. She had previously worked in community health, lived with her girlfriend and she had enjoyed renovating houses. Since becoming ill with ME Lucy had become unemployed, lived alone and she only left the house for essentials. Lucy had not believed that ME was a "real illness" (Lucy) before being diagnosed with the condition herself. The following interview extract highlights how a preference for ME over CFS is demonstrative of how the interview participants understood the positioning of their diagnosis within a wider classificatory framework and historical framing.

> *NW: What do you tend to call your illness? ME?*
> *Lucy: Yeah that's what it was called when I was diagnosed and anything else, I mean chronic fatigue to me doesn't actually fit necessarily what I've got. I can't even remember what the new one is. I actually don't think chronic fatigue syndrome and actually I think there's just too much other stuff. Actually there's a blanket load of people with bugs and things that we understand as society changes and they've just dumped them under a label.*

Lucy regarded the term, CFS as a "diagnostic dustbin" (Ferguson, 2015) because she believed that CFS was an umbrella term for a variety of poorly understood illnesses. This showed an understanding of how "diagnosis lumps patients together" (Zerubavel, 1996, p. 23), and it is demonstrative of the organising function of diagnostic labels. For Lucy, CFS is categorised with other "people with bugs and

things" which are presently unknown or uncertain. The idea of having "dumped them under a label" evokes Balint's (1964) reference to unorganised illness, being illnesses which might appear as random symptoms, ailments and complaints, but which become interpreted by a clinician and organised into distinct categories of diagnostic classification. From Lucy's perspective, the act of diagnostic "dumping" can be seen as part of a wider process of medical classification.

In her reference to "society (societal) changes", Lucy observes that diagnostic categories are fluid concepts, which evolve over time rather than becoming stagnant, fixed, labels. This shows an awareness of how ME has been malleable to societal and historical influences. The above extract underscores her cognisance of how physical and mental states come to be thought of as diseases (or not) through a process of social construction (Berger and Luckmann, 1966), rather than purely naturally occurring phenomenon waiting to be discovered. The social and historical contingency of diagnosis was also exemplified by Lucy's conviction that further research and scientific progress would eventually be able to unravel the mystery of ME. It was common for the participants to refer to their hope that further and improved research would result in progress for ME in terms of its prognosis and treatment. In wanting improved diagnostic techniques for ME there was also hope that the illness would gain more legitimacy. The desire for increased understanding and acceptability was recurrently cited as a reason for taking part in my study. The assumption that progress will reveal more information about ME is echoed Anderson and Mackay's (2014) claim that the uncertainty within specific disease entities has a particular status, where "we have not yet agreed on such a mechanism, we assume that it will ultimately be revealed" (Anderson and Mackay, 2014, p. ix).

The perception that improved knowledge can create improved diagnostic robustness was highlighted by participants, who referenced the degenerative neurological disease, multiple sclerosis (MS). The participants observed that the biomedical credibility of MS was aided by further clarification and improved diagnostic techniques. Similarities between MS and CFS/ME can be seen in that people with MS were often diagnosed with a psychiatric disorder before diagnostic methods advanced (Skegg Corwin and Skegg, 1988). The diagnosis for MS now comprises a mixture of signs, symptoms, MRI (magnetic resonance imaging), lumbar puncture and blood tests, but there still remains no one definitive test for MS, other than autopsy (Murray, 2005). The participant's awareness of societal changes affecting the labels of ME and MS illustrates an understanding of how medical knowledge is socially and historically located. It also evokes Blaxter's (1978, p. 10) much quoted observation that a diagnosis presents "a museum of the past and present concepts of the nature of disease".

In addition to this, Lucy rejected CFS as a label to denote her symptoms because it failed to fully encapsulate her illness experience. The CFS label did not prove to be meaningful for her. Lucy felt that ME better reflected her illness experience because she believed ME represented a range of symptoms.

In the following extract, Evelyn also supported the view that the medically favoured term CFS did not accurately signify the wide range of symptoms she had encountered.

> *NW: What do you tend to call you illness?*
> *Evelyn: I call it ME. I don't call it chronic fatigue syndrome because then it sort of sounds like you're just. I would call more what I had before the virus more chronic fatigue syndrome because I was tired all the time but I didn't have any of the symptoms.*
> *NW: Yep*
> *Evelyn: But when I got the virus I would call it ME because I'd have all the other things, which meant it wasn't just chronic fatigue.*

This interview extract identifies where Evelyn's preference for either ME or CFS altered during the course of her illness, because of the changing symptoms. As Evelyn's illness progressed, CFS did not correspond with her subjective experience of the illness. Gina also reflected on CFS failing to adequately mirror her wide-ranging symptoms.

> *NW: Do you feel that friends and family understand your illness?*
> *Gina: Erm. I don't think anyone knows what it is but the people I've said it to will say oh yeah I'm quite fatigued at the moment and I'm like but it's not like fatigue I'm quite sick as well. It's erm not the reality of what the condition is.*
> *(Later in the interview)*
> *NW: What do you tend to call you illness?*
> *Gina: ME erm I think it's because I knew what it was. Before I got ill I'd heard of ME and then I had in my mind what my perception of ME was and to me that was quite a serious illness. I'd never heard of chronic fatigue syndrome and I don't think it absolutely represents what I've got.*

Gina's interview illustrated how ME is more culturally available than CFS on the basis that she had heard of the diagnosis. She also felt that the ME label reflected a serious illness whereas chronic fatigue syndrome emphasised a commonly experienced symptom, fatigue. It can therefore be seen that, for the interview participants, the label often functioned as an explanatory mechanism that structures an illness narrative which had very little to do with formal diagnostic classification systems. In the absence of strong biomedical evidence for disease and its treatment, illness narratives may serve to express what Bury (2001, p. 269) refers to as "culturally available concepts of disease and illness".

The overwhelming majority of participants stated a preference for using the label ME. The below excerpt is from an interview with Phil who was unusual in favouring CFS. He felt that it represented the severity of the fatigue and its effects.

> *Phil: Because no one knows what I'm talking about when I say chronic fatigue syndrome although I think chronic fatigue syndrome is a much more fitting name for it because ME is supposed to be something to do with your muscles but I've never had a problem with keeping the exercise up and actually when it's worse the exercise helps. CFS is much more apt and I've never had an issue with it. Other people do because it's called fatigue and undervalues it but I don't know like I mean yeah sure people think it means you're just like tired. Fatigue awful. You tell someone with chemo that fatigue is something minor! Well of course it's not and if you really have bad fatigue then you can't do anything. With calling fatigue it doesn't mean that there aren't bad symptoms with it and around it. I still see when I get dizziness that sure they are enough in themselves but they are completely linked to fatigue. It's linked to a number of unpleasant things not just feeling tired. So yes I think it's pretty fitting.*
> *NW: What does your GP call the illness?*
> *Phil: I can't even remember but I know the specialist clinic is the ME slash CFS clinic. I think that generally speaking in this country you refer to it as ME because no one refers to it as CFS. Really, like if people call it CFS or ME I don't read into it. Like if they say ME I don't think they're discounting the fatigue aspect of it and vice versa.*

Whereas Gina had felt that fatigue as a symptom was undermined by being an everyday experience, Phil articulated an example of the difference between fatigue and tiredness by referring to patients who had undergone chemotherapy. By doing so, Phil framed the serious nature of fatigue and its effects which helped to unpack his preference for CFS. However, Phil does signal the drawback of CFS being that it is not used within common parlance because "no one refers to it as CFS" (Phil). Unlike Phil, the majority of the participants felt that the focus on fatigue in chronic fatigue syndrome only undermined the severity of their fatigue and fell short of encompassing the other symptoms that they had experienced.

It is also noteworthy that while the predominant personal preference was for ME, some of the participants would change their language within clinical encounters. This adapting of the diagnostic label can be seen in the below excerpt from Martin's interview, where he recalls making the decision to use the label ME in an attempt to enable doctors to take his illness seriously.

> *NW: …You tend to call your illness ME rather than CFS?*

Martin: Yes just because um I think when I was seeing doctors that didn't care they were talking about chronic fatigue and were quite dismissive and uninterested…As one doctor said to me 'it's not fatal just get on with it (shrugs)' um so I think that also there's the context of, I think CFS appeared in the 1980s as a term and ME predates that and I think that that last twenty years there's been a strong psychological move in the UK which argues that CFS is psychosomatic and erm I did see a clinical psychologist who I'm still seeing, who I had this discussion with less than a month ago suggesting that my symptoms were all in my mind. The example he gave was quite contemporary. His example was, I like a programme called Sherlock?

NW: Yeah (nods)

Martin: … erm there isn't a master code he actually he was using that analogy that I just have symptoms which feed off each other, that the problems like depression will sort themselves out…So, it's a it's, I mean I like the fact that people who call it ME tend to take it more seriously. I think we're struggling to get the illness taken more seriously by a lot of medical professionals …Unfortunately I think that chronic fatigue has been associated with people not believing that you're seriously ill. Um whereas ME it y'know, it may not be the perfect description I think it's one which is well enough for the time being because it respects (smiles) patients a little bit more (nods).

Martin's interview extract highlights the clinical tensions between patient and doctor. He felt that clinicians responded to CFS with flippancy because of an historical association with it being psychosomatic. Martin felt that being told his "symptoms were all in my (his) mind" undermined his illness. Much like Lucy, Martin had an historical understanding of ME, where he referred to CFS in the 1980s. This awareness influenced how he understood the meanings attached to the labels of CFS and ME. Martin's more recent experience of the ME label was one where the illness was treated more seriously, engendering sympathy rather than stigma and dismissiveness. Poignantly, the historical constructions of ME continued to socially inscribe upon the experiences of people who had recently been diagnosed with the illness.

There were further instances of participants changing their language specifically for clinicians. They did so in an effort to negotiate their diagnosis and access elements of the sick role (Parsons, 1951), such as accessing treatment and social support. Rosie had experienced different clinicians throughout her long illness, so she had learnt to use clinical language to avoid awkward consultations.

NW: Do you tend to call you illness ME?

Rosie: I do actually tend to use ME. Yeah

NW: Is there any particular reason why you use it?

Rosie: I'm actually really sneaky and I tend to use CFS with doctors if I think it will make them less resistant (laughs). I just feel that, I realise that ME's not accurate but also I feel that CFS doesn't sound as serious as ME even though it's meant to be more descriptive. I find it quite irritating as a descriptive term.

Rosie altered her language in a way that would fit within the medical discourse used by her doctor. This altering of diagnostic label in clinical settings is a demonstration of how patients employed strategies to negotiate their care and make their doctors "less resistant" (Rosie). However, it also shows narrative surrender (Frank, 1995), whereby Rosie relinquished her own version of the illness to encourage her doctor to be more willing to accept her illness narrative. Rosie's approach to communication is also consistent with Goffman's (1963) suggestion that stigmatised individuals use information control to minimise the impact of stigma in social settings and to avoid hostile situations. It can therefore be seen that Martin and Rosie were using a means of information control to avoid the stigma that they had found to be associated with the terms CFS and ME.

This section has shown that neither ME nor CFS were deemed wholly satisfactory labels to reflect how the participants experienced their illness. However, there was a strong preference for the term ME because it was more culturally recognised and friends and family were more familiar with the term. Similar to the findings from research by Jason, Nicholson and Sunnquist (2016), the participants showed a preference for ME over CFS because CFS seemed to emphasise fatigue, which the respondents felt undermined the seriousness of the condition and the wide-ranging debilitating symptoms that CFS/ME can encompass. ME therefore better reflected the symptoms they experienced, and the participants felt that ME was taken more seriously. In rejecting the medical tendency to use the diagnostic label CFS, the participants asserted their own claim and identity upon ME. However, social setting and audience also played a role in whether ME or CFS was used by patients, especially in clinical interactions where the participants adopted the language of their clinicians. Taking ownership of the ME label might be regarded as a way of patients appropriating a structure for their own illness narrative and identity. By rejecting the medically preferred term CFS, it is possible to see an act of micro-political resistance by patients against the psychologising of the condition.

4.3 Uncertainty and Epistemic Doubt

While the previous section explored the meanings attributed to the diagnostic labels CFS and ME, the current section concentrates on the social and epistemic implications of holding a contested diagnosis. One of the key issues within doctor-patient interactions was where the participants did not feel they were treated as genuine patients, even after receiving a diagnosis. The significance of being disbelieved is emphasised in the interview with Fran who valued belief and empathy over a diagnosis.

NW: How do you think you could have been better supported through all this?
Fran: I think having somebody there that did actually understand and believe I think that would have made a difference. It reminds me of how rape victims used to be treated when I first joined the force. You take their hand and you let them know that you believe. Even if you have any doubts you make sure that they believe that you believe sort of thing so yeah. That's the thing somebody who can understand and believe.

Fran drew on her own experience as a former police officer when she reassured rape victims that she trusted their accounts without giving them any indication of doubt. At the time of the interview, Fran was struggling with bureaucratic issues over accessing her pension and job. During the process of applying for the pension, she had found difficulty in proving she was ill despite holding an ME diagnosis. The ME diagnosis did not grant Fran access to the benefits of the sick role (Parsons, 1951), such as resources and exemption from her working role. The legitimacy of the ME diagnosis was questioned by both healthcare professionals and Fran's pension provider. Fran recalled the truthfulness of her illness narrative being questioned. The delegitimising experiences felt like an attack on her moral character. Fran's experience mirrored the findings of a qualitative study of women with CFS/ME and fibromyalgia which showed that the participants felt stigmatised by others who tended to doubt the validity of their symptoms (Asbring and Narvnen, 2002). The following excerpt from Emma's interview shows how a doctor informally questioned the nature of her illness after she told him she had been diagnosed with ME.

Emma: I cried from relief when I found out that it existed and that I had it and that I could prove to people that I had it but it didn't (looks up). I thought it would change a lot but it didn't change that much because a lot of the people don't believe it exists. I had doctors tell me y'know like not that it doesn't exist but my cousin who's a doctor was 'y'know it's not proven so it's not really. It's more in your head'. I had a lot of that and I still had people saying like because I'm highly functioning y'know I wasn't at the time 'well you know you're just lazy because we can see that you're healthy so you're not sick you just don't wanna work'.

Emma's interview extract highlights the impact of the "diagnostic utterance" (Fleischman, 1999, p. 10) when a clinician first conferred the ME diagnosis to her. The importance of being able to name her illness is show where Emma recalls how she "cried with relief". Emma had felt relieved by receiving a diagnosis because she had believed that her ME diagnosis would bring validation, meaning she would be able to "prove to people" that she was ill. Emma had spent three years, thousands of pounds and countless visits to clinicians in her search for a diagnosis. This period of searching can be described as a time in diagnostic limbo, which is highly stressful because of the uncertainty and ambiguity of

experiencing symptoms without an explanation from a diagnosis. After so much time in diagnostic limbo, a diagnostic label offered a sense of stability and validation to Emma's illness experience. However, Emma found that her expectations of diagnosis providing certainty and a "roadmap" were disappointed by delegitimation and stigma. The moral nature of diagnosis is evident where Emma recalls that she was accused of laziness, rather than being granted the right to be ill. The interview extract is also revealing where Emma comments that her cousin, who was a doctor, suggested her illness was psychological. Previous research has demonstrated that there is stigma attached to ME because it is often perceived as being a psychosomatic illness, which is denied an organic status (Cooper, 1997). Emma's recollection reveals the doctor's informal understanding of ME, where he or she equates the uncertainty of the condition to it being psychosomatic. This insight into the doctor's understanding demonstrates how healthcare professionals might assign a formal diagnosis while informally placing their own personal beliefs upon those diagnostic labels. The patient / doctor dichotomy is therefore not simply subjectivity pitted against objectivity, since both may play a role in the doctor's thinking.

Nevertheless, Emma's reference to her cousin stating that "it's not proven" further highlights the tensions between scientific objectivity (signs) and the personal subjective experience of ME (symptoms). The epistemic tensions between patients and their clinicians are demonstrated by Emily in the interview extract below.

> *Emily: Even not being a scientist I thought that scientists were supposed to be open-minded. I thought that was one of the main credentials of being a scientist. Open your mind to the possibilities otherwise you're in the wrong job. You've got to. That was the main thing that we've all been let down by, by doctors. Sort of being left to think that we're all mad people*.

Emily's account shows how the uncertainty surrounding the ME diagnosis made her consider whether she was mentally ill. Emily had initially been amenable to exploring psychological treatments in the hope of recovery, but this changed as her illness progressed. Later in her interview Emily emphasised firmly how she felt that her illness was organic and that it did not have psychological origins. Emily's interview excerpt illustrates the sense of enigma and confusion that can arise where the "lived experience is contradicted by a lack of objective confirmation" (Whelan, 2007, p. 957). Barker (2005, p. 106) referred to this apparent contradiction as an "epistemological crisis", where the patient is left to process the embodied and subjective feelings of their illness since medicine is unable to objectively verify its existence. Barker (2005, p. 106) suggests that during an "epistemological crisis" the patient will confront how they know what they know. Emily trusted her embodied knowledge over the proposed medical advice and treatments. The dearth of biomedical explanations for CFS/ME appear to leave a vacuum for alternative theories, such as those relating to the behavioural and psychosomatic. Emily was critical of the lack of evidence for the psychological framing of her condition, suggesting that the

psychological approach to ME was unscientific. Emily can be seen to be using the gold standard of evidence-based medicine to argue against the psychologising of her illness. For Emily, the diagnosis of ME failed to palliate the uncertainty surrounding why she was ill. In some ways the diagnosis created more anxiety because she had been left to "think that we're all mad". Emily's quest for a biomedical diagnosis continued years after her initial ME diagnosis.

There were further examples of participants having been given an ME diagnosis yet not being treated as if they were legitimate and credible patients. This experience of delegitimation can be seen from the excerpt from Rachael's interview.[18]

> *NW: How could you have been better supported throughout your experience of ME so far?*
> *Rachael: If the doctor had believed me and not said I was making it up it would have helped. The paediatrician should have picked up on the Turner syndrome back then and erm that would have really helped. It was like push yourself and at the beginning stage. It wasn't helpful at all.*
> *NW: Was that what led your parents going private, the not being believed?*
> *Rachael: Yeah they just dismissed me when I turned 16 and said get on with it. So we thought it was worth checking nothing had been missed.*

Rachael's experience of being disbelieved by healthcare professionals confirms previous research, which has showed that ME patients reported delay, negotiation, and debate in their diagnosis, stemming from medical disbelief (Dickson, Knussen and Flowers, 2006). Rachael was discharged from paediatric secondary care because she had turned 16 but she subsequently received no follow-up support or treatment. Although Rachael still felt unwell and had an ME diagnosis, she was deemed fit by her paediatrician. In her adult years, Rachael was diagnosed with further health conditions which included colitis and a chromosomal disorder. The diagnosis of the additional conditions should have ruled out ME, because ME is a diagnosis of exclusion. Technically Rachael no longer had ME, but she believed that the disorder was the underlying illness related to her additional conditions. The explanatory power of ME was integral to Rachael's patient experience and the ME diagnosis helped her to understand her embodied experience within the context of suffering with broader health issues.

The following interview extract from Amy presents another instance of the truthfulness of the patient narrative being questioned by healthcare professionals. Amy had been diagnosed with ME as a young adult but some of her doctors had later asserted that she was either well or she had an eating disorder or depression.

[18] Although my sample focussed on adult ME, Rachael had been diagnosed as a teenager and she was in her 20s at the time of the interview.

Amy: On and off. When I go to the GP I don't even mention the ME any more. They look at you gone mad. They're not interested as far as they're concerned I don't have it. There's nothing wrong pull yourself together sort of attitude. I don't know. I go there. I mean I know it's related to ME (laughs) but they won't have it. It's hard with them people.
NW: Have any of them being willing to help you when it comes to ME?
Amy: No apart from Dr X (redacted) he was good but as for GPs never.

Amy was diagnosed with ME fifteen years ago and during that time her life had changed from enjoying gymnastics and being a busy student to becoming housebound. Amy reported that her main symptoms were fatigue, stomach, and bowel problems as well as pain and difficulty concentrating. Amy's life had changed dramatically but her illness experience was disregarded, despite having had a clinical ME diagnosis confirmed within both primary and secondary care. For Amy, "diagnostic limbo" (Corbin and Strauss, 1988, p. 22) did not end with the diagnosis of ME because debate ensued over whether she had an eating disorder, an illness that she refuted. Amy felt that her views and experiences of ME were dismissed. In a similar way, Lauren felt that her age and gender affected how she had been undermined. She recalled one particular clinical encounter in the following interview excerpt.

Lauren: I just want someone in Eastenders or a character in a soap gets it, it would be really helpful because most people have a perception of other diseases like cancer it's terrible. And it's in the media a lot. I think because of the psychological connotations of ME as well and there's a stigma attached to it. People don't like to talk about the symptoms because they are so strange. It's linked to stigma and mental illness I think now.
NW: Have you experienced that then, the stigma?
Lauren: Erm a little bit I have been to another GP from the surgery because my GP wasn't there and he doesn't know me and we spoke the phone and he was a little condescending and he said" what do you expect me to do". I felt that because he was a man he was a little "oh she's a middle aged woman she's neurotic" (laughs).

Some of the female participants felt that clinicians perceived them as being hysterical or neurotic. This echoes the case of endometriosis, where medical experts undermined the credibility of patient accounts by representing patients within medical literature as nervous, irrational women who exaggerate their symptoms (Whelan, 2003; 2007). Barker (2011) has argued that contested illnesses, such as ME, continue to be shaped by their feminisation and a cultural milieu that equates women with irrationality. The feminisation of ME re-emerged in the clinical encounter described by Georgia.

Georgia: I was a little bit scared and kept going back to the doctor who then said to me 'I'm not sure there's anything wrong with you. I think that perhaps you are worrying about your daughter going off to university'. I said my daughter's not going off to university until October and this was in March and erm how dare you say that my whole life the one thing I've done best in my life is to be a mum. What she has achieved is what I want for her. This is how her life should be. "no, your symptoms are that you're getting worried about that" which I thought was an awful thing to say. By this time I had started to look on the internet and things I'd never heard of ME or CFS before I'd sort of remembered the 80s yuppie flu thing and hadn't noticed it back them. I mentioned ME to my doctor and he basically said 'well it doesn't really exist, some people like to give a name to a collection of symptoms they can find no reason for. It's going to be really hard for someone to point to that and say that's what you've got'.

The doctor seemed to be making reference to Georgia's role as a single mother whose child would soon be leaving home to go to university. The clinician appeared to be suggesting that Georgia's symptoms were being caused by what is commonly termed empty-nest syndrome. Traditionally, empty-nest syndrome has been solely attributed to women (Karp, Holmstrom and Gray, 2004) and the reactions of the mothers are said to include, grief, dysphoria, identity crisis and depression (Borland, 1982), despite both parents being affected (Bouchard, 2014) Georgia had been scared by her symptoms and looked to her GP for both reassurance and an explanation. Georgia felt dismissed and undermined when she was told that her symptoms were caused by worry or nothing was wrong. Conversely, telling Georgia that she was fine caused her greater anxiety because she felt very ill. The theme of "epistemological purgatory" (Barker, 2005, p. 7) therefore resurfaces through Georgia's account, where the biomedical account of her symptoms contrasted with her own subjective and embodied experience. Georgia repeatedly visited her doctors' surgery to try to receive further tests. However, Georgia's clinicians insisted that she was either well or she had ME. Georgia was confused by the way her clinicians referred to ME as being either a mental illness or not an illness. Equating ME to a mental illness or a fake illness evokes Jutel's (2011c, p. 13) suggestion that in western societies, "less physical means less real".

The current section has shown how receiving a diagnosis of ME can alleviate uncertainty and worry while also causing further confusion and anxiety. Accordingly, the current section has shown how diagnostic limbo and "epistemological purgatory" (Barker, 2005, p. 7) can continue after a clinical diagnosis of ME. One of the key findings within this section has been that the ME diagnosis did not fully grant the participants the legitimacy of the sick role (Parsons, 1951). Having highlighted the experience of being without a diagnosis, the social significance and social consequences of the ME diagnosis are emphasised in the section that follows.

4.4 Withholding a Diagnosis and the Significance of Holding a Label

Huibers and Wessely (2006) have questioned the value of diagnosing ME, suggesting that the ME diagnosis is a trade-off between empowerment, illness validation and group support on the one hand, and the risk of diagnosis being a self-fulfilling prophecy of non-recovery on the other. Participants within my study experienced having an ME diagnosis withheld by their clinicians and this section explores the epistemic positions between the participant and their doctors. Phil felt that he had a positive experience of the ME diagnosis and the relationship with his doctor. The following interview extract highlights how Phil had the ME diagnosis withheld from him.

> *Phil: All my tests were negative and I was a bit hesitant to mention ME because I didn't want to look like a hypochondriac or anything. I was like well y'know look I hope you don't mind but I've had a look into it and I'm not trying to second-guess you or anything else. He was like don't worry y'know with all the information out there it's perfectly fair enough. He said 'to be honest with you I was thinking ME anyway, I didn't mention it because sometimes people can get so creeped out. You tell them it's ME and that's the end of everything else. They think it's a life sentence'. I was like to be honest with you out of everything that I've found it could be that's by far the best thing.*

Phil's experience demonstrates the asymmetrical power dynamics between himself and his general practitioner. Firstly, the excerpt from Phil's interview highlights how he performed his own classificatory work and self-diagnosis, which prompted a clinical diagnosis from his doctor. The last sentence is particularly insightful for showing how Phil had already considered a hierarchy of illnesses by ordering them from the least desirable to the ones that he felt he could better live with. This shows how classificatory work is not just performed by healthcare professionals. Self-diagnosis is welcomed within the context of patient empowerment and access to information through the rise of the internet (Hardey, 1999). Yet, Jutel and Banister (2013) found that even in the case of influenza,[19] and against public health advice, patients still wanted the medical authority of diagnostic confirmation and were reluctant to assume responsibility for diagnosing themselves. Patients can therefore be willing to perform informal classificatory work but seek recourse to their doctor to confirm and corroborate the self-diagnosis. Later in the same interview, Phil mentioned that he had been worried he might have HIV or diabetes prior to receiving his ME diagnosis. After having researched the symptoms of HIV and diabetes, he felt that it was "better" to have ME because his research had led him to suppose that ME would be easier to manage. A diagnosis of ME was better than a diagnosis of HIV and diabetes, which in turn were better than no diagnosis at all.

[19] Influenza can be debilitating but it is temporary (Jutel and Banister, 2013) compared to how ME can be disabling and chronic.

Secondly, Phil's recollection of the clinical interaction suggests that his GP was withholding the diagnosis of ME based on the belief that the ME diagnosis leads people with ME to surrender to the illness. The concept of "epistemic injustice" (Fricker, 2007) is evidenced against the participants when the clinician who has the knowledge and power to diagnose withholds access to that information. This illustrates an imbalance in doctor-patient power relations where the doctor not only withholds access to resources, such as those accessed through the sick role, but they deny the patient knowledge of themselves and their embodied experiences.

Phil clearly indicated that he did not want to undermine the doctor's ability by noting his reluctance to "second guess" the GP's ability to diagnose. Phil made it clear to his GP that he was not questioning the epistemic privilege obtained through medical training. However, Carel (2016) has suggested that the patient experience is also a type of epistemic privilege, but it is the healthcare professionals' epistemic privilege that "really matters within healthcare practice" (Carel and Kidd, 2014, p. 16). There was acknowledgment of Phil's epistemic privilege where the doctor accepted that Phil's experience of his symptoms had led him to research and perform his own diagnostic work. Yet, by denying Phil's access to expert knowledge in the form of a diagnosis, the GP had "interpreted the speaker to have diminished capacity qua testifier and bearer of knowledge" (Blease, Carel and Geraghty, 2017, p. 551) and Phil suffered what Fricker (2007, p. 10) refers to as "testimonial injustice". In this case, the implications of "testimonial injustice" (Fricker, 2007, p. 10) are that Phil was not trusted with the knowledge of his own illness, yet at the same time he was not absolved from the responsibility of being ill. Consequently, Phil found himself in the realms of both diagnostic limbo and social limbo until his ME diagnosis was clinically confirmed.

Like Huiber and Wessely (2016), Phil's GP suggested that the ME label can have a negative impact on patients where Phil recalls being told, "you tell them it's ME and that's the end of everything else. They think it's a life sentence". One of the conditions of the sick role (Parsons, 1951) is that the patient is obliged to try to get better. However, Phil's GP suggested that when people receive the ME diagnosis they do not try to recover. The function of the ME diagnosis is therefore being questioned and so is the characterisation of people with ME. In the following vignette, Dave claimed that patients are excluded from knowledge and decisions about their own health because they are not regarded as being deserving. He also made reference to the self-fulfilling prophecy of illness, which Phil's doctor had alluded to.

> *Dave: Oh actually and another thing is that people with CFS don't deserve to be spoken to actually and to make informed decisions about their own life. I don't know if you've seen the Royal Society of GPs response to the government's 'no decision about me without me' paper'?*
> *NW: Hmm*

Dave: In that they specifically mention chronic fatigue syndrome as, oh I can't remember now. They see it as a serious mental health problem for which it would be dangerous to allow patients to decide on their own care…

Later in the same interview

NW: ME, CFS yeah erm did you have anything to add to that?

Dave: Well actually (interference with the phone at 34mins 15 secs) patients diagnosed with ME versus patients diagnosed with CFS but it's quite routinely thought that people being diagnosed with ME creates this self-fulfilling negativity because it's poorly understood neurological untreatable condition whereas is you're diagnosed with CFS you suffer from an empowering inspiring narrative of illness that can be overcome and there is a way. I think that's the difference but it's still referred to as yuppie flu by some researchers passed onto reporters of things which are significant or worthwhile. I think there's an idea in our culture that patients need to be managed that the priority for the patient is to be as well as possible but instead it's about finding a managed outcome and manipulate them a way that's considered functional but yeah whatever. I'm not terribly keen on what is sometimes referred to as paternalism. If it's their will then it's not really paternalism it's just an inclination.

Dave suggested that ME patients are perceived as having a responsibility to manage themselves "to be as well as possible" and to be functional while the doctor is expected to facilitate the patient's improvement. Dave was therefore confirming the societal expectations of the sick role (Parsons, 1951) where the patient enters the asymmetrical patient-doctor relationship, and the function of the sick role is to reintegrate the sick person into society. Parsons' sick role (1951) has been criticised for being outdated and paternalistic, but Dave also voiced the same criticisms over the antiquated approach to care in ME, whereby doctors feel a need to manage patients and make decisions on their behalf. Later in his interview Dave suggested that the ways in which doctors treat people with ME then feed into the stigma experienced outside the clinic.

Dave: I mean I think this all feeds into the same sort of attitude that patients don't deserve to be allowed to make informed decisions about their own healthcare that it's acceptable for those in positions of power to manipulate and manage. I think you can't treat people like that now without creating prejudice and stigma and that's just. I can't think of any group that's been treated in a way that isn't also dismissed by society more generally.

Dave therefore demonstrated the "testimonial injustice" (Fricker, 2007, p. 10) of having been excluded as a testifier in his own illness, when he was not involved about decisions regarding his health/illness. However, through their position and professional knowledge, doctors are seemingly granted decision-making authority over patients (Freidson, 1970). The following extract from Grace's interview

demonstrates how receiving an ME diagnosis was an important factor in improving her health. Receiving a diagnosis had meant that Grace felt less scared by her symptoms and she was able to make changes to aid her recovery, which included reducing her hours at work and taking a less stressful position within her workplace.

> *Grace: One day I was working and I was suddenly light headed and dizzy and erm. I felt like all the blood had rushed out of my body and I was like I just couldn't do anything I had to sit down and my legs were so tingly quite a strange sensation. My colleague had been quite concerned about me for a long time and she said I'm not going to put up with this any more I'm just gonna call an ambulance which is perhaps a bit extreme but in hindsight it was quite scary and it was the right thing to have done and to have got a diagnosis and realise what's been causing it. It put me on the road to recovery to look after myself and put myself first.*

The importance of being able to put a label to her illness was also illustrated by Katie's interview.

> *NW: How did you feel when you had the diagnosis?*
> *Katie: Just to start with really relieved cos I was like this is what it is and I can deal with it and then the next day not so good (laugh) because it kind of hits you that this is it (laughs) and although you will get better and you know you will come out of it, it's always (sighs) going to be there and you're going to be conscious of it. That lasted a day and then I thought yeah get on with it just carry on.*

For both Katie and Grace, the ME diagnosis led to a sense of acceptance, and they made lifestyle changes to facilitate recovery. Consequently, the diagnosis empowered them to make positive health decisions such as maintaining a healthy diet and avoiding undue stress. Experiences of the contested condition fibromyalgia show how chasing a diagnosis can hinder patients recovering (Hadler, 1996). Through having a diagnosis of ME, Katie and Grace were able to focus upon getting better. The symptoms of ME overlap with other conditions, such as MS (multiple sclerosis) and the participants performed their own classificatory work in which they feared their ME was something that they considered to be worse. In Evelyn's case, she feared having a terminal illness before having her ME diagnosis.

> *NW: How did you feel when your tests came back normal?*
> *Evelyn: Just confused, it felt like I was dying. I felt I had something terminal erm and just for it all to come back clear was confusing for one and for another. It was sort of it was almost pointing to me making it up or being psychological which didn't help. Like family and friends, because it's a confusing illness anyway and when everything comes back normal it's hard for*

family and friends to not think there's nothing wrong with you sort of thing. Erm so it was a really awful time but he did all of these tests and I went to get the results and eh said it's all clear you don't have any immune thing you don't have this and you don't have that. Erm so I said well what do I have and he said well now that everything has been ruled out erm you have chronic fatigue syndrome/ME. That's all we can put it down to.

Evelyn had felt so ill that she feared that she was dying. Feeling abnormal when tests results were normal created ambiguity and confusion. Existing without a diagnosis meant that friends and family were questioning her mental health and integrity. However, once Evelyn had an ME diagnosis, she felt relieved that her condition was not terminal, alleviating some of the uncertainty she had struggled with. Evelyn was also able to communicate her illness to those around her once she had a name for her condition (Jutel, 2011b). Evelyn's experience highlights how the absence of a diagnosis denies the patient an explanatory framework both for themselves and for others to reference (Jutel, 2010b).
The final section has highlighted the impact of withholding a diagnosis by demonstrating how patients exist in a social and diagnostic limbo until they receive a label to qualify their symptoms.

4.5 Conclusion

The chapter began by asking, what is in a name? The significance of asking this question was to attempt to understand how people with ME make sense of a condition which is contested. Despite its shortcomings, the term ME served as the best possible shorthand to denote the illness that the participants experienced. The participants' rejection of the term CFS can be seen as a micro-political struggle against how ME has been medically framed as a psychological illness. However, ME also serves as a functional label which encapsulates more than fatigue. Respondents also felt ME was less associated with psychosomatic explanations. Although the ME label was imprecise, the participants suggested that with further research and knowledge more about the condition would eventually be understood. Despite the uncertainty encompassed by the ME diagnosis, there remained hope that the ME diagnosis would eventually provide more clarity and legitimacy. However, the participants' view of the ME diagnosis presently showed how it was a category which contained a group of inexplicable illnesses and symptoms underlined by fatigue.

The diagnosis of ME unsettles and challenges how we might traditionally conceptualise diagnosis. Diagnosis can be a roadmap, giving a sense of direction to the treatment and prognosis. Labelling a condition can also provide a stabilising force for our identities and illness narratives. However, the current chapter has shown how the ME diagnosis often contrasts with patients' expectations from the "diagnostic utterance" (Fleischman, 1999, p. 10). The second section of this chapter demonstrated how the clinical diagnosis of ME diagnosis lacked legitimacy. The issue of legitimacy was made apparent

by contextualising the experience of the ME label within the participants' broader illness experiences. Medically, the ME diagnosis did not biomedically explain the symptoms or give the certainty of a prognosis. Socially, the diagnostic label of ME did not always convey a serious and complex illness to the friends and families of the interview participants. Further, the ME diagnosis was not able to readily grant access to the legitimacy of the sick role (Parsons, 1951), or its resources. Moreover, the participants were often accused of being mentally ill or malingering by individuals within their social networks and by their healthcare professionals. The social and the medical spheres of legitimacy are not mutually exclusive, but rather feed into one another. This is particularly poignant in Amy's interview, where her cousin, a doctor, informally regards ME as being a non-entity or a psychosomatic illness. The diagnosis of ME might be seen as being a "diagnostic illusory" (Nettleton and Kitzinger, 2014, p. 134), which is when a diagnosis raises false hopes with the expectation of certainty and intelligibility. The diagnostic illusion of the ME diagnosis was especially salient when the participants experienced "epistemological purgatory" (Barker, 2005, p. 7), which is when the patient is left to process the subjective feelings of their illness when medicine is unable to objectively validate its existence, leaving the patient in an "epistemological crisis" (Barker, 2005, p. 106).

The "epistemological purgatory" (Barker, 2005, p. 7) is further exacerbated by how the participants' unexplained physical suffering was framed by psychological explanations, which felt alien to the embodied experience of the participants. Where the symptoms of ME were framed by psychologising the illness the participants experienced self-doubt and greater uncertainty. The participants were left questioning their own mental health despite feeling mentally well. Feeling the illness physically, while being told it was a mental health issue, created further ambiguity over their embodied experience. Underlying "epistemological purgatory" (Barker, 2005, p. 7) is a common difficulty within chronic contested illnesses, when the patient experience clashes with the biomedical approach to the body. The insights from the participants' experiences of being diagnosed with ME illuminate the broader mechanisms of diagnosis in relation to medical authority and labelling. The medical profession's exercise of authority was inextricably linked to the participants' reliance on physicians' epistemic rights to define diseases and apply disease categories to patients (Parsons, 1951; Freidson, 1970; Starr, 1982). The participants' self-diagnosis and their own classification of disease seemingly reinforced the official epistemic hierarchy of medicine, which places evidence-based medicine above individual experience. When the participants rejected the psychological framing of ME by healthcare professionals, they often did so by suggesting there was a lack of medical evidence.

The viewpoints of the patient and doctor can therefore be mutually constitutive even if they do not agree on the diagnosis or the nature of ME. Both their health beliefs are operationalising within the same system that promotes and values medical classification, where "patient and doctor alike both pursue diagnosis as the making sense of illness" (Jutel 2019, p. 17). The current chapter highlights the epistemic

privilege of clinicians who are the gatekeepers of the "sick role" (Parsons, 1951) through being the labellers of disease and people. The classificatory work of doctors can be seen as being more impactful and authoritative than that of patients, as the "communication of diagnosis is a socially significant moment that is central to the expression of medical authority in society, and for the organisation of patients' experience of health and illness" (Heritage and MacArthur, 2019, p. 262).

The first two sections of the chapter pointed to how the ME diagnosis was functional, while lacking the explanatory power and certainty which patients might expect from a diagnosis. However, by exploring the plight of having a diagnosis withheld, the social significance of receiving a diagnosis is amplified. When a diagnosis was withheld by clinicians, the participants were left in an indeterminable state of diagnostic limbo, which extends to being in a social limbo. As Nettleton (2006, p. 1176) has suggested, "we are not very forgiving of no diagnosis and do not give permission to be ill easily". If we do not have a label for our illness, how can we communicate our experience to those around us, or indeed, ourselves? Although, the first section showed that ME could be an unsatisfactory shorthand for the participants, it did provide an anchor around which they were able to frame a narrative and understanding about their illness. In having a diagnosis withheld, suspended or delayed, the participants were wronged in multiple ways. Through being denied a diagnostic label, the participants were not the granted the communicative element of a diagnosis. The ability to communicate their illness is needed so that patients have the ability to tell their social network, "I have x", which is laden with social significance (Jutel, 2011b). Holding a diagnosis is a starting point, with which individuals can try to elicit understanding and empathy from their social networks. It is hence proposed that "it may be necessary to embrace medical uncertainty, and also to accept patient experience in order to facilitate diagnosis, treatment, and recovery process" (Zavestoski *et al.,* 2004, p. 161).

The chapter has shown evidence of epistemic injustice in the participants' experiences of the ME diagnosis. Fricker (2007) suggested that epistemic injustice is where someone is wronged specifically in their capacity as a knower, wronged therefore in a capacity essential to human value. A specific type of epistemic injustice, "testimonial injustice" (Fricker, 2007, p. 10), is highlighted where the patients experienced their ME diagnosis being withheld. "Testimonial injustice" (Fricker, 2007, p. 10) is also shown where patients were disenfranchised during the diagnostic process. This type of injustice occurs when a speaker is unfairly accorded a lower level of credibility because of prejudice, such as the stigma attached to ME. In the case of "testimonial injustice" (Fricker, 2007, p. 10), a listener (implicitly and/or explicitly) interprets the speaker to have diminished capacity as a testifier and bearer of knowledge. The result is that the speaker's (the participant's/patient's) contribution to the shared epistemic enterprise is unfairly excluded or relegated to a lower status as a result of negative stereotyping associated with the speaker's characteristics (i.e., having ME). The participants were therefore wronged as knowers of their own bodies and experiences through having their patient narrative dismissed. The respondents were

also wronged as bearers of knowledge, where they had their diagnosis withheld. Testimonial injustice (Fricker, 2007, p. 10) is a useful concept for crystallising the limited accordance that the clinicians assigned to the patients and their embodied knowledge. The consequences of testimonial injustice (Fricker, 2007, p. 10) can be seen where the participants were denied the legitimacy given by the sick role even when they held a formal diagnosis of ME. The sick role gives permission for patients to stop their normal roles, such as working, and the sick role provides the patient with access to resources. By withholding the ME diagnosis, the patient is not given the chance to enter the sick role and they are denied the bureaucratic function of diagnosis.

People with ME uncomfortably bestride and evade the boundaries of subjectivity and objectivity, scientific knowledge and patient experience, mental disorder and physical suffering, illness and disease. This liminal experience, of being "betwixt and between" (Turner, 1969. p. 94) categories will be further explored in the subsequent chapter. However, the strained relationship between subjective patient experience and alleged medical objectivity run throughout this thesis. Following on from this chapter, it will be argued that the process of an ME diagnosis is perhaps better regarded as being a reflexive and reflective process which is anchored by the ME label, rather than a fixed eureka moment of diagnostic certainty. The next chapter will examine the diagnostic process in greater detail and continue to position the diagnostic label within the broader illness experience of ME.

Chapter 5
Diagnostic Process: Morality and Mental Illness

Georgia: For me looking at all I went through in the early days you need people to be believing you. I think yeah. The mental side of things could stop degenerating if you're believed.

5.1 Introduction

While the previous chapter elucidated the significance of the ME label, the current chapter focuses upon how the interview participants experienced the process of being clinically diagnosed with the condition. The research found that the mean average time to receive a diagnosis was two and a half years, and the NICE (2007) guidelines suggest that a diagnosis should take six months. The longest waiting time for a diagnosis was fifteen years, whereas the shortest waiting time was three months. The lengthy mean average waiting time partly reflects the difficulties that the participants encountered when trying to secure a diagnosis and it is an illness "you have to fight to get" (Dumit, 2006, p. 577). The diagnostic process is approached as a reflective and reflexive process, which extends beyond the clinical encounter. Rather than observing diagnosis as being one cognitive moment or "diagnostic utterance" (Fleischman, 1999, p. 10), the chapter shows how the process of being diagnosed permeates the lives of the participants outside of the clinic. The study therefore attempts to highlight how the diagnostic process is positioned within the participants' broader illness experiences of ME.

Chapter five offers a contribution to the sociology of diagnosis by illuminating the diagnostic process of ME, which is replete with issues of morality, uncertainty, and contestation. By exploring the clinical process of the ME diagnosis, the chapter seeks to provide "a greater understanding of both the fluidity and the fallibility of the diagnosis" (Jutel, 2009, p. 294). The process of being diagnosed with ME is complex and contradictory. Contradictions can be seen where the participants were portrayed as being over-bearing perfectionists and, at the same time, as being malingerers. They also experienced being told that they were mentally ill, without a 'real' illness. Psychiatry pervaded the diagnosis and treatments for the participants. While in the first clinical instance it was the general practitioners who proposed an ME diagnosis, 37 out of 42 of the participants had their diagnosis confirmed within secondary care. The specialism of the secondary care consultants varied: 29 participants were diagnosed by a psychiatrist/psychologist; five saw a neurologist for a second opinion and two had their ME diagnosis corroborated by tropical disease specialists. The remaining participants either could not recall the specialism of the secondary care clinician or they were not sure to which area of medicine they had

been referred. Nine of the participants chose to pay for private healthcare to obtain a second opinion or rule out other conditions through further tests.

After the confirmation of an ME diagnosis within secondary care the participants continued to be seen by an ME clinic, if there was one available. Access to secondary care and ME clinics within the NHS (National Health Service) depended on where in the country the individual lived and how far they were able to travel. One participant was two hours away from her nearest ME clinic. She was prevented from attending for health reasons and not having transport. When patients were referred to an ME clinic, they reported that the clinics were dominated by psychiatrists and occupational therapists who offered counselling, cognitive behavioural therapy (CBT), graded exercise therapy (GET) and expert patient programmes. The clinics varied in what they were able to offer the participants. At one clinic in a northern city, counselling and CBT and confirmation of the diagnosis were offered. One clinic in the south of England and another in the East of England confirmed the ME diagnosis and assisted the participants with treatment options which included counselling, occupational therapy, nutritional assistance, and physiotherapy. The range of support and treatments therefore appeared to depend upon where the participants lived. Secondary care for ME might be regarded as being a "postcode lottery" (Graley, May and McCoy, 2011, p. 738), which refers to differences in healthcare provision between different geographic areas.

Participants who did not have access to an ME clinic tended to be sent back to primary care after having their diagnosis confirmed by a hospital consultant. Treatments from GPs included antidepressants for insomnia, pain, fatigue and depression. However, amongst the participants there was a reluctance to take antidepressants because they felt that antidepressants were associated with mental illness. Other treatments available from GP referrals included CBT, access to an occupational health nurse and group counselling. Two female participants were admitted to hospital as inpatients and their treatments included antidepressants, cold baths, and electrotherapy. In eight cases, the participants were expected to attest psychological wellbeing by undergoing mental health interventions to prove how the underlying cause of their illness was not psychiatric. Particular attention is paid to the therapies and treatments for ME and it will be shown how psychiatry dominates the diagnostic process. The chapter highlights how the diagnostic process and treatments of ME are misaligned with how the condition is medically categorised. The World Health Organisation (ICD-10, Code G93.3)[20] classifies CFS/ME as a somatic neuro-immunological condition and the UK All-Parliamentary Group for ME/CFS (2010) identifies the condition as a long-term neurological condition. It will be revealed how the incongruity

[20] The ICD-11 has now been approved and will be put into effect on 1st January 2022. It lists CFS/ME as a neurological disease in 'other disorders of the nervous system', section 8E49.

between diagnostic label and diagnostic process impacts on those living with the condition, leading to confusion and uncertainty.

The introduction has offered a background to the participants experiences of the diagnostic process. This chapter will begin by discussing depression and its role in the experience of being diagnosed with ME. Depression was often regarded by the participants as being the result of living with ME rather than a cause or symptom of the condition. The first section reveals how the lack of support and the discreditation of ME fed into depressive feelings. The second section will discuss the treatments offered to the participants and it will be suggested that the mental health approach to ME frames the condition. Two types of psychological approaches are identified which correspond to behavioural and coping. An ensuing discussion explores issues of patient blame and responsibility. By drawing on the work of Goffman (1963), it will be shown how the participants attempted to avoid stigma by concealing emotions and upsetting life events. However, the chapter commences by showing how the participants found themselves in an iterative loop of psychologising.

5.2 The Cycle of Depression

Spandler and Allen (2018) have drawn attention to how ME has been medically framed as a psychiatric problem. Further, Horton-Salway (2004; 2007) found that patients had experienced the symptoms of the ME being medically reinterpreted as signs of depression. Depression was a recurring theme within the interviews, and it commonly manifested itself in two ways; firstly, when ME was regarded as being tantamount to depression and, secondly, where the participants were accused of imagining their symptoms. The recognition of having felt depressed at some stage during the diagnostic process was common amongst the majority of the participants. Only two participants reported having depression prior to becoming ill with ME, and their depression continued into their illness journey with ME. The significance of this finding is that most of the participants were therefore not suffering from depression upon the onset of ME. Instead, it was found that as the duration of feeling unwell continued and the social ramifications of ME increased, some of the participants found themselves feeling depressed. Moreover, depression was expressed to be the product of living with ME, rather than the underlying substantive issue.

Georgia's recollection of being diagnosed with ME was fairly typical of the participants' experience as a whole because she had felt isolated, frustrated and lonely. Despite receiving a ME diagnosis, Georgia was not granted the legitimacy or benefits of the sick role (Parsons, 1951) until she was diagnosed with depression. She had been diagnosed with depression after having tried to commit suicide. In the extract below Georgia recounts her time in a depressive state, and she felt that she had overcome her depression by the time of the interview.

> *Georgia: The depression came after feeling ill because no one was listening, there was no one to turn to and no one believed me. Erm yes I did get obviously extremely depressed and I had buried my head in the sand. I hadn't faced up to it. I hadn't been depressed before erm yes so I was very tearful but I'd say to people well who wouldn't be? Of course I'm tearful, of course, I'm low I can't do anything you know. Erm but I have to say the antidepressants have helped because mentally I became more tearful. I couldn't move. I couldn't find anything to be happy about, to laugh about. Now I just do today. What happened yesterday what happens tomorrow I have no control over. All I've got is today really.*

By asking, "who wouldn't be" depressed? Georgia attributed her depression to the specific set of social conditions in which she found herself. She recalled that depression was not a feature of the illness presentation when she first felt fatigued and in pain. Georgia believed her depression was caused by the social effects of her illness, when she had been rejected and undermined by clinicians and the people within her social network. Being disbelieved and told that she was imagining her symptoms fed into her depression. Somewhat incongruously, Georgia had entered a cycle of depression in part because she was constantly being told she was depressed, despite having adamantly maintained that she was not. It is therefore possible to see how "testimonial injustice" (Fricker, 2007, p. 10) was enacted upon Georgia because little credibility was given to her narrative as a patient and a knower of her own health status.

Georgia's depression was further compounded by the inability to function as well as she wished. She had felt that she was losing her independence and becoming a burden on her children by needing them to care for her. Charmaz (1983, p. 169) illuminates the plight of the chronically ill where:

> over time many debilitated chronically ill persons become dependent and immobilised. As they suffer losses of self from the consequences of chronic illness and experience diminished control over their lives and their futures, affected individuals commonly lose not only self-esteem, but even self-identity.

Georgia was conscious, to an overwhelming extent, of lacking control over her life due to the effects of ME. Brown and Harris (1978) acknowledge a biological basis for depression, but they also ask the us to consider how life's events and challenges play a significant role. In their discussion of assumptive worlds, Brown and Harris (1978, p. 234) observe that when expectations for the future can no longer be realised, there is the potential to have the feeling of "a great loss". Georgia could not envisage a future throughout the time she was depressed but at the time of the interview she tried to focus on the present, where she states, "I just do today". There had been a struggle with looking to the future because

Georgia's life had changed so dramatically. Kirsty also recalls her experience with antidepressants and struggling to look to the future.

> *Kirsty: I had plans and had to take antidepressants, horrible boyfriends. It was a blur and I blocked a lot of that out I think. He was horrible and I wasn't achieving what I wanted. I didn't tell my employer because I just wanted a straightforward part-time job.*
> *NW: Did you see a counsellor?*
> *Kirsty: No, I should have but I took anti-depressants instead, my doctor said there are two options. You can take the tablets and start feeling better soon or you can wait for a counsellor, and it will take whatever, a long length of time.*
> *NW: Were you then referred to anyone?*
> *Kirsty: No just standard drugs once a day (laughs) for a year and a half.*
> *NW: Did they help?*
> *Kirsty: Yes completely, I felt I was drowning, and they calmed me down*

Kirsty had thought she was in remission from ME only to be re-diagnosed after being ill with glandular fever. Her decision to take antidepressants was partly pragmatic, based on her urgent need for an effective solution which meant that waiting for counselling was not a viable option. The attraction of the antidepressants was that they were quicker and helped Kirsty to cope with the ME and the negative impact that it was having on her life. However, chronic illnesses are not experienced within a social vacuum. Further "life events" Brown and Harris, 1978, p. 80) and challenges such as a "horrible boyfriend" (Kirsty) and family loss filtered into Kirsty's deteriorated mental health. Kirsty felt that her goals could not be achieved because of her ME and this left her feeling that both her present life and her "assumptive world" (Brown and Harris, 1978, p. 106) were outside of her control. Kirsty referred to the feelings of frustration and hopelessness as "drowning". Martin also found he became depressed because of the change in his personal circumstances and as a consequence of receiving no medical support.

> *Martin: Yeah. In terms of diagnosis one thing I've remembered is that the first GP said that 'you have post viral debility I don't know what to do', erm in the end it was the mental health team that helped because the symptoms of ME are quite like depression. Not getting treated and getting worse I was getting depressed. And in the end the only support I got was through the mental health team.*
> *NW: What kind of support did they give to you?*
> *Martin: Someone to talk to. To chat to really and talk about pacing and not panicking because I was having panic attacks and things. I was very lucky to get that support. They were clear that there wasn't a mental health issue. As I seemed to be getting worse, that was helping.*

Martin had been a successful teacher and a keen amateur athlete before the onset of ME. At the time of the interview his elderly parents were caring for him in the family home following his divorce. Martin attributed the divorce to the strain that living with ME had placed on his marriage. Martin was also left with infrequent contact with his son due to the debilitating nature of his symptoms, which made it difficult to speak on the phone for long durations. All of the participants faced major "biographical disruption" (Bury, 1982, p. 167) from having ME. Narratives of being energetic and frenetically busy before the onset of ME support the findings of Ware (1992) and Whitehead (2006b), who have shown that a life before and after ME was clearly defined.

For Martin, depression was the result of worsening ME and receiving no help. However, his co-diagnosis of depression meant access to treatment and care which helped his gradual recovery from worsening mental health. The support that Martin obtained from the mental health team enabled him to better cope with the symptoms and social effects of ME. For example, Martin mentioned pacing, which is something that many of the participants did in their daily lives so as to avoid the so-called booms and busts of fatigue. The counselling helped Martin to manage his anxiety which was caused by living with medium to severe ME. It is notable that it was a co-existing diagnosis of depression that provided access to treatment and the sick role (Parsons, 1951), and this was also true for other participants. Treatment and support for ME, however unsatisfactory, was often haphazard and unavailable to participants who faced referral delays and long journeys. This might suggest that the benefits of the sick role (Parsons, 1951), such as access to treatment, are more easily obtained where depression is formally diagnosed alongside ME. This finding is suggestive of ME being ranked lower than depression in the clinical hierarchy of disease classification (Album, Johannessen, and Rasmussen, 2017; Album and Westin, 2008).

This section has focused on exploring how the participants in the study saw depression as being a product of living with ME. From the participants' perspective, the loss of their preconceived futures fed into feelings of depression, as did the difficulties of living with the illness itself. However, the disbelief from healthcare professionals and the patients' social network also fuelled depressive feelings. The lack of medical recognition meant that wider social acknowledgement of their suffering was hindered. The cycle of depression can be seen where patients are told they are depressed despite feeling otherwise. With lack of support and recognition for patients' suffering the accusation and/or label of depression almost becomes self-fulfilling. For Jutel (2011b, p. 76) "how medical authority may transform the patient narrative, rendering foreign what once was personal… is most salient in the case of the contested diagnosis". The current section has shown how the psychologising of the participants' symptoms was at odds with their embodied experience of the illness. The diagnostic process exacerbated confusion over the nature of ME and the implications of depression fuelled self-doubt and uncertainty. The next

section will show the diagnostic process is incongruous with how ME has been classified as a neurological condition.

5.3 Treatment Defining the Aetiology

The World Health Organisation classifies CFS/ME as a somatic neuro-immunological condition (ICD-10, code G93.3) and in the United Kingdom, the NICE (2007) Guidelines state that CFS/ME is a real illness with unknown origins. ME is therefore medically classified as a neurological condition or a condition of unknown origin. However, the current section shows how the treatment of ME appears to frame the condition as a psychological disorder. The recommended treatments for ME include graded exercise therapy (GET) and cognitive behavioural therapy (CBT) (NICE, 2007). The NICE guidelines are currently being revised and updated (NICE, 2020) but they have indicated that GET might be more harmful than helpful to patients. NICE (2007) also recommends that counselling, occupational therapy and physiotherapy can be involved in treating ME while antidepressants can be prescribed to treat the symptoms, such as pain. The majority of the participants were offered antidepressants and they reported that the antidepressants were presented as a way of treating the fatigue, pain, depression or insomnia from ME, as well the condition itself. The participants also identified how their treatments tended to be psychological/psychiatric, which led to confusion over the nature of the condition and whether ME was a psychological or physical illness.

The following extract from Mike's experience highlights two different mental health approaches to treating ME, with differing implications. The first approach was based upon his personality/behaviour causing the ME while the second approach might be regarded as focussing on coping strategies.

> *Mike: His* (GP) *view was to, he recommended the psychologist and he seemed to come from it very much from a mental viewpoint. Kind of a, I think his view was. I think what he said to me was 'know this is a verbal kicking for y' but you need to change. If you don't change you're not going to get out of this and if you do get out of this you're just gonna put yourself back in it again because you keep'. I'd done an iron man challenge the summer before and I think he was picking up on all that kind of stuff. Y'know 'why do you do these things why do you have a need to prove yourself? Why are you doing this that and the other?' I'd been seeing an erm because I was getting depressed about this if y'like and getting wound up about this. I was seeing someone from 'let's talk' if that's what you call it. So that was a kind of CBT kind of person but that didn't go very well because the first person I saw went home sick and the second person I wasn't getting anywhere. They were saying I needed to prove my self worth and I was like 'well not really'.*

Mike highlights a behavioural approach to ME where it was proposed to him that his illness was due to pushing himself too hard. He had previously taken part in numerous triathlons, and iron man challenges prior to having ME. He had seen two psychiatrists who had claimed that his drive for competition was responsible for his ME symptoms. However, Mike rejected this explanation because it did not reflect how he perceived himself or his illness. The frustration of being told that his behaviour was causing his illness led him to seek counselling because he felt himself becoming depressed.

The behavioural approach to ME has been highlighted by Hart and Grace (2000) who have suggested that typical ME patients have been portrayed as being perfectionist and overly driven individuals. Furthermore, for people with ME the "illness attributions are likely to be interpreted as constituting part of the illness cycle itself by working to guide the patient into abnormal and dysfunctional illness behaviour patterns" (Horton-Salway, 2001, p. 248). In the next excerpt Mike discusses his experience of being treated by two different psychologists who offered alternative explanations for his illness.

> *Mike: She's private but she's really good…her side of it is the mental side of it if you like. If you think this is your mind doing something or helping to keep you in it. It's a bit hard to work out where it's all going. I understand that it's all kind of okay I know the two are all linked. I know it used to be you've got a physical problem, or you've got a mental problem but they're a lot more linked. I get that but there's definitely two approaches where one person is sort of saying 'you're driving yourself into this and it's giving you physical symptoms and the other side of it you've got something we don't know what it is and that's physical and that's effecting you mentally.*

Mike believed he was depressed because having ME had effected every area of his life, but he particularly struggled with limited exercise and a reduced working life. Despite having welcomed counselling, Mike refuted the insinuation that his symptoms were psychosomatic. He highlighted the linkages between mental and physical health but found that the two mental health approaches, coping and behavioural, confused him, because the treatments seemed to contradict one another in the ways they explained and treated ME.

The treatments that the participants experienced imply psychological disorder and it is primarily psychiatrists/psychologists that performed the act of treating. Nine of the participants had psychological assessments to ensure there was no underlying mental illness. This raises the question: to what extent does the treatment define the aetiology of ME? Rather than the diagnostic process being a neatly arranged linear progression from the display of symptoms, to diagnosis, followed by treatment, Goodwin and McConnell (2014, p. 42) assert that, "if categories are not selected for classification in favour of more prescriptive terms, they fall out of use and the treatment then begins to define the disease". A similar point is made by Vos (1990) who suggests that finding an effective drug can define

a health condition, instead of the diagnosis leading to the treatment. The label and aetiology can therefore be applied and understood after apparently successful treatment. While the previous chapter focused on how the diagnostic label was pivotal to patient experience of ME, therapies and treatments are just as important.

The current section has shown how the participants' experience of diagnostic labelling and diagnostic process are intertwined yet seemingly misaligned with one another. Although ME is not classified as a psychiatric illness, the condition is treated as such. Further to this, the psychological framing of ME is incongruous with how the participants experience and interpret their condition. Within the mental health approach to treating ME, the coping strategies focused upon the social and personal ramifications of living with what can be a chronic and disabling illness. However, the behavioural line of reasoning appeared to find fault within the individual and this has implications for issues of responsibility, both in terms of the cause of ME and in recuperating. The following sections reveal how an association with mental illness has wider implications for the social acceptance of the illness as an apparently real condition.

5.4 Blaming the Patient

The behavioural approach to ME stands in contradiction to ''the fine line of not holding the patient responsible for his (their) illness but of clearly holding him responsible for his recovery" (Sullivan and Loeser, 1992, p. 1830). This segment of the chapter will expand upon the predominance of the behavioural approach, drawing from the interview data and focussing upon issues of responsibility and blame. The interviews with the participants highlighted how many of the participants felt they were held responsible for their own illness, particularly where they experienced an emphasis on ME being psychosomatic and/or caused by a behavioural flaw. It will be shown that attributing the cause of ME to psychological dysfunction implies a social and moral deviance by suggesting that the individual 'chooses' to be unwell.

George's interview extract highlights the moral implications of the ME diagnosis. He believes that patients with ME are not unreasonable in their rejection of the medical emphasis on the biopsychosocial explanations for ME. George articulates how blaming the individual for their illness only further stigmatises ME patients.

> *NW: How do you think that the, it's quite difficult to answer but, how do you think the public perceive ME?*
> *George: I think it really varies. The thing that really interests me is this campaign where they represent patient claims of the over exaggeration of biopsychosocial role of CFS as indicating*

a sort of unreasonable and stigmatising use of our mental health or our failure to understand how our mind and body interacts. Y'know all those sorts of antipsychiatry. There's quite a lot of that stuff which seems quite nasty especially given that a lot of research in this area have produced poor work and then spun and misrepresented their results in papers. Erm but I think also we then have a hardship where we're in a situation in which people think that people's behaviours play a role in perpetuating it you're also going to increase the extent to which those hardships are stigmatised. So erm so someone like Alex Marks who was involved in one of the first controlled randomised trial for CBT success for CFS and he was also someone who built his career on treating transvestites claiming that this was going to help them to overcome their sexual deviance. We are now seeing a litany of excuses coming out from medical researchers saying that were trying to help they hadn't realised the social costs of their work upon those they make inaccurate claims about. It seems like this is a problem which is recurring, and no one gets held accountable.

George felt that the patient resistance towards what he referred to as the biopsychosocial role of ME was justified because of the poor quality of medical evidence for the biopsychosocial elements of ME. While the biopsychosocial approach to medicine attempts to avoid a Cartesian mind-body duality, George accuses it of propagating the claim that ME is psychosomatic. Concern over ME being regarded as a functional illness, is echoed by Kennedy (2012, p. 5) who suggested that:

> the term psychosomatic therefore appears most often used as a default diagnosis of mental illness causing somatic complaint against patients with illnesses where there are difficulties in either diagnosing or treating: a default response to uncertainties and gaps in knowledge.

Moreover, the contest and ambiguity surrounding ME leaves a vacuum for poorly evidenced psychosomatic explanations.

George drew on the comparison of transgendered people being treated for sexual deviance, suggesting that there are social costs to medical treatments and medical classifications. He compares this example to the plight of people with ME where they are being told that their behaviour is the cause of the illness, which suggests a moral deviance. Kirmayer (1988, p. 83) neatly surmised that ‘‘patients are then either rational but morally suspect in choosing to be sick or irrational and thus morally blameless but mentally incompetent.” However, if mental illness was less stigmatised then perhaps it would not be so rejected by ME patients. The moral implications of being labelled as mentally ill are being rejected, as well refuting the psychologising of the illness itself.

Making the patient accountable for the illness neutralises the threat to biomedical authority posed by unexplained or uncontrolled sickness (Jackson, 2005). An example of this can be found where Sullivan (1998) noted that professionals often prefer the term somatisation to chronic pain because it explains the pain as being a defect within the individual. Focusing on deficiencies shifts attention away from medicine failing to have an answer, which is a challenge to the authority of medical epistemology. Instead, the locus of fault, blame and responsibility is redirected towards the patient. The case for considering the shortcomings of medical episteme is deflected, rather than critically reflected upon. Questions of responsibility are by no means exclusive to contested illnesses, as Sontag (1978) demonstrated in her work on cancer. Sontag (1978) drew attention to the way that certain personalities are perceived as being blameworthy for predisposing them to developing cancer. However, for the participants in my own study, the very existence of their symptoms and suffering was being queried and, consequently, so was their integrity and sanity.

The excerpt below highlights an experience of the behavioural mental health approach, where a personality flaw was blamed for causing Emily's ME.

> *Emily: I know my husband, this sounds really bad but he said 'he's just diagnosed you with ME and he hasn't touched you, how can that be? He hasn't examined you.' Then he went into this whole thing about, I don't know if it's all over Britain but down here the whole ME thing is run by psychiatrists. So within a few weeks I was thinking that I now had a psychiatric disorder which I was open minded to in a funny way…So I thought okay I'll open my mind to all of this but I think in that first appointment something really really annoyed me. He said 'you said you were a runner, when you were a runner did you push yourself really hard?'. I said 'of course I did'. He said 'well if you were running would you ever stop in the middle of a run?'. I said 'well, why would I stop in the middle of a run' wondering where this was going. You go to the end of a run when you're a runner. Even if you throw up you'd carry on. He's like 'oh that's interesting, do you think you push yourself too hard?'. I was sat there thinking 'you're so way off that we're not even eye to eye here, you're not listening to me, you're not thinking that I'm a woman who pushes herself too hard and has now made herself ill'. I'm actually one of those people who doesn't do that.*

While Emily was open-minded to a mental health problem, she did not recognise the psychiatrist's suggestion that she was someone who "pushes herself" against her limitations. Further, the lack of sensory touch only confirmed the emphasis that the consultant placed upon Emily's verbal answers. The absence of a bodily examination felt as though it invalidated her embodied suffering. According to Emily, in whatever way she answered the psychiatrists' questions, she would be perceived as having a mental illness. This experience echoed that of Rosie during a psychiatric assessment.

Rosie: He insisted that I went for a full psychiatric referral erm
NW: Hmm
Rosie: And I went to see a psychiatric nurse who asked me some extremely strange questions. I mean it was fifteen years ago and it's still vivid in my mind. I mean she said. Because they had the 11 plus in X (redacted). She said, " Did you achieve the 11+?" (mimics an RP accent) just the phrasing was so weird and the question was so weird what on earth did it have to do with anything? Erm, yeah I was then starting to enter this twilight round where everything I said about myself confirmed that I was a typical ME sufferer so I went back to my GP and they said "ohhh you're a typical over achieving ME sufferer!"

For both Emily and Rosie, their answers were reduced to being a result of their ME. Goffman's (1961) "Asylums" focused on the institutionalisation of patients but his work has relevance through having showed how labels could mean that the patients' behaviour was repeatedly interpreted as a result of their having been categorised as mentally ill. This finding highlights the interplay between labelling and the diagnostic process of ME, where the stigma of an initial ME diagnosis appears to engender prejudice within a psychiatric clinical setting. A caricature of a stereotypical ME patient was depicted in the interviews, when the participants felt that they were being interpreted as perfectionist over-achievers. It is therefore possible to see stigmatisation as a heightened form of categorical inference. Stigma lumps the people who share the feature that elicits stigmatisation or what Goffman (1963, p. 11) calls the ''blemished'' (in this case it is the ME label) into a group. Projected onto these people are certain other basic personal characteristics which signify characteristics that are seen to lead to deviant behaviour.

Whether ME was regarded as psychosomatic, real, genuine, organic, or fake, largely appeared to depend on the subjective views of individual healthcare professionals. Doctors are trained to see patients in a particular way, through their "professional vision" (Goodwin, 1994, p. 606) but Rosie's story points to how ME appears to be open to personal and medical interpretation. The ambiguity over the nature of ME is elucidated by Rosie's recollection of being a hospital in-patient for her ME and then treated for a phobia to socialisation.

Rosie: There was a psychiatrist at the time who was attached to the (redacted name) Hospital, he came to see me and he said "I'm really upset that you haven't been admitted as a psychiatric patient erm as far as I'm concerned there is no such thing as ME. You have a phobia to socialisation. I'm going to get you admitted and when I get you admitted as a psychiatric patient, I will not take you to the psychiatric ward. I'll keep you in the loudest busiest open

ward I can because you need exposure to these things to rehabilitate you". At this point I was wearing earplugs constantly I had erm ear protectors. Was being spoon-fed.
NW: It sounds horrific.
Rosie: It was horrific because I was terrified that he was going to take control because my GP was in two minds whether it was a psychiatric condition or not. There were nurses who didn't feed me there were nurses who wouldn't help me to use a commode they said "you've got to walk to the toilet or we're not going to help you, you can just piss yourself".

It is evident that the psychiatrist did not believe in ME, which is to say that he did not accept the validity of an ME diagnosis. Rosie was treated with neglect because the nurses believed she was faking her symptoms. This thesis has previously shown how ME has an association with mental illness. However, in Rosie's case, ME was regarded as being a completely illegitimate and defunct diagnosis which needed to be replaced with a "real" mental disorder.

The diagnostic jurisdiction of the psychiatrist is demonstrated by the epistemic privilege of being able to re-diagnose Rosie, without her consent or her contribution in forming the new diagnosis. The previous chapter observed the testimonial injustice (Fricker, 2007, p. 10) that many of the participants experienced through having a diagnosis withheld and by being excluded as a co-participant in the diagnostic process. In Rosie's case the harmful social consequences of epistemic injustice were also apparent. When Rosie became a hospital in-patient and treated by psychiatrists her patient testimony was further diminished, making her more epistemologically vulnerable. Later, Rosie endured treatments which included electrotherapy and cold baths during her time as a psychiatric inpatient which caused her to have post-traumatic stress disorder (PTSD). The damaging effects of "testimonial injustice" (Fricker, 2007, p. 10) and epistemic vulnerability are therefore clearly evidenced. Rosie's story highlights how diagnosis confirms the professional authority and status of doctors, who have a monopoly on framing how Rosie's symptoms were understood. The authority to frame and re-diagnose Rosie is potentially derived from an "interpretive process" (Leder, 1990, p. 141) and "professional vision" (Goodwin, 1994, p. 606) which are the result of medical training and a biomedical approach to understanding the body.

The asymmetrical power dynamics between patient and doctor are further evidenced by Amy's experience. Amy had been diagnosed with ME but her diagnosis was invalidated when she became a psychiatric patient. Amy was deprived of patient autonomy after being threatened with being sectioned if she did not comply with admittance to a psychiatric ward.

NW: What sort of things did they tell you or advise you?

Amy: Just to get up there's nothing wrong with you. You're depressed. I was depressed but because of the state I'd ended up in it wasn't d' you know what I mean?
NW: That you were depressed because you'd become ill?
Amy: Yeah and they started getting people like psychiatric nurses, doctors and people like that involved. I had social services come an' they took me and put me in a mental health ward. That was probably the worst time I've had with this. The worst. Basically what they said was because my weight was so low and they couldn't find a reason that I wasn't weighing (pause and inhales) they said you've got anorexia, you're doing it deliberately. So because my weight was so low they put me. They said they could get a court order to section me so I went. I had no option. I was stuck in there for about 4 months erm.

Amy maintained that she had depression due to living with ME which featured persistent pain and rarely leaving her home. However, Amy's view of her health contrasted with the opinion of healthcare professionals who removed her choices and decision-making through their psychiatric intervention. Amy was unable to embody the Parsonian sick role (1951) by fulfilling the obligation to be a compliant patient. She resisted the diagnoses of anorexia and depression in addition to being reluctant to enter a psychiatric ward. Amy recalls being perceived as being deviant when she was accused of "deliberately" losing weight. Despite not considering herself anorexic, Amy's treatment proceeded down the route of psychiatry, where she was obliged to consent to entering a psychiatric hospital or face being sectioned. This 'choice' was not a frequent occurrence within the interview data, but it occurred in two instances.

The ME diagnosis was therefore treated as being invalid, failing to give Amy access to the sick role (1951). Amy was labelled with ME as well as anorexia and depression yet paradoxically told that she was not ill. This not only undermines the diagnosis of ME, but it succeeds in diminishing the validity of both anorexia and depression. Without equating ME to Morgellons disease,[21] it is useful to reflect on the work of Fair (2010, p. 609), who proposed that "diagnostic protocols attached to ME or CFS may vary across different patients and according to the interpretation of particular clinicians". It is possible to see how differing clinical interpretations of ME affect the treatment and care involved in the diagnostic process. This finding potentially challenges expectations of diagnoses because part of the

[21] "Morgellons is characterised by open skin lesions and infections, protruding fluorescent fibres and a host of related neurological problems. Morgellons sufferers believe that their sores and itchiness are caused by an unknown infectious pathogen. However, the overwhelming majority of medical experts believe that Morgellons is simply a new name for the longstanding psychiatric condition, Delusional Parasitosis" Fair (2010, p. 597).

function of a classificatory system is to engender consistency and continuity across medical practice (Bowker and Star, 1999).

The treatment of Rosie and Emily, echoes how women with hysteria were regarded, when they too were reassigned to a different diagnosis. This is not to suggest that ME is the same as hysteria but Hustvedt's (2011) work provides an example of how relabelling can change how patients are treated and identified. Charcot's study of hysteria saw his patients; Blanche, Augustine and Genevieve revered as having a real disease. The patients also regarded themselves as being afflicted with a real illness. When banished from the hysteria ward to one for insane women:

> the hysterics suffered not only from the lack of privileges and freedom this punishment entailed, but also from the humiliation of being classified, if only temporarily, as mad, not hysterical (Hustvedt, 2011, p. 303).

When Blanche, Augustine and Genevieve were rediagnosed their treatment and care altered despite the symptoms of their illness remaining the same. Further to this, their new diagnostic label was regarded as punishing and humiliating which shows how different diagnoses have tangible social consequences. When the participants were effectively expelled from an ME diagnosis and officially re-categorised as having a mental disorder, they too saw their self-determination curtailed.

The diagnostic process of ME highlights how sufferers are seen to transgress the categorical division between mind and body and confound the codes of morality surrounding sickness and health. Stereotypes of ME patients and prejudicial assumptions affected the diagnostic journeys of participants. Their diagnostic experiences are highly dependent on how their healthcare professionals interpret and understand ME. The absence of biomedical evidence for ME, leaves a vacuum for alternative explanations for the nature of the condition and its treatments. The current section has pointed to how ME is a stigmatised illness. The next section will address the challenge of information control where the participants were conscious of appearing mentally well but physically ill.

5.5 Information Control and Hiding Emotions

Some of the participants recalled attempting to conceal distressing life events and hide negative emotions when interacting with others. They tried not to seem overly emotional because they feared fulfilling what they saw as being the stereotype of a typical ME sufferer. Georgia's interview shows how she was conscious of the need to appear mentally well when she consulted her GP.

Georgia: There's a part of me that will say if I relate it to the breakdown of my marriage, to the death of my mum, to my son breaking his leg then people are going to say that it is erm in your head type of thing. I think it gives an excuse to the medical profession because who knows whether this illness would have happened if those events hadn't. I don't want other people to be told it's stress that your body or mind can't deal with and I think it's a cop out. If someone gave me evidence then fair enough but saying it's all in your head is too easy. I'm still confused by it all to be honest.

Georgia did not attribute her illness to the challenging life events which had happened to her. She rejected the explanation that ME was caused by her inability to cope with difficult circumstances. Georgia conceded that she might have been willing to accept a psychological/social reason for ME, if there was better medical evidence to support the claim. Georgia therefore requires biomedical evidence for the psychologising of her illness in the same way that medicine requires biomedical evidence to testify to the presence of disease. It can therefore be seen that Georgia is rejecting the psychologising of her condition while embracing the biomedical approach to illness and disease.

The participants found it particularly problematic when expert jurisdiction was claimed without the knowledge it ought to rely on, and evidence was replaced with more normative judgements. Rogers and Pilgrim (2010) explain that those who are seen as having psychological origins for an illness are more stigmatised than people who have biomedical reasons for their symptoms. In having concealed her recent spate of demanding life events, Georgia was trying to avoid being regarded as mentally ill. Such a label seemed to lack an evidence base and deflected from her experience of physical suffering. Georgia's story shows an awareness of how labels can cause issues for patients when they obscure the complexity of their condition (Goodwin, 2010).

A further reason for concealing disconcerting incidents was a concern on the part of participants that biomedical reasons for symptoms might be missed. Munson (2000) claims that the assumption that ME is functional risks misdiagnosis, because people diagnosed with the condition are perpetually disbelieved. Diagnostic Labels can hinder the search for an alternative cause for the symptoms experienced by a patient (Goodwin, 2010). Much like Georgia, Emily was cautious to hide distressing life events because she did not want to strengthen the perception that her illness was caused by a behavioural response to stress.

Emily: At the same time my cousins, sorry (intakes breath), children were murdered (cries) and I didn't tell the doctor because he might think it was a psychiatric problem but looking back it just wears your immune system down. That I would say is a problem with the GP system that

> *you're very afraid of telling them emotional problems because you're scared that they'll think that. I don't think I've ever told my GP that or the ME people.*

While Emily acknowledged the role that stress and grief can play in suppressing the immune system, she did not believe this was the reason she became ill. Instead, she hid her emotional problems because she did not want doctors to form an impression of her as being unstable or depressed. This finding supports Tucker's (2004) study, which found that people with ME posit themselves as having a legitimate physical illness to avoid the stigma of psychological disorder. Patients surveyed by Bowen *et al.* (2005) also used concealing strategies to avoid stigmatisation.

Goffman (1963) suggested that in cases where a stigmatising attribute is known or may bring discredit, individuals can use techniques of information control to minimise the impact of stigma in a social setting. This has the effect of reducing the tension between the stigmatised and others. Goffman (1963) called this technique of information control "covering". When a stigmatising attribute is not known about, or discernible, he argues that individuals go to great lengths to conceal the attribute and pass as normal. In the cases of Georgia and Emily, their respective clinicians were considering whether the (stigmatising) attribute of an ME diagnosis was a label to which they could be assigned. The participants were therefore left in a quandary as to what should be withheld, not just in the clinical interaction but also in everyday life. It was clear from the interview data that emotions were something which needed to be controlled, managed and concealed. The preponderance of gender also feeds into the subject of emotions. Lian and Robson (2019, p. 26) suggest that from a biomedical viewpoint:

> apparently susceptible vulnerable women who do not manage to live up to the ideals of culturally legitimate ways to handle tiredness and harsh life events risk social exclusion and stigmatisation from the successful majority.

It is perhaps for this reason that it was only the women in my study who voiced how they were conscious of needing to conceal their emotions.

5.6 Malingerer

Definitions of malingering "always contain reference to two components, firstly that symptoms must be invented or exaggerated and secondly that this is done for external gain" (Turner, 1997, p. 409). Although instances of malingering are rare (Turner, 1997; Bass and Wade, 2018) all except two of the participants encountered the accusation of malingering when the legitimacy of their illness was questioned. Accusations of malingering were also connected to the participants' mental health and

blaming the participants for their own illness. Allegations of malingering were further exacerbated by the invisibility of ME.

In the next interview extract it is apparent that Georgia was made to feel like she was either a malingerer or mentally ill.

> *NW: Up until this point had you always seen the same GP?*
> *Georgia: … He said the only thing is that you need to have had it for 6 months before he'll see you. I said I can't understand this I'm an intelligent woman and I've been telling you I'm not well. The most basic of tasks are difficult for me. I'm not a malingerer, I've never been unwell you know I'm telling you, begging you. Have I got to wait until I can't walk until I'm taken seriously and it did come to that. He reckoned he referred me but three years later and I've never seen the expert. I saw another doctor and she said what do you want me to do I don't know. She said I think you're depressed.*

Georgia recalls feeling stigmatised when she approached her GP for a diagnosis. Lian and Robson (2017) found that people with uncertain illnesses, such as ME, reported their greatest dissatisfaction at not having their illness taken seriously within clinical encounters. While Georgia was looking to her GP to validate her suffering with a diagnosis, the clinical encounter left her feeling more lost and uncertain.

Amy also sought help from her GPs but their dismissiveness made her feel worse when she was accused of malingering and laziness.

> *Amy: I don't know really. From the GPs definitely. It makes it a hundred times worse when you're being told it's not real when you already feel like crap (whispers crap). No. Yeah the GPs have got a lot to learn they make it so much worse for people. Everyone's got the same attitude, not just the GPs.*
> *NW: How do you think the public perceive it?*
> *Amy: Just a fake. So many comments.*
> *NW: Like what?*
> *Amy: Like it's not real. It's not in the mind. How many times have I heard it's all in the mind (laughs). So many times I've heard that one. Erm*

Amy believed that was public perception that ME was a fake illness. She believed that this negative perception of ME pervaded medical settings and wider public domains. The allegation that Amy's illness was "all in the mind" suggests that ME is accredited with a low status of believability. Lucy also

felt that her GP undermined her symptoms, by attributing her fatigue to a stressful job and mental distress. In the following extract her tiredness was not interpreted as being a symptom of illness but the product of a challenging job.

> *NW: Did you go to the doctor when you collapsed that first time?*
> *Lucy: Yeah my normal one was great but she was away and I saw a locum because I was always tired, had a sore throat and I'd just had a growth removed. He said pull yourself together and get back to work. He said it because you're watching people die. I said I don't have an issue with it and it's not a big issue for me and then I went and collapsed at work.*

Even though the symptoms of ME are wide ranging, a key symptom of the illness is fatigue. All of the participants experienced fatigue as one of their symptoms. The participants recounted how others would equate fatigue to tiredness, but for the participants, there was a clear distinction between the two. In Widerberg's (2005) tiredness studies, she found that participants reported how having too much to do was normal for them. This weariness often manifested in the Widerberg's (2005) participants feeling worn out with bodily symptoms such as headaches and soreness. It is possible that the perceived normality and everydayness of tiredness meant that the participants struggled to communicate their chronic and often disabling fatigue. Lucy's doctor's insistence that she go back to work and "pull yourself together" shows how the sick role (Parsons, 1951) was withheld, as Lucy was not exempt from a working role despite feeling ill. Severity and longevity are integral to whether a person is able to access Parsons' sick role (1951). If the illness is long lasting and regarded as being a minor ailment, there is little chance of gaining full access to the sick role (Parsons, 1951). Drawing from Freidson's (1970) work which expanded on Parson's sick role (1951), it might be suggested that ME could be classified as an illegitimate stigmatised illness, where there are few sick role (Parsons, 1951) benefits, if any.

Thus far, the section has addressed how fatigue is often misconstrued as being the same as tiredness which is an everyday minor ailment rather than a symptom. However, there is also the subject of the illness itself being invisible to the eye and evasive to biomedical examination. Participants interpreted comments of "looking well" as an accusation of actually being healthy, well and malingering (Jutel and Buetow, 2007). This point is exemplified in Georgia's interview extract.

> *Georgia: The weather helped because I could sit out in the garden for half an hour and then gradually build it up. The only thing was that because I'm dark haired I started to get a bit of colour and then people would say 'oh you don't look unwell' and it is just erm. Well yeah it's just been horrendous, just horrendous.*

Yet, as Kirsty articulated, a disability does not have to be visible to be real.

> *Kirsty: Just because my general experience of it is that people have been thinking I'm making it up. So people, teachers, erm frustration with it, with me, it's generally teachers other children and school, employees, employers. They don't get it they don't understand it they don't want to try to get it. You look alright so how bad can it be. What's wrong with you? That's really ignorant thing of all disabilities have to be visible.*

Even when being told "you look well" is given as a compliment, the fragility of the ME diagnosis and an accumulation of previous negative experiences leads to the compliment being received negatively. Martin emphasises how question marks metaphorically hang over the individual who "looks well" while claiming to be ill.

> *NW: Do you have any ideas about what could support people with ME more generally?*
> *Martin: I think that we do have a perception issue to tackle, which is 'know people say to me 'you look well' and they mean that as a compliment but at the same time it's a question 'what's wrong with you? Is there anything wrong with you? You don't look ill. Why have you got a blue badge?*

It might be argued that an invisible illness is easier to manage because it is possible to try to pass as a normal, if one should so wish (Goffman, 1963). However, in order to receive support, care and adjustments the disability or illness needs to be communicated and this, again, raises the dilemma of information management. Ann Davis (2005, p. 180) suggests that:

> the revelation of invisible disability can often be greeted with a scepticism that can be both difficult and painful to dispel. Since it is impossible for most laypersons to verify the truth or falsity of many claims of invisible disability, an interlocutor's willingness to believe that the individual has an invisible disability may be contingent on his or her willingness to assume that the person is both credible and informed.

There is no way to biomedically verify ME because it is invisible to tests as well as being indiscernible to the human eye. Ann Davis (2005) touches on the issue of the ME diagnosis being open to interpretation across different sites and individuals, including healthcare professionals. The participants frequently experienced their illness being disbelieved and some of the reported consequences of disbelief included suicidal thoughts and attempts. Kapur and Webb (2016) found an elevated risk of suicide in people with ME, with stigma and unsupportive social interactions as risk factors for suicidal

thoughts or actions among patients Lauren recalls a situation where she had to request the emergency services for a fellow online forum user.

> *Lauren: I did actually, there's a girl in the forum who's 24? And she wanted to commit suicide a couple of weeks ago so erm I had to send the police and get them to go and check that she hadn't erm because she just she posted her final (trails off inaudible muttering)*
> *NW: Did she come back online?*
> *Lauren: She listed what tablets she had to kill herself online but there was me and another woman saying "don't do this" and then she'd gone to sleep but she hadn't told anyone she'd gone to sleep. Whether she's taken her tablets and gone to sleep or y'know just went to sleep naturally. Yeah it's awful y'know she says "it's not just the ME, people don't think you're unwell".*

The last line is perhaps the most poignant, when Lauren paraphrases the young woman referring to dealing with a chronic illness at the same time as being faced with constant disbelief. Dummit's (2006) research highlighted how people with ME are under the increased pressure to fight for an acknowledged legitimacy, as well as living with the chronicity of the illness itself. It is therefore evident that the charge of being a malingerer is tied to the ascription of blame as well as the invisibility of ME. This is further compounded by the subjectivity of symptoms, such as fatigue and pain, which are hard to measure and communicate. The social consequences of the ME diagnosis can include stigma in addition to suicidal thoughts and attempts.

5.7 Conclusion

The previous chapter on labelling elucidated the "liminal" status of the interview participants where they evaded classification while being pushed to the margins of social life. Expanding on that discussion, the current chapter argues that the diagnostic process of ME highlights how the participants inhabit a poorly understood mind-body borderland (Jackson, 2005), while straddling the boundaries of morality and responsibility. The participants experienced medical uncertainty, while occupying a liminal space exacerbated by contestation and invisibility. Within the diagnostic process of ME there exists an unsettled tension between acknowledging patient rights and subjective experiences while maintaining the integrity of medical knowledge and authority.

Chapter five has shown how patients with ME experienced their diagnosis being "dismissed as illegitimate, - framed as 'difficult', psychosomatic or even non-existent" (Moss and Teghtsoonian, 2008, p. 7). This finding was particularly evident where the ME diagnosis was replaced with an allegedly real diagnosis, with replacement diagnoses including anorexia, social phobia and depression.

Within the hierarchy of medical classification (Album, Johannessen, and Rasmussen, 2017; Album and Westin, 2008) ME ranks somewhere below mental illness, yet at the same time the condition is often equated to being a mental illness. The treatments that the participants experienced are confusing to patients because the treatments imply that the cause of ME is psychological. However, the participants felt their illness was physical and the psychologising of ME was incongruous with their embodied experiences of ME. Locating the explanation for ME in psychology ascribes responsibility and moral blame to the patient in a way that fosters patient opposition and scepticism towards the diagnosis (Kirmayer *et al*., 2004). The psychologising of ME results in the medical narrative of the condition being alien to the participants. The participants felt especially alienated from their diagnosis when their behaviour was attributed to being the cause of their illness.

While a physical explanation for a symptom confers, in most cases, a lack of personal responsibility for its onset, a psychiatric one implies that the patient might have the ability to both manage and reverse physical symptoms. This is an interpretation that may seem impossible to the patient with the potential to stigmatise and shame (Jutel, 2015). Cohn (2010, p. 67) has shown how brain scans have offered people suffering with psychiatric illness the "opportunity to redress previous distress and narratives of responsibility by reclassifying their condition as any other banal and external physical illness". Cohn (2010) found that evidence of disease meant that there was the potential for the locus of responsibility to shift away from the individual. The emphasis on personal responsibility for causing the ME is especially problematic when we consider a key finding from chapter four, that participants experienced their diagnosis being withheld. How can an individual be held accountable for their illness when they are not entrusted with a diagnosis? The current chapter has also shown how the participants are accused of both malingering and being overreaching perfectionists. There is a recurring finding whereby the participants find themselves in a situation where they struggle to gain legitimacy for themselves and their condition.

The diagnostic process of ME is also incongruous with how the condition is medically classified. The chapter has shown how psychiatry/psychology dominates the diagnosis and treatment of ME. However, the condition has been classified as a neurological condition by the World Health Orgaanisation (ICD-10, G93.3) and the UK All-Parliamentary Group for ME (2010). NICE (2007) suggests that ME is an illness of an unknown origin with a unknown cause. Yet, all of the participants were offered some form of psychological intervention. Psychiatry is a legitimate form of medicine and has a diagnostic framework for disease, as does physical medicine. However, the participants were critical of the psychiatric framing of ME and the psychological treatments because the supposition lacked an evidence base.

In terms of the wider contribution of this chapter, it has illuminated how the process of diagnosing is not necessarily unidirectional, because the treatment of CFS/ME appears to dictate the aetiology of the condition. It also suggests that the official classification of an illness/disease is not always aligned with the treatment or the overall diagnostic process. Biomedical knowledge and medical authority have been shown to both validate and stigmatise those who look to medicine to explain their suffering. In having explored the diagnostic process of ME, the research has demonstrated how medical jurisdiction is not impervious to normative assumptions and patient stereotypes. Finerman and Bennett (1995, p. 2) succinctly summarise the case of my participants, who were "forced to fight both health threats and social stigma or sickness-induced shame". The next chapter will further consider the social consequences of living with ME and how the stigma and symptoms of the conditions can trigger social withdrawal.

Chapter 6
Loneliness and liminality

NW: Has your illness affected your relationships?
Kirsty: Yeah I'm isolated and limited. When people haven't known what it is they have asked is it life threatening and then I say no but it's quality of life threatening because you have to change the way that you live your life.

6.1 Introduction

The focus of this chapter is on how people with an ME diagnosis face loneliness and social isolation. The chapter draws on some of the central themes already discussed in this thesis, including stigmatisation and discreditation; and the liminal experience of living with a contested condition. Whereas the previous chapter discussed the diagnostic process of ME, this chapter largely concentrates upon the consequences of the ME diagnosis. It will be shown not only how loneliness persists beyond the initial labelling of ME, but also how exploring loneliness is integral to understanding how people live with the condition and the diagnosis.

Even before the Covid-19 epidemic, research on loneliness was gaining considerable traction. It is currently estimated that loneliness affects 7.2% of the general British population[22] (Office for National Statistics, 2021). Loneliness had already transformed from being a private individual issue to a public health concern, with persuasive research showing the adverse health effects of loneliness. Loneliness is linked to poor health behaviours such as smoking, alcoholism and sleeplessness (Cacioppo *et al.,* 2002; Hawkley, Thisted and Cacioppo, 2010) and negative health outcomes, such as obesity (Lauder *et al*., 2006) and high blood pressure (Hawkley *et al*., 2010). Loneliness has also been found to play a role in mental health issues, including depression and anxiety (Cacioppo and Hawkley, 2010; Heinreich and Gullone, 2006) and to have an impact on mortality (Holt-Lunstad, 2015; Victor and Bowling, 2012). The Jo Cox Commission brought loneliness to the forefront of government policy. In conjunction with

[22] This figure is likely to have been impacted by Covid19 and the government lockdowns which restricted face-to-face socialising.

the charity Sense (2017), the Jo Cox Commission published a report[23] showing how disability affects loneliness. The Sense (2017) report shows that over half of disabled people (53 per cent) reported feeling lonely, increasing to three-quarters (77 per cent) for young disabled people.

Despite the prevalence of an alleged loneliness epidemic, and the public health nature of the issue, it remains a surprisingly under researched area within sociology. Loneliness and its connection to aging have been key areas of research focus, despite loneliness having been found to present a significant risk to younger people (Luhmann and Hawkley, 2016; Qualter *et al.,* 2015; Victor and Yang, 2012), but less attention has been paid to how loneliness is connected to disability and chronic illness. Sociology has often portrayed loneliness as being the product of individualism (Riesman, Glazer and Denny, 1961; Putnam, 2000) and the resulting rise of living alone (Klinenberg, 2013; Kislev, 2019) and, whilst Elias (1985), Slater (1975) and Yang (2019) have tackled loneliness as a specifically sociological problem, the concept has tended to be buried within sociological literature on aging, social networks and social connections. This chapter invests in a sociological approach that instead situates loneliness and social isolation within the wider social environment in which they are experienced (Franklin *et al.*, 2018), thereby reflecting the understanding that loneliness shapes and is moulded by structural factors such as living arrangements and sociocultural norms (Barbosa Neves, Sanders and Kokanović, 2019).

The preliminary data chapter (chapter four) elucidated how the participants found themselves with a "liminal" status (Turner, 1969, p. 94), existing somewhat ambiguously "betwixt and between the normal day to day, cultural and social states" (Turner, 1969, p. 94) and being neither legitimately ill nor fully healthy.

> The attributes of liminality or of liminal personae ("threshold people") are necessarily ambiguous, since this condition and these persons elude or slip through the network of classifications that normally locate states and positions in cultural space. Liminal entities are neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial. (Turner, 1969, p. 94)

The analysis in this chapter is also influenced by the concept of liminality (Turner, 1969; van Genep, 1909; Little *et al*., 1998), which can be described as the "status of those falling between socially recognised and medically sanctioned categories" (Brown, Huszar and Chapman, 2017, p. 696). In particular, this chapter draws from the work of Little *et al*. (1998), who identified three key themes as

[23] A full copy of the Sense (2017) report 'Someone cares if I'm not there', explores why loneliness affects so many disabled people and it can be accessed here. 23 disability focussed charities contributed to the report. The key findings from the Sense report are included in the Jo Cox Commission's final report on loneliness.

integral to understanding how cancer patients experienced the process of liminality. The current chapter utilises their concept of "boundedness" (Little *et al*., 1998, p. 1486) which can be described as a "persistent awareness of limits to space, empowerment and available time" (Little *et al*., 1998, p. 1486). Boundedness will be used to highlight how the participants found their lives were increasingly spatially restricted to the home. The participants also experienced boundedness where the pace of their lives slowed, and their days were structured to avoid exerting too much energy.

The second concept which is borrowed from the study by Little *et al*. (1998) is "communicative alienation", which is defined as "a state of variable alienation from social familiars, expressed as an inability to communicate the nature of the experience of the illness, its diagnosis and treatment." (Little *et al*., 1998, p. 1486). Communicative alienation is utilised to demonstrate how the interview participants felt that they were often living on the peripheries of social life. The concept will be used to elucidate how people with ME struggled to find common talking points with those living without the condition. The chapter will therefore explore how the experiences of boundedness and communicative alienation formed part of the participants' feelings of isolation and loneliness.

The current chapter will also demonstrate that social withdrawal can often be seen as a necessary coping mechanism for people with ME, and that this in turn leads to loneliness. Through the data from the semi-structured interviews it was possible to elicit the unanticipated themes of social isolation and loneliness, which emerged as part of the everydayness of living with ME. Highmore (2002) argued that the everyday should be brought forward instead of remaining in the backdrop, and this chapter brings the daily experience of ME and loneliness into the foreground. Moreover, the chapter shows how social isolation and loneliness are difficult concepts to disentangle in the specific case of those living with ME. The chapter will begin by discussing how living with ME often necessitated social withdrawal by the participants, who suffered significant "biographical disruption" (Bury, 1982, p. 167), which altered their sense of self. The chapter explores how many of the participants experienced symptoms which impinged on their ability to socialise. This discussion will then be followed by an analysis of how the participants experienced communicative alienation through contrasting their own lives with seemingly normal lives, creating an emotional distance with members of their social networks. The chapter will then conclude by focusing upon the emotional distance caused by being discredited and stigmatised with the ME diagnosis. The chapter begins by discussing the definitions of loneliness. This is especially important given how loneliness is often conflated with similar and overlapping concepts, such as social isolation. The chapter also positions ME within the existing literature on loneliness and social isolation.

6.2 Defining Loneliness and Social Isolation

Many definitions of loneliness exist, yet they all share a common negative summation about a perceived

deficit or missing qualities within social relationships (de Jong-Gierveld and van Tilburg, 2006). The most widely used academic definition of loneliness is provided by Perlman and Peplau (1981) who claim that there is a difference between actual and desired social relationships in their conceptualisation of loneliness. They suggest that loneliness is "an unpleasant experience that occurs when a person's network of social relationships is deficient in some important way, either quantitatively or qualitatively" (Perlman and Peplau, 1981, p. 31). Klinenberg (2013, p. 95) shows how the rise of "solo-dwelling" is a welcome development amongst urbanites rather than a cause of loneliness. Being alone or socially isolated can be welcome, so they should not be conflated with loneliness. At the same time, technology connects us more than ever before without the need for physical presence but loneliness nevertheless appears to be rising (Cacioppo *et al*., 2015). This suggests that feeling socially connected involves more than having the physical presence of others or the means to communicate with them.

Loneliness is therefore complex and is widely regarded as being multidimensional. It has commonly been examined through its *emotional and social aspects* (Weiss, 1973). Emotional loneliness occurs when individuals feel a lack of close or intimate attachment to people with whom we have a bond, such as with close friends, relatives, or partners. The emotional aspect of loneliness is addressed where loneliness is defined as "the subjective, unwelcome feeling of a lack, or loss, of companionship" (Cattan *et al.,* 2005, p. 42). In contrast, social loneliness results from a lack of belonging to a wider network of individuals who share some common social identity, such as values or interests.

The issue of loneliness has, however, not been an explicit focus within the literature on ME, except for one literature review by Bouazreg and Rockach (2020). Bouazreg and Rockach (2020) found there was no evidence of previous literature having concentrated upon loneliness and CFS/ME. However, they based their conclusions on loneliness related concepts, which included: isolation, isolated, alone, alienating and alienation. Yang (2019) is critical of social scientists who mix the concepts of loneliness, social isolation, and aloneness. These concepts are perhaps better regarded as being related but separate concepts which are difficult to disentangle (Killeen, 1998). Accordingly, Wigfield and Alden (2018, p. 1019) propose that loneliness and social isolation share a lack of "social connectiveness" yet remain distinct concepts.

The topic of loneliness and social loss is detailed within the broader literature on CFS/ME but it is often a sub-focus. Reference has been made in it to the related themes of social withdrawal (Asbring, 2000; Asbring and Narvanen, 2002; 2004; Taylor, 2005), social isolation (Dickson, Knussen and Flowers, 2008) and social loss (Ware, 1999; Anderson and Ferrans, 1997). Attention has also been given to how the loss of friendships has been part of the experience of living with CFS/ME (Reynolds and Vivat, 2010; Travers and Lawler, 2008). A meta-synthesis of qualitative research on ME found that that people with CFS/ME are socially marginalised (Anderson *et al*., 2012) and, even when their condition is

accepted by healthcare professionals, their illness is often trivialised. In addition to this, a study which combined the contested conditions fibromyalgia and CFS/ME found that participants had less opportunity to grow from the illness experience when compared to women with explicable chronic illnesses (McInnis *et al*., 2015). McInnis *et al*. (2015) suggests that this is because the stigma of CFS/ME triggers social withdrawal. Consequently, the literature shows that stigma and social withdrawal are interrelated. The marginalisation of people with ME coupled with social loss does, however, warrant further examination of loneliness and social isolation. Accordingly, the chapter begins by addressing the research data with a focus on how living with ME - its symptoms and fluctuations - often necessitated a need to socially withdraw from others.

6.3 Social Withdrawal: Too Tired for Company

The symptoms of ME made it difficult for the participants to socialise as they had done prior to the onset of the illness. Their capacity to engage with others was therefore reduced. The key symptoms that each participant shared were chronic fatigue, pain and general malaise. Previous research (Sense, 2017) has found that pain (Werner, Isaksen and Malterud, 2004) and fatigue (Dickson, Knussen and Flowers, 2008) have a significant impact on people's ability to be sociable. The effect of these symptoms on daily life meant that mobility, concentration and dealing with stimuli were especially difficult. The symptoms reported by the participants were wide ranging and included headaches, joint and muscle issues, cognitive difficulties[24], dizziness, nausea, sleep difficulties, palpitations, stomach cramps, flu-like symptoms, painful lymph anodes, difficulty swallowing, immobility and neuralgia. While some participants did report depression, it was more often regarded as being a consequence of having ME rather than a symptom, or indeed a cause (see chapter five). With the worsening and fluctuating of symptoms, the participants saw both their social space and their social lives reduced. This led to less contact with people and the participants found that they became increasingly lonely and socially isolated.

In many cases it was the family that cared for the participants when their illness warranted it. The majority (39 out of 42) of the participants lived with family members or a partner/spouse, with the exception of three. Of the three participants who did not live with family, one person lived next door to their family, another lived with a housemate, and another lived alone but near to their family. Most of the participants were therefore not "solo-dwellers" (Klinenberg 2013, p. 39) as they lived with others, yet they still experienced loneliness and this highlights how aloneness and loneliness are different concepts. Klinenberg (2013, p. 39) showed how "solo-dwellers" tended to have fulfilling social lives

[24] Cognitive difficulties are often referred to as "brain fog", which is a common term used by ME sufferers and it was frequently used by the interview participants to refer to when they had struggled to think or concentrate.

because they would seek company and social activities outside of the home. However, the participants, despite not being solo-dwellers, were restricted to their bedrooms and homes, which often prevented them from making new social connections and curtailed maintaining old ones. This chapter largely concentrates on the participants' relationships with those were not key caregivers. While their relationships with caregivers were often strengthened or intensified through having ME, other relationships ebbed away. It was the decline of these friendships and relationships that created a sense of loneliness and which might point to a deficit in the quantity of social connections, as highlighted by Perlman and Peplau (1981).

While scholars have distinguished between social isolation and loneliness, it was more difficult to separate the two concepts in the interview data. Loneliness and social isolation were frequently compounded by the participants feeling too tired to talk, despite wanting social interaction. This supports Hart and Grace's (2000) research which showed that people with ME desired social interaction while being unable to physically bear it. However, it was also the case that some respondents felt too ill to even want to be in the company of others. For example, Dave had developed ME at a young age and he had been a student during the onset of ME. His student friendships had ebbed away but Dave reported having close relationships with his family and his partner.

> *NW: Have any of your relationships changed since you were ill?*
> *Dave: I've not really kept in touch with friends really as a result of not being well enough to meet up and do activities and then probably as a result of feeling so bad I didn't really care about the relationships I had as much as I should have.*

Feeling too fatigued and ill to care about maintaining or seeking relationships was a common theme in the interview data. Leanne found that dealing with ME not only meant that she had lost friendships, but the illness left her unable to enter into a romantic relationship, which she believed would have been too burdensome.

> *NW: Has it impacted on your relationships? Whether family friends, partners (trails off)*
> *Leanne: Yeah (sighs) yeah it does. I'm currently single and I don't have a kind of boyfriend sort of relationship to worry about erm but I could imagine that it would be very difficult. I haven't got time to focus on anybody but myself at the moment.*
> *NW: Yeah*
> *Leanne: It sounds really selfish but you just don't. You've just got so much on, getting yourself better that I just think another person, their demands this that and the other. I don't even think I could cook dinner. If Mr Right knocked on the door I'd have to turn him away. I don't have the energy for it.*

Leanne demonstrated how she would be unable to fulfil the expectations of being a girlfriend where she anticipated reciprocating cooking dinner for someone. Reciprocity was a recurring subtheme across the interview data, whereby the participants struggled with being unable to reciprocate in relationships, and there was often guilt attached to this realisation. Leanne had adjusted her work to part-time and her parents cooked her meals and undertook all of her domestic tasks so that she could focus on keeping her job. She had recently moved back into the family home to be better supported. While this adjustment had brought her physically and emotionally closer to her parents, Leanne had lost friends by being too fatigued and ill to socialise. Prior to becoming ill Leanne had enjoyed a social circle which had revolved around regularly playing different sports. One of the consequences of her illness was that she was no longer able to play any sports and her social network was greatly reduced.

Wherever possible, the participants tended to try to conserve their energy for work or familial responsibilities, with little or no energy left for anything else. The symptoms that they experienced meant that they were often too unwell to socialise and not one participant was well enough to work full-time. Those who did work, either changed their jobs or work patterns or altered both due to their illness. Twelve participants worked part-time, one studied full-time, three studied at university part-time and one participant did some local voluntary work. Any work was interrupted by lengthy periods of bed rest. An example of such a lifestyle change can be seen where Grace had been a full-time teacher and she changed her job to become a part-time teaching assistant, reducing both her hours and her workload. Where participants were able to work part-time, they were left with little or no energy for socialising and tended to only see their immediate family and/or partner. The change in job or employment status had a profound effect on the feelings of loneliness experienced by those who were interviewed.

The changes in working hours, job role and employment status were all key alterations in the lives of the participants. It Affected how they perceived their social network, because this was often tied to the workplace, and they missed the regular social contact that employment brought. The change from being busily employed to being unable to work had a significant effect on Josh and his family.

> *NW: How has your life changed since becoming ill?*
> *Josh: Err quite dramatically I've found. I used to work a lot of hours and I had a good social circle as well and I went from that to pretty much erm seeing no people but my wife everyday erm and sometimes the children but I can't really deal with that. We'd just had the loft converted and it was just too much effort to come down two flights of stairs to do anything and one by one friends disappeared I suppose and yeah. So I went from being around people all the time to not being around people at all very quickly.*

When asked what a typical day looked for Josh now he replied:

Josh: The last few months I've been getting out a bit more and doing a bit of exercise. On the days that I go out I go to the GP referral programme for the gym and the swimming pool. I have carers in at 7am in the morning and they'll do a bit of physio in the gym, they wheel me to and back in my wheelchair. I'll come home and I'll sleep. Erm, I wake up in time to see the children home from school. I'm in bed all day. I try to sit down with the family and eat in the evening but it doesn't happen everyday maybe like 3 times a week. I go back to bed again and watch telly or play on my guitar or something like that but mostly it's just lay on the bed.

Josh had felt lonely and isolated through having ME because he was unable to work, socialise or spend time with his family. He had also expressed guilt at being unable to work or help his wife parent his three children. As a result of the changes that ME had brought to the family's lives, Josh's wife had a nervous breakdown. Friends had marginalised them and family did not understand the illness that Josh was dealing with. It is evident from the interview extract that ME pervaded Josh's day-to-day life, which led him to socially withdraw from others. Despite living with four other people, Josh was both socially isolated and lonely because he was both socially and spatially restricted to his bedroom. This highlights how it is difficult to differentiate social isolation from loneliness in the case of people living with ME. The participants rarely left their homes and were often restricted to their bedrooms. What follows is an excerpt which demonstrates how having ME permeated the minutiae of daily living for Evelyn as the illness left her struggling with fatigue.

NW: What does a typical day look like for you now?
Evelyn: A typical day now? Struggling to wake up in the morning. I manage to get up and I'll feed my cat, have some breakfast and then that's it I'm tired again. Well I'm always tired but to the point that I have to rest and then I spend most of the day sitting or in bed erm. I do occasionally go out and visit family not too far away and it's a massive struggle and then if I have done something like go to an appointment or visit family then I have to go and sleep afterwards straight away to sort myself out just because the overwhelming need to sleep is so strong and I'm exhausted and I need to get over it. A lot of the time is spent in the flat on my own because being around company makes me even worse.

Evelyn reflects on her social situation again later in the interview:

Evelyn: I'm housebound. I've been to see a neurologist and he believes that's happening now is that I'm really unconditioned from all of those years of not having exercised and I'm completely unfit. Yeah so now it has reached a bad level and I've also become a bit of a recluse because I find socialising very exhausting and it's cut me off a lot from friends and family, it's

very very. I couldn't be any more different to the person I was before really. Extremely bubbly and now being like a recluse, which is the nicest way of putting it. So yeah essentially the ME effects every single thing I do. Like the vacuum cleaner I had so that it's not too heavy. My food has to be able to cook all at the same time so I can rest while I'm cooking. There isn't anything in my life, which hasn't been touched by the ME, it's disturbed everything.

Evelyn identified as a recluse who only saw her family because she is largely housebound. This presents a stark contrast to the "bubbly" person she perceived herself as being before the onset of ME. Evelyn had to become a more passive version of herself in order to cope with her ME and she socially withdrew from others. In "The Loneliness of the Dying", Elias (1985) described increasing isolation as the dying get sicker and more isolated in modern western societies. Elias (1985, p. 12) also pointed to the historical changes where the process and image of death and the dying have been "pushed further behind the scenes, are isolated". In a similar way, the worsening of ME sees the individual become increasingly invisible to the rest of society.

Socially withdrawing from others was a necessitated and unhappy aspect of living with a chronic and often disabling illness, but nonetheless a lonely position to be in. The dramatic "biographical disruption" (Bury, 1982, p. 167), from being healthy and active to suddenly bedbound and/or housebound, does share similarities with the findings from Clarke and James (2003), who found that participants had lost touch with their friends as well as a place within friendship networks. Moreover, the participants frequently felt isolated and separated from the daily round of life, including work, family and recreation. They became outsiders, distant from the activities of everyday living while being unable to adopt a fully legitimised sick role (Parsons, 1951), even after receiving a diagnosis. The constrained and restricted spatial and social patterning within the lives of the participants meant that the "biographical disruption" (Bury, 1982, p. 167) invalidated the identity they had before having ME, as their previous lives became more distant. All of the participants had seen their lives significantly changed through having ME, from the minutiae of how they functioned day to day to the larger issues of careers and families. Some participants had moved home (Lucy moved to a bungalow because she struggled to walk) and they changed who they lived with (moving back to the family home was common). What became clear from the interviews was that in social withdrawing there was a sense of "boundedness" (Little *et al.*, 1998) to the experiences of the participants, which was shown through them expressing their feelings of restrictedness. Yet there was also an impression of "boundedness" (Little *et al.*, 1998) in relation to the surrender of social and working roles, and the participant's loss of empowerment. This section has shown how social withdrawal and loneliness is often part of living and/or coping with ME. The following section reflects upon the consequences of feeling marginalised, where the participants found difficulty in relating to the lives of others.

6.4 Normality Talk and Communicative Alienation

The current section focuses upon the concept of "communicative alienation" (Little *et al*., 1998, p. 1486), which is utilised to elucidate how the participants felt marginalised through being unable to relate to apparently normal lives and everyday conversations. The interviews were replete with normality talk. Normality talk here refers to where comparisons were made between themselves (the participants) and their expectations of what someone of their age and gender might usually be doing. Normality talk created an emotional distance between us (people with ME) and them (people without ME). From the interview data, it was found that the participants had constructed an idea about what a normal life looked like, and this was a life without ME. A seemingly normal life narrative tended to have a linear progression without disruptions, obstacles or negativity (Hockey and James, 2003), which contrasted with their own. The creation of otherness (them), tended to be applied to friends rather than family members with whom they cohabited. Melissa constructed an idea of what a "normal" life would look like and frequently made comparisons in the interview.

> *Melissa: I mean I haven't had a relationship for years they're just too tiring, too much. Most women of my age are settled but I won't be able to, not if I want to work. The most important thing is to work. A normal life has been taken from me. It's like being on the other side of a mirror, just looking in.*

Melissa considered her illness to be chronic, occasionally disabling, and on-going but without hope of a recovery. For Melissa, there is a conscious resignation that a normal life is an impossible illusionary goal for her. She felt forced to make difficult choices between a career and a personal life, rather than being able to combine having a family and a job. The issue of a future family appeared in the narratives of the female participants but this did not appear in the transcripts of the male participants. It cannot be assumed that the prospect of children was any less important to the male respondents, but the men did not express any concern about whether they would have a family. Woollett and Boyle (2000) have drawn attention to how women might feel they are breaking the conventions of normality by not having children. This might explain why some of the women in the interviews compared themselves to women who had children and/or a partner. Nevertheless, the men in this study, who were already fathers, did share their worries regarding parenthood and the reduced time they now spent with their children. Even though the fathers in the study wanted to be with their children they were often too unwell to fully partake in family life, as they had done before the onset of ME.

Asbring (2001) found that people with ME reprioritised aspects of their lives because of their illness. All of the participants made lifestyle adjustments and it is especially reflected in the case of Melissa. Where other peoples' lives seemed multi-dimensional to Melissa, her own felt narrowly fixed on trying

to manage her ME symptoms. Melissa found the experience of ME even lonelier after becoming unemployed and moving in with her parents due to a flare-up of ME. Her social space therefore shrank, as she was living in her childhood bedroom without having the social network from her job. Although her workplace had not known about her illness, because she felt they would be unsupportive, Melissa missed the social contact with her colleagues. Despite the change from living alone to cohabiting with her family, Melissa felt lonelier because she was emotionally alienated from her mother and father. She experienced an emotional distance with her parents because they did not believe in the existence of ME and they questioned whether she was actually physically ill.

In the following excerpt, Alex conveys how she no longer felt part of the normal world because felt left behind while others continued to lead full lives. Alex had previously had a demanding professional career and largely raised her children alone. Alex was no longer working due to ill health, and she felt angry at her lack of mobility as well as continually feeling ill and fatigued. She relied on her partner for help with everyday tasks, such as getting washed and dressed, but her partner did not believe that ME was a real illness. The interview had to take place when her partner was out of the house because he did not like her to talk about being ill. Having been unable to speak about her ME had made Alex feel even lonelier and the interview was partly seen as an opportunity to discuss her experiences in the hope that talking would prove to be cathartic.

> *NW: But if you're happy to answer how it affects your relationships with people?*
> *Alex: So he's (her partner) got to know a lot of people. I'm slowly getting to know people but I don't really get to see them and when I do see them they're like 'oh, how are you?' and I don't know what to say any more. I just don't know what to say. I just don't have the conversation and you don't live in the normal world any more. You're not going out there and doing a job and that sort of interesting stimulations, keeping up with things. And sometimes you know I think what am I going to say? I've never been like that, I'm a talker, it drives me mad.*

Alex had moved to a new area two years before the interview and this played a role in the loneliness she had felt. She had been unable to meet new people due to falling ill with ME. However, her story was one of loss where she had lost her career, friendships and independence through her deteriorating health. Alex was acutely aware of being socially disconnected through lacking social commonalities with new acquaintances. Alex was unable to talk about hobbies, travel, work or the books that she had read. Alex was not able to discuss these things because she spent most of her days resting in bed, sleeping or trying to do small everyday tasks such as wash or dress. The absence of shared experiences meant that Alex struggled to converse with others. Alex's life was focussed on achieving tasks which we might take for granted when we are not ill. The socially ambivalent state of ME, and her being severely affected by ME, meant that crucial social and cultural prompts to guide interaction were

unavailable. For Little *et al*. (1998, p. 1486) "communicative alienation" was an integral part of living with liminality, and it "expresses a state of variable alienation from social familiars brought about by the inability to communicate and share the nature of the experience of illness, its diagnosis and treatment". Alex highlights how her communicative alienation is punctuated by the loss of language and the sense of being left behind by the "normal world", living a liminal existence. Not only was Alex unable to share her illness experience with others but she was also at a loss for words because her everyday experience was structured so differently to people who do not live with ME. This "communicative alienation" (Little *et al*., 1998, p. 1486) therefore extended beyond the diagnosis and treatment of ME, permeating her day-to-day life which was bounded by restrictions in time and space. The feelings of "communicative alienation" (Little *et al.*, 1998, p. 1486) can also be seen in the following excerpt from Rosie, who was bedbound for five years, as she reflects on this period of her life.

> *NW: Did your relationships change when you became ill?*
> *Rosie: Yes, yeah I think they would anyway I'd kind of got used to people not seeing me. It was incredibly lonely the first few years that I was ill and I didn't know how to communicate with people either. People would visit me and I'd feel incredibly guilty about people with you know doing things in their lives that I'd missed out on that I'd missed out on stages in their life. I was quite envious of people. I think for a lot of people it's an adjustment period. I know my sister was going through that (she has ME) but I don't think she's really come quite through that yet.*

The feelings of jealousy originated from others continuing with their lives normally by getting jobs or moving out of their family home, while Rosie remained bedbound. Her situation made it difficult to engage with others leading seemingly normal lives. Rosie encountered "communicative alienation" (Little *et al*, 1998, p. 1486) when she was unable to relate to the lives of her friends and peers. Rosie was feeling much better at the time of the interview and living independently with her boyfriend. She had been diagnosed fifteen years ago as a teenager and once she felt well enough to occasionally use a computer again, she had found online relationships easier to maintain than face-to-face relationships. Conceived as a form of "social pain" (Cacioppo *et al*., 2006, p. 1054), loneliness highlights deficits in social relations and motivates people to reconnect (Cacioppo and Patrick, 2008; Qualter *et al.*, 2015), as Rosie had done online.

Rosie was previously part of an organisation called the "Association of Young People with ME" and she had fostered online friendships through their forum and using her Facebook and email accounts. These relationships were easier for two reasons: firstly, they did not require her to travel and secondly, they were with other young people who had ME, and they "know tired doesn't mean tired, it means ME tired but I don't have to explain" (Rosie). Therefore, within these friendships, Rosie had a shared

understanding of the ME illness experience which bridged the "communicative alienation" (Little *et al.*, 1998, p. 1486) that she had often encountered with her peers who did not have ME.

However, there is a sense of temporality to such relationships. Rosie had recently distanced herself from these online ME social networks because she felt she no longer fully belonged. Rosie found herself somewhere between health and illness, a liminal state where she was not well enough to have recovered, yet no longer severely disabled by the illness. Her ME had improved and she did not want to remember how ill and lonely she had previously felt. Wishing to forget this time was underlined by her explaining that she wished to avoid discussing the years that she was bedbound. This mirrors the empirical findings of Sandaunet (2008) who found that one of the reasons that women with breast cancer withdrew from online support groups was that they did not feel ill enough to take part. There is a temporary appreciation of online social networks for so long as the shared commonality exists, (i.e., being ill with ME), but these friendships are left to fade when an individual's health improves.

Online friendships were valued by the participants but they were not a satisfactory replacement for being able to meet people face to face. In her interview, Rosie made reference to missing life stages and significant occasions, articulating feelings of guilt she had associated with being absent from events. Fran also felt that she missed significant milestones and life events:

> *NW: Is there anyone that you talk to about your illness?*
> *Fran: Privately?*
> *NW: Anybody?*
> *Fran: No one formally but some want to come over or meet somewhere, say how things are at the moment because they say 'oh do you want to come over or meet somewhere?' but I just have to say I can't do it. I was invited out with the family for a birthday meal and I can't even go for a meal and I just can't. It puts a lot of pressure on me and I feel guilty as well so yeah I've missed an awful lot so things like that yeah.*
> *NW: It sounds like the illness has impacted on your friendships and relationships*
> *Fran: Yeah hugely some people haven't forgiven me as it were but I try and say to myself they're not that good a friend if they can't stand by me when I'm poorly so*
> *NW: Certainly*
> *Fran: Yeah. There are good friends around but I don't see many people, so I have become quite isolated really. I can see it's only going to get worse. Yeah.*

Fran felt unable to celebrate over a family meal, but she was also too unwell to enjoy her own birthday. Missing life stages acted as a benchmark by which participants compared their lives with those of peers who did not have ME. Milestones experienced by family and friends marked how the participants were

themselves excluded from these seemingly normal experiences. Significant life events, in addition to normality talk, highlighted how the passing of time had a different tempo for the participants, for whom time and space were more narrowly restricted. For the participants in my study, their sense of "boundedness" (Little *et al.*, 1998, p. 1486) and "communicative alienation" (Little *et al.*, 1998, p. 1486) were intricately interwoven and central to how they experienced living with the loneliness of ME. However, a sharp awareness of how their lives differed from outwardly normal lives created a greater emotional distance, thereby exacerbating loneliness. This insight highlights how loneliness is more than an question of the quality or quantity of relationships. The frustrations underlying social relations also play a role in engendering feelings of loneliness. The next section will explore how discreditation compounded the loneliness felt by the interview participants.

6.5 Discreditation and Social Rejection

The stories of the participants all involved some social loss. The disbelief and discreditation surrounding ME often led to the decline and deterioration of friendships. Scepticism over the condition and doubt over the nature (psychological or somatic) of ME, placed a strain on familial ties. However, the participants also experienced rejection when friends and family severed relations with them. While social withdrawal was a means of living with the symptoms of ME, the need to withdraw from others was also sometimes necessitated by wishing to avoid negativity, scepticism, and disbelief from others.

The impact of discreditation is stressed in the interviews of four participants who had tried to commit suicide. The reasons for trying to commit suicide included living with the symptoms of the illness, but disbelief also played a large role in their desire to no longer live. When healthcare professionals, family and/or friends had not believed the participants were legitimately ill, they felt alone in dealing with their condition. In the extract below, Evelyn recalled how ME left her being a recluse and she referenced the pressure that being ill had put on her relationships. Evelyn had tried to take her own life after feeling abandoned by the lack of support from the social network she had enjoyed prior to becoming ill. Evelyn described how her life dramatically changed upon the onset of ME when she had to leave university and her job as a dental nurse.

> *NW: Has your illness had any impact on any of your relationships, friendships?*
> *Evelyn: Yeah definitely.*
> *NW: If you don't mind my asking?*
> *Evelyn: No, I don't mind you asking anything. Erm it has affected every relationship erm and now I'm too poorly to date, so I'm 37 and not married and it's also robbed me of having children because I'm just not well enough. Well for one I'm not well enough to find a husband and two, I'm just too poorly to look after a child. So that's the worst thing but it has affected*

my friendships. Erm a lot of them have disappeared really my friends because they can't understand why I can't always see them and they take it personally. So I've only got one close friend who I've known for 20 years and she understands my illness. I see my family but it affects my relationship with my family. All of the time and sometimes they expect too much from me that I'm not capable of doing so there's not one relationship that the ME hasn't affected which is why I'm quite a recluse and I would think most of the people you interview say something similar.

Evelyn felt that her illness had impacted on all of her relationships. Evelyn compared herself to what she thought her life would look like at 37 years old and she felt that ME had "robbed" her of having a romantic relationship and starting a family. To a large extent her social withdrawal was due to her symptoms but being disbelieved and misunderstood also made Evelyn retreat from those who treated her negatively. When friends and family were sceptical over the illness Evelyn felt that they doubted her integrity. They questioned whether she was not seeing them because she was too lazy or because she did not wish to. There was a misalignment between the expectations placed on Evelyn and how she was unable to fulfil those expectations because of her illness.

Another participant, Georgia had tried to commit suicide six months prior to our meeting. Georgia felt alone and scared by her illness and only her children believed she had a real and physical illness. Roberts *et al*. (2016) found a six-fold increased risk of suicide in people with ME, which Kapur and Webb (2016) have interpreted as being the result of untreated depression. While Georgia felt depressed she believed that her depression had been caused by being disbelieved and being left with little social support. Georgia experienced being shunned and ignored by family, friends and healthcare professionals who had told her that her illness was psychological or non-existent. Again, we see the repeated experience where there is a divergence of expectations between the participants and their social networks. The people from whom the participants had expected support, then failed to provide it.

NW: Has having this illness changed any of your relationships? You mentioned your neighbours and children.
Georgia: It's funny because this illness has made me realise a lot about human kindness. A lot good and a lot bad. I lost a friend that I had since being 16 and she turned her back on myself and my children. She can't deal with it. I had to let that go because I'm not strong enough to (pause) a few other friends as well. My neighbours have been. Normally with neighbours you say hello and get on with your life. They recognised that my children are lovely and I wasn't coping and we were on our own not knowing what we were dealing with. Yeah their help was. I don't know we would have got through it.

NW: I noticed people talking to each other when I was walking here and you don't get that everywhere.

Georgia: Yeah we're very lucky. Other friends no. In fact, the reverse really which is a shame really. It's hard to take and all that was happening when I was at my lowest. It was a combination of everything. It was people's assumptions about me and what I was going though. Even my dad that I was refusing to take medication and it was because I had symptoms from the medication which made me feel worse. It was all that and those closest to me weren't getting it, it was tough.

Those closest to Georgia had not only failed to help but they worsened her situation through disbelief and being unable to empathise with her condition. It was shown in chapter five how the participants were constantly told that their illness was imagined or that they were mentally ill. Here, it is demonstrated how this insistence created an emotional distance between Georgia and her social network. Her father had helped to care for her but tensions arose when he had accompanied Georgia to a consultation with her GP. Her GP had prescribed antidepressants and told them both that ME was not real and this impacted on how Georgia's father viewed the illness as well as how he treated Georgia. The participants found they were particularly lonely when they were alone in their belief that their illness was real and physical. In a systematic review of literature on children with ME, it was found that being disbelieved was one of the key issues they faced with social loss (Parslow *et al.*, 2016). Emma experienced social loss through the strain that ME placed upon her friendships. Emma had been told that her friendship group regarded her as being unreliable and/or a hypochondriac rather than being legitimately ill.

NW: How did you deal with that?

Emma: Erm it's been difficult. One thing that really hurt because I always have to cancel plans because I get tired and I had a friend say to me recently. We'd made plans for dinner and it was completely unrelated to ME. I had a mole removed and I had stitches coming loose so I had to go to A and E so I told her like you know I need to cancel and I need to go to A and E and I saw her a few days later and she was like so I told everyone you cancelled and they were like 'yeah just as usual'. I was like first of all not as usual because I don't go to A and E all the time and even if it is usual it's not something I enjoy. I don't enjoy not seeing my friends and but I'm sort of learning because I just used to cancel and say I'm tired. Now I say my chronic fatigue is flaring up therefore I can't come and if you frame it in that way people are more understanding. But it still hurts and my dad still thinks that I don't have ME. Which it is.

Emma was often unable to socialise as much as she wanted to because she frequently felt too unwell to leave the house. She had left her job and become a part-time student because this gave her the flexibility

and autonomy to manage her illness. Emma's father believed that she did not have ME and he paid for her to have additional tests at a private clinic. Even when the tests returned negative, Emma's father continued to reject the ME diagnosis. Mazzoni and Cicognani (2014) found that for people with lupus, social support from family and friends could be problematic where they were worrying too much or denying the existence of their illness. Emma changed the way she communicated her illness to people so that her friends could better understand her illness. She had found a way of softening the "communicative alienation" (Little *et al.*, 1998) by managing the relational gap between herself and others. She realised that tired sounded like an everyday occurrence whereas chronic fatigue resonated more seriously with her peer group.

The majority of participants in my study showed an awareness of being in a perpetual state of ME sufferer, even if they were no longer a patient in the care of any health professional or health body. Little *et al*. (1998, p. 1492) referred to this experience as "sustained liminality" where the cancer patients in their study entered a chronic phase and identified with cancer for the remainder of their lives. This "sustained liminality" (Little *et al*., 1998, p. 1492) is especially accentuated with ME because symptoms can fluctuate in intensity or even remit, while new signs of illness can unexpectedly appear. The heightened "sustained liminality" (Little *et al*., 1998, p. 1492) and the uncertainty this engendered created a social limbo because the participants felt unable to plan for the future. The participants were deeply aware of needing to conserve their energy in order to stay as well as possible. It was therefore challenging to maintain an equilibrium between attempting to live a full life while ensuring that they avoided worsening their health. Another young participant also recounted being mistrusted and disbelieved by friends and family. Having spent over a decade being housebound, Amy was no longer seen by healthcare professionals or indeed anyone else except for her immediate family who cared for her.

> *NW: Has your illness changed any of your relationships with your family and friends?*
> *Amy: Yeah*
> *NW: In what ways have they changed?*
> *Amy: Well the family were not convinced of what I had again they didn't believe in ME it was a fake illness. Y'know that kind of stuff.*
> *NW: Was it just your immediate family or everybody?*
> *Amy: Everybody (nods) it was. Erm friends I had at the time slowly disappeared. They used to visit me and they slowly disappeared but life goes on I suppose. Any relationship I've had in recent years it's always had a negative impact on. It's almost impossible to have decent relationship. Hmm*

Amy felt that she had been ostracised by everyone but her parents and sibling because those around her did not believe that ME was a credible illness. The issue of invisibility and ME was discussed in chapter five, which focused on the diagnostic process of ME. Chapter five highlighted how the stigma of ME was tied to the condition being medically undetectable and unexplained. However, the current chapter has pointed to the participants themselves being largely invisible from social and public life. There was a pattern where the spaces inhabited by the participants were restricted to the home, often unseen by healthcare professionals or their wider social networks. The people with whom the participants cohabited tended to believe in their illness because they saw them at their worst. Those outside of the home did not see the worst effects of ME as the participants only ventured outside of the home when they felt well enough. Somewhat perversely, this only perpetuated the idea that the participants were not suffering from a real illness. Lucy also rarely left her home due to chronic pain and limited mobility. In the following interview excerpt, she suggests that ME had significantly impacted on multiple relationships.

> *NW: Has the illness had any impact on your relationships, friendships?*
> *Lucy: Yeah I think so most of my family can't deal with it. My oldest brother phones a lot but he lives in France and my sister is really good and she lives in New Zealand. My youngest brother asked if they could put me in sheltered housing when I fell out of my wheelchair and there is a real strain on those relationships. Others don't get it because they don't get it unless they've seen me unwell. Friends, I've had to do a bit of soul searching with because of the person I am I'm normally there to deal with lots of people's problems and erm it has affected because I have some really good friends that understand that if I cut off I need some space and I can't cope, I need some energy. Oh actually I had one friend say to me last year because she was drunk I really thought you were just being lazy but you're not well are you? But I think that if you can't be supportive to them and be who they want you to be they move on because it's too scary for them.*
> *NW: The people closer to you now, are they newer friends?*
> *Lucy: Some are and some aren't. There are some people who have been there throughout and probably saw me go through the worst part of it and some of them are relatively new within the last sort of 15 years of my life and yeah but yes it's a bit of a sort out of what you need and don't need.*

Lucy found that some friendships deteriorated because she could no longer provide support in the way she had done prior to having ME. Lucy suggests that some friends had understood how her wellbeing occasionally depended on the need to socially withdraw. However, socially withdrawing as a way of living with ME also perpetuated adverse judgements, because the participants were not seen to be ill,

in the most literal sense. However, Lucy is positive about how ME has forced her to be more discerning in her friendships and who she chooses to entrust with knowledge of her condition.

6.6 Conclusion

It has been shown how the personal challenges of living with loneliness and ME are a part of the larger social issue of what is said to be an epidemic of loneliness (Killeen, 2002). Kirsty's extract at the beginning of the chapter affirms how ME has damaged her quality of life. The symptoms as well as the measures taken to manage and cope with the illness can also have a devastating effect on patients' wellbeing and social connectedness. The current chapter has highlighted how people with ME are especially invisible because they largely inhabit the private space of the home, where they are limited to interacting with cohabiting family and/or significant others. They are therefore neither literally nor metaphorically seen to be ill. A powerful theme running throughout this chapter was "boundedness" (Little *et al*., 1998, p. 1485), which has been described as a "persistent awareness of limits to space, empowerment and available time" (Little *et al*., 1998, p. 1485). The symptoms of ME prevented the participants from engaging in social life to the extent that they desired, limiting the spaces they inhabited and curtailing their interactions with others. However, the fluctuating nature of ME and how the condition is contested also placed a strain on the participants' relationships, with some friendships deteriorating or disappearing. The participants therefore experienced loneliness through the loss of social connections and the declining quality of existing relationships (Perlman and Peplau, 1981).

The stigma attached to loneliness and ME contributes to how they are both positioned as a private matter; they are somewhat taboo topics which can be difficult to discuss. The contribution of this chapter is that it has attempted to bring the issue of loneliness to the foreground of the sociology of health and illness by focusing upon the contested diagnosis of ME. It is considered important to explore the experiences of people who self-disclose that they are lonely because this can offer insights into how to understand, manage and mitigate against these painful experiences (Mahoney *et al*., 2019). Cacioppo *et al*. (2006) has suggested that the discomfort and pain triggered by loneliness acts as a trigger to compel us to make social connections and seek out company. However, the participants are somewhat restricted in being able to act upon the pain of loneliness. Opportunities for social interaction are often limited and finding people who will empathise with their illness can be challenging. The chapter has pointed to how the participants found themselves unable to communicate their illness experience, which extended to finding difficulties in communicating their day-to-day lives. However, feeling communicatively alienated is also caused by the reluctance of others to empathise and listen to the participants' narratives. The stigma attached to ME, evidenced by disbelief and discreditation, is likely to exacerbate the loneliness felt by people with the condition. The participants often found themselves alone in their conviction that their illness was real and that they were genuinely suffering.

The background literature (see section 6.2) to this chapter demonstrated how loneliness and social isolation have been regarded as conceptually distinct categories. However, the interview data showed how the participants regarded loneliness and social isolation as being tantamount to the same thing. Scholars have tended to view loneliness as being unwanted while social isolation bears the potentiality of being desired (Cacioppo *et al.,* 2011; Perlman and Peplau, 1981; Weiss, 1973). However, the juxtaposition of unwanted and desirable sits uneasily where social withdrawal is necessitated by illness, negativity and rejection. It is therefore tentatively proposed that loneliness and social isolation are not exclusive categories but interrelated in the specific setting of living with a contested and chronic illness, such as ME.

Covid-19 and the associated social restrictions have had an impact on the loneliness experienced by people with ME but in a positive way. Brewer and Stratton (2020) did not explicitly focus upon loneliness, but their research suggests that people with ME felt less alone because they had more opportunities for social interactions due to increasing reliance technological communications during the periods of lockdown. The finding also highlights the importance of social context because social restrictions potentially created a levelling effect, where no one was able to interact in person outside of their own household. My research has provided an exploratory study where loneliness and social isolation have been shown to be significant social consequences resulting from living with the ME. However, there is potential to explore how technologies can support patients with ME to feel better connected, more visible, and less lonely.

Chapter 7
(Un)Fashionable Illnesses or Il(legitimate) Diagnoses?

> *Nervous exhaustion is compatible with the appearance of perfect health. For this reason, as well as on account of the slippery, fleeting return of symptoms, patients of this class get but trifling sympathy.* George Beard (1880, p. 171)

7.1 Introduction

This chapter examines the history of two fatigue dominated illness - neurasthenia and the Royal Free Disease - which are potential "borderland antecedents" (Aronowitz, 1992, p. 173) to contemporary ME. By way of explanation as to how the concept "borderland antecedents" (Aronowitz, 1992, p. 173) has been applied to the current chapter, neurasthenia and the Royal Free Disease are approached not as historical clones of ME but, rather, as distant relatives which bear some of the same striking features and idiosyncrasies of ME.

This chapter acknowledges that medical knowledge is "socially conditioned, and contingent upon (but not reducible to) a specific cultural and historical context" (Lian and Bondevik, 2015, p. 921). Moreover, the chapter recognises that medical knowledge is socially constructed and interpreted by humans. It is therefore endowed with social norms and cultural values that are historically specific (Brown, 1995). Blaxter (1978) used alcoholism as a case in point for understanding diagnosis as both a category and as a process. She underlined the historical and social contingency of diagnosis, and highlighted that diagnosis warranted more sociological investigation than it had previously generated. Blaxter (1978, p. 10) suggests that a diagnosis is "a museum of past and present concepts of the nature of disease." Therefore, much as I might have identical eyes to my great grandma, ME has inherited some of the characteristics of neurasthenia and the Royal Free Disease, without being tantamount to the exact same diagnostic label.

The history of neurasthenia and the Royal Free Disease as presented in this chapter does link ME to these two other diagnoses. It does not, however, assert that the diagnosis of these disorders is the same as ME. This chapter seeks to elucidate the cultural and social framing of two fatigue dominated illnesses – neurasthenia and the Royal Free Disease – and how they have been interpreted within different historical periods.

The basis for exploring the histories of neurasthenia and the Royal Free Disease emerges from both a theoretical and an empirical imperative. Brown (1995, p. 39), a key figure within the sociology of diagnosis, suggested that we can view diagnoses as the "sociomedical archives wherein we find the history of action by all levels of the health care system". Contemporary diagnoses therefore bear the social imprints of their antecedents. Brown (1995) also believed that controversial diagnoses can illuminate how diagnostic categories emerge. ME is one such controversial illness (Rosenberg, 2002; 2006) and it will be shown in this chapter how neurasthenia and the Royal Free Disease became increasingly contested as their organicity appeared to ebb away.

For the reasons discussed above it is necessary to look to the past to see how people have historically understood illness and disease. This chapter focuses upon the diagnoses of neurasthenia (1869-1930)[25] and the Royal Free Disease (1955-1970) by drawing from research conducted at the Wellcome Trust library and archives. Both neurasthenia (Rosenberg, 1962; Wessely, 1996; Abbey and Garfinkel 1991; Ismail, 2004), and the Royal Free Disease (Ramsay, 1986) encompassed a wide range of sporadic symptoms dominated by persistent fatigue, characteristics that they share with ME. This chapter will provide an analysis detailing how neurasthenia and the Royal Free Disease have been named, understood and explained within two different historical periods. The chapter draws inspiration from the biography of diseases series published by the University of Oxford Press. Each book in the series focuses on a specific disease providing an historical narrative of the disease's life course. The books detail the emergence of contemporary classifications and practice, which further our understanding of medical practice and illness experience. The lives of neurasthenia and the Royal Free Disease are short but significant and this chapter focuses upon how they emerge and eventually dissipate from medical usage.[26]

Scholars (Richmond, 1989; Taylor, 2018) have suggested that ME and neurasthenia are fashionable illnesses or culture bound syndromes (Wessely, 1990; Abbey and Garfinkel, 1991). This chapter explores the idea of a fashionable illness and "fashionability" (Andrews and Lawlor, 2017, p. 241), but refocuses on issues of legitimacy. Diagnoses are therefore shown as being in a state of flux, rather than being stringently in or out of fashion. The chapter will demonstrate how neurasthenia and the Royal Free Disease emerge as legitimate organic illnesses and decline in credibility as they become associated with mental illness.

[25] The archival research did include 1868 and 1954 to contextualise the diagnoses (see chapter three for more information).

[26] Signalling a finite end to neurasthenia is problematic because the term neurasthenia is still used in other countries, such as China and Japan (Lutz, 2001).

The theoretical framework underpinning this chapter is largely drawn from the work of Rosenberg (1992, p. xiii), who has been influential in the concept "framing diseases". Framing offers an alternative to social constructionism, avoiding obscuring the embodiment of illness. Framing is the need to explain how a specific disease has a role "as a structuring factor in social situations, as a social actor and mediator" (Rosenberg, 1992, p. xviii). Rosenberg (1992) argues that this role as social actor is more evident when it comes to morally charged and contested diagnoses in the past, such as alcoholism, and in his later work Rosenberg (2002; 2006) suggests that ME is a contested illness. Once diseases are framed, or defined, they provide a frame which can shape identity for patients and impact on their illness experiences. Different diseases present varying opportunities to frame our sense of self and our identities at different times (Rosenberg, 1989; Rosenberg and Golden, 1992, p. xv). Aronowitz (2008, p. 1) has argued that framing offers an insight into "the ways we generally recognize, define, name, and categorize disease states and attribute them to a cause or set of causes." Exploring how neurasthenia and the Royal Free Disease have been framed offers a way to deduce how diagnoses shape the social reality of the healthy and the ill (Jutel, 2009; Jutel, 2011b).

The next section will begin by offering a brief overview of neurasthenia and how George Beard framed the nervous disorder. This will then be followed with a discussion concerning how neurasthenia came to be perceived as being fashionable, but later declined in legitimacy. Here, the gender and class nuances of the neurasthenia diagnosis are highlighted to demonstrate how a diagnosis can frame different intersections of society in varying ways. A summary of the research findings on the Royal Free Disease (1955) will then be presented, detailing its emergence and decline. The chapter suggests that as the Royal Free Disease emerged it was framed by poliomyelitis (polio) and the Royal Free Hospital outbreak was subsequently understood to be a contagious virus. However, when a retrospective analysis of mass hysteria was applied to the Royal Free Disease, its psychologisation came to affect how contemporary ME has been contested. The chapter concludes by suggesting that the allegation that ME is a fashionable illness shows continuity with how neurasthenia and the Royal Free Disease have been historically framed.

7.2 An Introduction to Neurasthenia in Victorian England

George Beard was an American neurologist, who reclaimed the term "neurasthenia" in 1869 when he published an article in the Boston Medical and Surgical Journal. In this article, Beard (1869) asserted that neurasthenia was the most neglected nervous diseases of his time. According to Bynum (2003), the neurologist van Deusen (1869) coined neurasthenia, but Beard was a fashionable New York neurologist who propelled neurasthenia to become a prevalent diagnosis. Evidence suggesting that Beard reinvigorated the term neurasthenia is found where Beard (1874, p. 3) suggests that "neurasthenia is a term that is nearly forgotten". Beard produced his clinical text in 1880 and subsequently expanded on

the aetiology of neurasthenia in his book, “American Nervousness Its Causes and Consequences: A Supplement to Nervous Exhaustion” (Beard, 1881). Within the current section of this chapter the focus is mainly on the primary texts written by Beard, which were analysed at the Wellcome Trust Library. It is necessary to concentrate on the publications of Beard because it was through his work that neurasthenia emerged as a popular diagnosis and would eventually come to be regarded as an allegedly fashionable disease (Chricton Miller, 1920).

Despite a dearth of scientific evidence, the neurasthenia diagnosis flourished in both England and the United States, while being more popular in the latter (Porter, 2001). The acceptance of neurasthenia in the United States might be explained by Beard (1881) having initially used racialised and nationalistic arguments to suggest that Americans were more developed and sophisticated than Europeans, and therefore more susceptible to neurasthenia (Veith, 1968; Haller, 1971; Luthra and Wessely, 2004). Neurasthenia brought Beard an international reputation in the late nineteenth century (Rosenberg, 1962). His ideas were based on a theory of “nervous energy” (Beard, 1880, p. 3) that is, the health and capability of the nervous system where there is a “poverty of nerve force” (Beard, 1880, p. 3). If the nervous energy was depleted or abused, the individual would experience nervous exhaustion along with its debilitating symptoms.

The Greek meaning of neurasthenia can be interpreted as lacking nerve strength (Beard, 1880). Beard (1880) wrote a long list of 46 symptoms, which were dominated by nervous exhaustion. He divided nervous exhaustion into celebrasethenia (exhaustion of the brain) and myelasthenia (exhaustion of the spinal cord). The symptoms comprised, but were not restricted to, fatigue, insomnia, headaches, vertigo and flashes in the eyes. Neurasthenia was also a multisystemic condition, which had the potential to affect any organ or function (Sicherman, 1977). The symptoms were wide-ranging and seemingly unrelated, but Beard (1880) contended that they contributed to one single disease category. A typical neurasthenic patient presented the physician with a rich variety of symptoms (Beard, 1880). A diagnosis by exclusion, neurasthenia could be established only after a thorough physical examination and an appraisal of the patient's discomfort had ruled out any other condition.

In his pamphlet, “Certain Symptoms of Nervous Exhaustion”, Beard (1878) discusses the aetiology of neurasthenia. The numerous treatments listed by Beard in the pamphlet appear to be physical and directed at the body rather than the mind. Beard (1878, p. 2) stated that, internally, he used “preparations of phosphorous, cold-liver oil, and sometimes arsenic. I made a large use of the cold liver oil emulsion” and, “Externally, I use cold and hot water bags to the spine with studious caution” (Beard 1878, p. 3). He also recommended applying electrical currents, massage, plentiful food, absolute rest and cauterizing the urethra (Beard, 1878). The eminent physician, Charles Dana (1923) recalled witnessing Beard using deep injections into the urethra, cold compounds and localised electrical currents in his

treatment of neurasthenia. Beard (1878) believed that neurasthenia could be relieved and even cured with the correct treatment. Although Beard suggested that neurasthenia was caused by mental exhaustion affecting the mind, his treatments were physical. Sicherman (1977) claims that Victorian doctors were only comfortable with organic diseases during this period. An emphasis on the organicity of neurasthenia was therefore essential in preserving the credibility of the nervous disorder. Even though neurasthenia affected the mind, Beard (1880) reinforced the organicity of neurasthenia.

While neurasthenia was a popular diagnosis on both sides of the Atlantic, the scholarship of Beard was not without criticism. Gijswijt-Hofstra (2001) and Wessely (1996) have argued that the British medical establishment were skeptical about neurasthenia. Initially, neurasthenia was thought to largely afflict cerebral men. Many physicians had considered themselves to be neurasthenics and felt offended at being labeled vulnerable (Spitzka, 1881). Despite such skepticism, neurasthenia remained a prevalent diagnosis in Britain in the late Victorian era and early Edwardian period. This section has provided an overview of Beard's conceptualisation of neurasthenia by drawing from his publications. Beard framed neurasthenia as an organic illness. This was integral to the perception of the disorder as being credible. The next section will consider how neurasthenia rose to become an allegedly fashionable illness.

7.3 The Rise and Social Significance of Neurasthenia

The legitimacy of neurasthenia was reinforced by Beard (1880) marking the seriousness of the nervous disorder. The gravity of neurasthenia was made evident by addressing the invisibility of the symptoms. Beard (1880, p. 171) claimed that:

> Nervous exhaustion is compatible with the appearance of perfect health. For this reason, as well as on account of the slippery, fleeting return of symptoms, patients of this class get but trifling sympathy.

Beard (1880, p. 171) was adamant that "nervousness is (was) a physical not a mental state", which science had not yet been able to elucidate. Beard (1878, p. 2) further claimed that the symptoms of neurasthenia were therefore:

> not imaginary but real; not trifling, but serious; although not usually dangerous. In strictness nothing in disease can be imaginary. If I bring on pain by worrying, by dwelling upon myself, that pain is as real as though it were brought on by an objective influence.

Moreover, Beard did not believe that the origin of the suffering (mental and/or physical) altered the reality of the experience, but he was aware that the invisibility of the symptoms could undermine how

neurasthenia was perceived. The insistence on neurasthenia being an organic disease therefore bolstered the legitimacy of the nervous disorder.

Whether neurasthenia was regarded as being psychological or somatic is the subject of contest amongst scholars of history. Neve (2001) has suggested that in the British context the general population interpreted neurasthenia as lying somewhere between insanity and physical disease. However, Beard's texts saw "no hint in Beard's writings of a psychological aetiology for those ailments in which there was no discernible anatomical change" (Rosenberg, 1962, p. 252-253). Beard (1880) suggested that mental exhaustion was caused by physical changes that required a physical cure and not a moral treatment or a psychological intervention. In its infancy, neurasthenia was framed by Beard (1880) as an organic nervous disorder.

Despite a lack of scientific evidence for neurasthenia, the condition appeared to flourish because it made good sense within the specific historical and cultural context. The contemporary sociologist, Stockl (2007) suggests that a diagnosis needs to make sense in order for it to be useful, and I argue that this is exemplified by neurasthenia. Beard (1884) was able to draw on popular intellectual literature to demonstrate a pathology and aetiology for nervous exhaustion. Examples included the works of Thomas Edison on electricity and Herbert Spencer and his ideas on inheritance (Beard, 1884). When Beard resurrected neurasthenia ideas based on energy were prevalent within the neurosciences and psychiatry. Bynum (2003, p. 1753) suggests that:

> At a time when notions of electricity and energy were permeating neurophysiology, neurology and psychiatry, the idea that a patient's nervous system was operating at less than an optimal setting, made good sense.

Neurasthenia was therefore framed by the intellectual and cultural repertoire available to Beard (1884), which made the condition intelligible to both patients and physicians alike. Beard's (1884) aetiology of neurasthenia was a combination of social commentary and medical theory. Beard's (1884) social observations can be seen where he suggested that neurasthenia was caused by modern society and modern technologies, which included the steam engine and the telegraph (Kim, 1994). Jutel (2009) has suggested that a diagnostic category emerges out of an individual/societal concern that elements of the illness/disease are sufficiently problematic to require medical attention. Neurasthenia became popular when a Victorian emphasis on productivity and progress meant that fatigue and a reduction in energy were especially undesirable. It might therefore be argued that Beard's (1884) conceptualisation of neurasthenia spoke to societal anxieties over the hastened development of technology and industry. In a similar vein, Rosenberg (1962) has proposed that that the pace of industriousness had provoked unease within Victorian society. There was sometrepidation regarding the harmful effects of the emerging

sciences and technologies. Rosenberg (1962, p. 259) therefore suggests that Beard's achievement lies in the recognition of the societal problems at the time and "not in the ephemeral materials out of which he fashioned his solution". The prevalence of neurasthenia partly increased because it was emblematic of broader cultural concerns, which made the diagnosis seem both logical and socially significant.

In the preface to the 1905 edition of Beard's clinical text, "A Practical Treatise on Nervous Exhaustion (Neurasthenia)", Rockwell (1905, p. 5) remarked that neurasthenia "affords to the profession a convenient refuge when perplexed at the recital of a multitude of symptoms seemingly without logical connection of adequate cause". Rockwell (1905, p. 5), also noted that "neurasthenia is now almost a household word", thereby suggesting that the condition had become commonly known by 1905. Although Rockwell (1905) was critical of whether the diagnostic label was being applied to true neurasthenics, he saw value in being able to attach a label to a perplexing combination of mysterious symptoms. Rockwell's (1905) observation resonates with Balint's (1964) suggestion that clinicians have the responsibility to organise seemingly disorganised symptoms into a disease. Rockwell (1905) acknowledged that the application of the neurasthenia label may not always be accurate or reflective of patient experience but, as a physician, he valued being able to name a group of symptoms. Consequently, the diagnostic category of neurasthenia provided a classification for a confusing and inexplicable set of symptoms which were dominated by fatigue.

Neurasthenia also became popular because it was initially associated with moral superiority and credibility, which provided sufferers with the opportunity to positively identify and frame themselves. Beard marks neurasthenia as a credible nervous disorder by differentiating it from commonly known but less well-regarded conditions, such as hypochondria and hysteria. Beard (1878) also distinguished neurasthenia from anemia, a condition that he believed would lead to hysteria. The ranking of conditions speaks to what scholars (Album and Westin 2008; Album, Johannessen, and Rasmussen, 2017) have contemporaneously referred to as a hierarchy of illness and disease. In the case of neurasthenia, the nervous disorder was elevated above hysteria, anemia, and hypochondria. Neurasthenia was initially engendered with a sense of seriousness and credibility by being clearly demarcated in this way.

It is possible to see how physicians attached judgments of character and morality to patients through the neurasthenia diagnosis. The historian Sicherman (1977) proposed that the moral superiority of the neurasthenia label conferred many of the advantages - and few of the liabilities - associated with illness, and that it was preferable to its nearest alternatives - hypochondria, hysteria, insanity, and even accusations of malingering (Sicherman, 1977). Sicherman (1977) therefore appears to be arguing that the diagnosis of neurasthenia provided a balance between obligations and benefits. In other words, neurasthenia enabled access to a form of the sick role (Parsons, 1951), which highlights the social significance of the diagnosis. Sicherman (1977) claimed that moral considerations, in addition to the

physician's empathy for particular patients, undoubtedly influenced diagnostic decisions in ambiguous cases. Patients were more likely to be diagnosed with neurasthenia if they seemed deeply concerned about their condition and eager to cooperate, whereas hysterics were accused of deception. Silas Weir Mitchell (1871) was a leading physician in neurasthenia and an examination of his publication "Wear and Tear, or, Hints for the Overworked", sees him asserting that a hysterical woman was a time waster and lazy, whereas the neurasthenic was a good sort of person. It is therefore possible that neurasthenia engendered a partial form of the sick role (Parsons, 1951), providing access to treatment if the patient met the obligations of being compliant and cooperative.

Sicherman (1977) suggests that a neurasthenia diagnosis permitted some physicians to provide an essentially psychological therapy under a somatic label. Although the therapies and treatments of neurasthenia expanded as the diagnosis became increasingly prevalent (Schuster, 2011), it is necessary to be specific about timing because during the life course of neurasthenia the treatments and diagnoses altered. Sicherman's (1977) analysis of psychological therapies contrasts with my own examination of Beard's texts, because the treatments appear to be physical. However, it is possible that the treatment of neurasthenia "helped physicians to justify a traditional role of bedside medicine, threatened by the one-sided emphasis on science of providing advice and comfort to patients and their families" (Sicherman, 1977, p. 10). Support for this assertion can be found where Rockwell (1905, p. 5) notes that the neurasthenia diagnosis was "often as satisfactory to the patient as it is easy to the physician". The functionality of the neurasthenia diagnosis has been corroborated by Taylor's research (2018, p. 554) which found that despite medical skepticism about neurasthenia, the diagnosis was a "useful and pragmatic description of a large number of the patients who sought their (clinicians') advice". In its infancy, the neurasthenia diagnosis was able to navigate a delicate balance between maintaining the epistemic authority of medicine while incorporating the subjective experience of the patient.

A further function of the neurasthenia diagnosis can be seen when the diagnosis prevented affluent patients from being confined to an asylum. Given the religious and moral significance placed on health in Victorian societies, upper-class members of society had a keen interest in the symbolic meaning of illness, and they had the resources to influence how illnesses and diagnoses were framed (Porter, 2001). Evidence of the face-saving nature of the neurasthenia diagnosis can found in the experiences of the practicing physician Thomas Dixon Savill (1899). He claimed that when he gave a diagnosis of cerebral neurasthenia and neurasthenic insanity, patients avoided being removed to an asylum. Savill (1899, p. 160) wrote that in asylums, "as a rule nothing is done to diagnose or treat any obscure bodily ailment on which the mental condition may depend". Savill (1899) appeared to use the neurasthenia diagnosis as a way of determining the treatment pathway, particularly when he believed that patients could benefit from not being institutionalised. Vijselaar (2001) provides a contemporary analysis, suggesting that the diagnostic label of neurasthenia preserved the reputation of patients, preventing more affluent clientele

from the stigma of being diagnosed with insanity, and thereby confined to an asylum. This suggests that neurasthenia was a diagnosis serving to "obviate the stigma of psychiatric illness" (Porter 2001, p. 42). Vijselaar (2001) and Campbell (2007) indicate how there was a social value in the face-saving aspect of neurasthenia.

7.4 Neurasthenia: An (Un)Fashionable Illness?

The previous section showed how, immediately following the publication of George Beard's (1880) book, "A Practical Treatise on Nervous Exhaustion", neurasthenia was associated with moral superiority. To be labelled as a neurasthenic was a badge of merit and honour for middle to upper class gentlemen (Porter, 2001), even though Beard (1880) had maintained that neurasthenia could affect men and women. During its infancy neurasthenia was "commoner among men than women…consequences of the more active and more militant part played by men in the struggle for existence" (Ballet, 1908, p. 10). Ballet (1908) was a practicing physician, who contrasted man's hardworking nature with the vanities of women, whom he alleged had become fatigued with society life and being idle. Ballet (1908, p. 73) explained that men developed neurasthenia from being too "cerebral", while women had "mental enfeeblement" (Ballet, 1908, p. 73).

The emphasis on the greater societal pressures for men was echoed by the President of the Neurological Society, Seymour Sharkey (1904, p. 19) who voiced the widespread belief that neurasthenia was "more common in men than in women; as the mental and physical strains which men have to bear are greater than those which befall the opposite sex". During the late nineteenth century hypotheses regarding the causes of neurasthenia in women included over-education and involvement in business overexerting their mental powers. Retrospective analyses suggest that neurasthenia helped to keep women in their societal roles of the dutiful wife and mother at a time when women's rights were gaining in momentum and threatening the status quo (Lutz, 2001; Lian and Bondevik, 2015; Appignanesi, 2007). Showalter (1985) has argued that neurasthenia was women's response to leading unfulfilling and restricted lives. The suppressiveness of the neurasthenia diagnosis is potentially evident in the emphasis on mental weakness amongst female neurasthenics when compared to their exhausted, yet overly cerebral, male counterparts.

Neurasthenia was consequently endowed with a strong sense of masculinity, which made it a symbol of respectability amongst the male upper-classes and intellectual elites (Porter, 2001). Lawlor (2017, p. 364) argues that:

> A masculine will became seen as necessary for the efficient functioning of industry and commerce, and the concept of will would only become more significant both medically and socially as the century (nineteenth) wore on, the end result being the creation of neurasthenia.

The masculine framing of neurasthenia can be seen where a leading figure in neurasthenia, Silas Weir Mitchell (1877), asserted that men developed neurasthenia from overwork, competition, and economic acquisitiveness. Mitchell (1877) contrastingly proposed that women became neurasthenic from nursing sick family members, immoderate study during hormonal fluctuations, and excessive socializing. Further to this, the female neurasthenic was purportedly "self-pampering, self-concerned and prone to exaggeration." (Mitchell, 1877, p. 4751). However, when compared to a patient with hysteria, Mitchell (1884) believed that a hysterical woman was a time waster and lazy whereas the neurasthenic was a good sort of person, thereby ascribing a higher moral standing to the neurasthenic patient. Consequently, a moral judgment was incorporated into the neurasthenia diagnosis, which was especially salient for female patients (Appignanesi, 2007). Mitchell's assertions regarding character and morality also demonstrate divisive ideas about gender differences in illness behaviours. There is a sense of ridiculousness and flippancy regarding female neurasthenia when compared to the serious work ethic and intellectualism associated with male neurasthenia.

Mitchell (1877, p. 9) explained how he designed the famous rest cure for "women of the class well known to every physician - nervous women, who as a rule are thin, and lack blood". Such women were Mitchell's key patients during the second half of the nineteenth century, when willowy figures and pale complexions were the fashion of upper-class women (Sicherman, 1977). In "The Autobiography of a Neurasthene: As Told By One Of Them" (1910), Margaret Abigail Cleaves, a female doctor afflicted with neurasthenia, was keen to carve a distinction between an afflicted female malady of being idle and self-indulgent with the truer neurasthenic who was hardworking, cerebral and male. Cleaves (1910) had experience of treating neurasthenics with electrotherapy and her eminent professional standing as a female physician was rare for the time. She proposed that women rarely exhibited the truest and most severe form of exhaustion, such as that experienced by herself and male neurasthenics (Cleaves, 1910). This shows how she viewed men as being more credible neurasthenic patients than their fashionable female counterparts.

The issue of gender is particularly poignant in the rest cure treatment for neurasthenia, devised by Mitchell (1877). The rest cure was prescribed almost exclusively for women, and it included constant social isolation, bed rest and incessant feeding, sometimes for months on end.[27] Mitchell (1878, p. 36)

[27] The rest cure treatment was adopted by William Smout Playfair in 1892. Smout Playfair was a London obstetrician, which shows that the treatment was used on both sides of the Atlantic (Gijswijt-Hofstra, 2001).

placed strict limits on “brain work”, which he felt imposed nervous strain and might interfere with “womanly duties” (Mitchell, 1878, p. 36). He was in the patriarchal role of male doctor to his predominantly female patients, from whom he expected absolute obedience. Mitchell (1878) remarked on the difficulties in treating male patients who were less keen to submit to him than his female patients. He therefore relied on the prevailing gender roles in his rest cure treatment, by requiring his predominantly female clientele to submit to his treatment regime. The women were expected to meet the obligations of the sick role (Parsons, 1951) by trying to get better and acquiesce to medical care in exchange for being exempt from their normal social duties and blame. Even though Weir’s upper-class wealthy female clientele did not usually work, they were still exempted from their usual daily responsibilities as they were “unable to attend to the duties of life” (Mitchell, 1884, p. 9).

Although an exemption from normal social responsibilities might be viewed positively where it is necessary to facilitate a recovery, the rest cure also ensured a harmful conformity to the prevailing gender roles. Mitchell (1878, p. 36) believed that women were risking nervous collapse with their eagerness to take on new roles unsuited to their gender, including higher education or the political activities of “city-bred” women. How the intersections of class and gender framed the identities of the patients is difficult to fully ascertain because most of the archived documents were written by doctors, although some doctors were also neurasthenics. However, in the fictional account, “The Yellow Wallpaper” (1892) Charlotte Perkins Gilman drew from her personal experience of Mitchell’s rest cure. In “The Yellow Wallpaper” (1892), a young woman becomes increasingly mentally ill, as she endures no stimulation and months of solitude. Later, in “Why I (she) wrote the Yellow Wallpaper” (1913), Gilman explained that the rest cure brought her to the edge of sanity and she had chosen to resume writing although Mitchell had forbidden it. Gilman (1892; 1913) presented a darker narrative of neurasthenia to the one of female frivolity and fashion that was so often portrayed in the literature from the time (Appignanesi, 2007). In the confrontation between Weir Mitchell and Charlotte Perkins Gilman (1892; 1913), it is possible to see a nineteenth century microcosm of the tension between medical authority and patient experience.

Part of the early success of neurasthenia was demonstrably derived from an association with a refined character, something which was only available to the upper classes. Sicherman (1977) claimed that moral considerations, in addition to the physician's empathy for particular patients, undoubtedly influenced diagnostic decisions in ambiguous cases. Whereas neurasthenics seemed deeply concerned about their condition and eager to cooperate, hysterics were accused of deception (Sicherman, 1977). It can therefore be seen how subjective judgments about gender and class infiltrated clinical decisions, affecting the patients’ prognosis and treatment. Stereotypes appeared to play a key role, throughout the nineteenth century, in the extent to which the patient was likely to be viewed as culpable in developing illness and disease.

Beard's rationale for neurasthenia was based on the supposition that the educated and wealthy enjoyed their position in the social order by virtue of their more sensitive nervousness. It was this sensitivity, which made them susceptible to neurasthenia, that made the condition both a blessing and burden. In the latter half of the nineteenth century the labouring classes were, according to Beard, not sensitive or intellectual enough to warrant a neurasthenia diagnosis (Porter, 2001). The class status of patients with neurasthenia in England is depicted by Harrison (1913) in a cartoon from within the Wellcome Trust archives. It depicts a common cold asking a father for his daughter's hand in marriage (see appendix G) but the common cold is refused because of the social class gap. However, the cartoon is satirical in the way that it points to the modishness of neurasthenia making the legitimacy of neurasthenia questionable. Lawlor, (2017) has suggested that accusations of fakery have been attached to certain fashionable diseases, such as headache and hypochondria, and these narratives of satire and stigma have had serious but variable consequences for some groups of sufferers. Schuster (2011) argued that Beard and Mitchell consciously used neurasthenia to cultivate a community of middle and upper-class patients who could pay for their services and lend the diagnosis a degree of elitism. However, it was also this class-based exclusivity that made neurasthenia a soft target for mockery.

Schuster (2011) has suggested that the class, ethnic and gender boundaries which were propagated by Beard and Mitchell became loosened as more stakeholders in the illness emerged. By the mid-1880s the public discussion of neurasthenia had expanded, with marketers and writers making use of the neurasthenia diagnosis in their advertisements and stories (Schuster, 2011). The meaning of neurasthenia broadened and become popularised, thereby expanding the commercial market for neurasthenia (Schuster, 2011). Aspers (2010) suggests that access to fashionable items must be restricted to protect the identity of the firm or brand. It is possible to liken neurasthenia to a limited designer garment being copied and then sold in a fake/cheaper form to the mass market, such as in the case of Burberry, whose brand suffered because it became too accessible (Power and Hauge, 2008). This commodification of neurasthenia potentially transformed more patients into consumers of neurasthenia, which conversely made neurasthenia less exclusive and less desirable.

7.5 Neurasthenia: A "Fashionable" Illness Ebbs in Legitimacy

The previous section touched upon the eventual demise of the nervous disorder, neurasthenia. However, the current section explores the contributing factors which potentially led to neurasthenia declining from being a prodigious illness. It shows how the organicity of neurasthenia was undermined and how the nervous disorder became associated with mental illness. Within this chapter it has previously been argued that neurasthenia became prevalent because the diagnosis was able to explain a wide range of symptoms in multiple patients. However, this lack of precision also potentially contributed to the demise

of neurasthenia, leading to it being referred to as medicine's "dumping ground" (Skottowe, 1930, p. 106). As early as 1886 neurasthenia was criticised as being a "mob of incoherent symptoms borrowed from the most diverse disorder"(Clark, 1886, p. 23), with skepticism seemingly increasing as the nervous disorder became more fashionable. However, a lack of specificity also raised questions over the credibility of the illness. The diagnostic label of neurasthenia became progressively less useful as it encompassed too much and explained little. In failing to be explanatory or useful, the social functions attributed to neurasthenia wavered.

With the treatments and explanations of the disorder becoming increasingly invalidated and outdated, the structuring and explanatory function of the neurasthenia label continued to wane. Part of the social value of neurasthenia had been based on enabling physicians to explain a complex array of confusing symptoms. Doctors make sense of seemingly disorganised symptoms and reinterpret them to form an organised diagnosis (Balint, 1964). However, as the explanatory function ebbed, the neurasthenia diagnosis was no longer useful to physicians because the label could no longer rearrange illness into a coherent disease. Furthermore, during its infancy neurasthenia had held social value for patients for whom the diagnosis circumvented the stigma of mental illness. Patients had been able to secure the benefits of a diagnosis (sympathy, legitimation, treatment and care) without facing stigma and negativity. Yet, as neurasthenia ebbed in medical and social credibility, the label increasingly became a social burden.

The pluralisation of medical specialties evolving in the early Edwardian era meant that each branch of medicine understood neurasthenia through its own specific lens. Surgeons, for instance, understood neurasthenia to be the result of sick organs that needed to be removed; while psychiatrists interpreted the condition as the result of an imbalanced psyche (Campbell, 2007). A diagnosis can structure relationships within the medical profession, defining who should assume responsibility for particular disorders (Rosenberg, 2002). As medical knowledge developed, focus was diverted toward other conditions not yet commonly understood, reducing patients' ability to partake in the diagnostic process (Campbell, 2007).

The diagnostic process of neurasthenia had also altered from being one which was governed by clinicians to one including apothecaries and quacks (Schuster, 2011). Schuster (2011) pointed to how the diagnostic process of neurasthenia allowed physicians, patients, and popular culture to share authority over the disease. Freidson's (1970) work on the professional dominance of medicine focused on the pivotal role of diagnosis in reinforcing the medical authority of clinicians. An ability to construct a medical diagnosis from a complaint and physical or biological findings sets the doctor apart from the lay person and other professionals, confirming the medical practitioner's greater knowledge and status, as well as medicine's authority (Freidson, 1970). Consequently, it is possible to see how neurasthenia

became an embarrassment to growing medical professionalism through lay encroachment on medical authority and knowledge.

Neurasthenia also appeared to ebb in popularity as it became increasingly associated with mental disorder. Sicherman (1977) claimed that neurasthenia lost ground in the first two decades of the twentieth century because of improved diagnostic testing and an increased awareness of illness of psychological origin. As psychiatry gained in momentum, neurasthenia gradually became part of the broader diagnostic category of neurosis and its ties to neurology were severed (Gosling, 1987). Neurological disorders such as epilepsy, dementia, multiple sclerosis and Parkinson's disease had a proven anatomical basis in the nervous system or brain (Sicherman, 1977). Sengoopta (2001) suggested that as neurologists became more interested in the organic diseases effected by structural lesions of the brain, by the 1920s neurasthenia became a psychiatric concern rather than a physical one. Wessely (1996) has argued that the decline of neurasthenia was due to the growth of psychiatry and Beard's aetiology of neurasthenia being falsified. In a similar line of argument, Richmond (1989) proposed that once neurasthenia, melancholy and brain fever lost their organic bases, they morphed into new diagnoses to become illnesses of the mind. Evidence of this can be found as early as 1904, when a leading doctor questioned whether neurasthenia was an organic illness. Professor Dana (1904, p. 1220) states:

> A large number of these so-called neurasthenics and all the hysterics should be classed as prodromal stages or abortive types-a shadowy imitation of the greater psychosis insanity. Invented by Beard of America in the "sixties" to describe and to include a class of nervous affections more common in America than elsewhere, the term neurasthenia has been used with great elasticity since then to cover a multitude of obscure nervous affections of the most varied and opposing characters, to the great confusion of exact diagnosis and of scientific treatment.

According to this narrative, neurasthenia was an "invented" illness with "so-called" patients, indicating that the nervous disorder was transforming from being perceived as an organic illness to one that was caused by "insanity" rather than the nervous system (Dana, 1904, p. 1220). Dana (1904) regarded the neurasthenia diagnosis to be a random amalgamation of physical illnesses and mental disorders. Once neurasthenia lost credibility for being based on a false neurophysiology, patients were subjected to disapproval and neurasthenics became stigmatised as lazy liars (Wessely, 1996). After the somatic explanation for neurasthenia was disproven, a vacuum remained in which the legitimacy of neurasthenia was contested, and the morality/credibility of the patients became questionable. The arguments for the

demise of neurasthenia largely point to how the condition lost its social and explanatory value,[28] Neurasthenia became a medical misnomer in England by the 1930s, but a similar set of symptoms re-emerged in the Royal Free Disease outbreak in 1955.

7.6 The Royal Free Disease Epidemic

The Royal Free epidemic began in the Royal Free Hospital on 13th July 1955 when a ward sister and a doctor were first admitted as patients. In order to prevent the epidemic spreading the Royal Free Hospital closed until 5th October 1955 (Ramsay, 1986), which demonstrates the seriousness and concern with which the Royal Free Disease was viewed. At the peak of the epidemic, 292 members of medical, nursing, auxiliary medical, ancillary and administrative staff were affected and 255 of them were admitted to the hospital's Infectious Disease Unit for in-patient treatment (Medical Staff at Royal Free Hospital, 1957). A further 37 nurses were either looked after at home or in a hospital local to where they were living (Medical Staff at Royal Free Hospital, 1957). The Medical Staff at the Royal Free Hospital (1957) who witnessed the outbreak in 1955 commented on how they were convinced that the Royal Free Disease was an organic disease. Extensive investigations, which were conducted in the hospital, failed to reveal an aetiological agent of an infective nature (Ramsay, 1957). A toxic cause for the condition was investigated but no positive results were found (Compston, 1978). There were, however, some objective but inconclusive findings such as fever, lymphadenopathy, cranial palsies and abnormal signs in the limbs (Ramsay and O'Sullivan 1956).

Dr Melvin Ramsay was a leading epidemiologist who headed a research team at the Royal Free Infectious Diseases Unit in 1955 and he attempted to search for an aetiological agent. Ramsay (1957, p. 1199) described how the Royal Free Disease mimicked polio and hysteria, yet he regarded it "a grave injustice to diagnose hysteria in these cases without recognising that the condition is organically determined". Ramsay (1957, p. 1196) detailed that the symptoms were:

> Many and varied, headache being the most constant and giddiness (in most cases a true rotational vertigo) the most striking. Pains in the limbs, pains in the neck, pains in the back and chest, shivering and rigors. Paraesthesise, anorexia, nausea and even severe vomiting, pains in the ears, tinnitus, visual disturbances (usually diplopia), and muscle cramps and twitchings all occur.

[28] Neurasthenia survives today in a China (where it was introduced in the 1920s) (Kleinman 1982) and Japan (Schwartz, 2002) but it exists without the stigma of a psychiatric diagnosis (Schwartz, 2002).

The seemingly unrelated and extensive list of symptoms evokes Beard's description of neurasthenia, as does the insistence on the disease being somatic. There is a clear foundation for arguing that in the infancy of the Royal Free Disease those charged with investigating the outbreak were aligned with an organic explanation for the illness.

Three of the patients with Royal Free Disease did not recover and their condition became chronic. Eventually a persistent form of Royal Free Disease was described and became an exemplar of benign myalgic encephalomyelitis, which would be known as myalgic encephalomyelitis. The Royal Free Disease was deemed typical of a global pattern of outbreaks in terms of the reported symptoms, unknown aetiology and the high ratio of women effected by the illness (Acheson, 1957). It was believed that a new clinical entity had appeared. Acheson (1957) suggested that benign myalgic encephalitis was a sufficient name for British doctors to use to describe the disease and so benign myalgic encephalitis was conceived. This highlights the process by which ME became first described in medical terms.

7.7 A Retrospective Psychiatric Explanation for the Royal Free Disease

As early as 1965, there were accusations of the Royal Free Disease having been psychosomatic/psychological when the medical correspondent for The Sunday Times, Dr Alfred Byrne (1965), alleged mass hysteria amongst the nurses at the Royal Free Hospital (Ramsay 1965). However, the somatic basis for the outbreak at the Royal Free Hospital was more significantly undermined in 1970 when two psychiatrists, McEvedy and Beard (1970a; 1970b), mounted retrospective accusations of mass hysteria. McEvedy and Beard (1970a; 1970b) published two articles, entitled 'Royal Free Epidemic of 1955: A Reconsideration' and 'Concept of Benign Myalgic Encephalomyelitis', which brought the Royal Free hospital epidemic back into the medical and lay media headlines.

McEvedy and Beard (1970a; 1970b), argued that hysteria was more common amongst females. They supported this argument with McEvedy's previous work on over-breathing in schoolgirls. Moss and McEvedy (1966) had made the claim that the girls' over-breathing was the result of living together in the close single sex confines of a boarding school. McEvedy and Beard (1970b) supported their theory on mass hysteria through the "Concept of Benign Myalgic Encephalomyelitis", detailing how fifteen further outbreaks were overrepresented by female hospital staff. They suggest that in the Middlesex Hospital outbreak of 1953, the illness had also been believed to be polio. At the Middlesex Hospital, 14 nurses and 8 lay people were admitted to Princess Alice isolation ward over a ten-week period. McEvedy and Beard (1970b) suggested that this action was the result of increased medical vigilance due to polio. However, they alleged that the outbreak had been hysteria, due to the pattern of the effected hospitals having a high number of female staff under the age of 30. The fear of polio had framed the organic explanation for the Royal Free Disease outbreak, but that same fear was later being used to

support psychological explanations for the epidemic. The psychiatrists suggests that the Royal Free Disease "seems to us to have been an uncontaminated example of mass hysteria" (McEvedy and Beard, 1970b, p. 14).

Dr Melvin Ramsay responded by accusing the psychiatrists of being selective in the cases they had chosen from the Royal Free saga, thereby skewing their conclusions (Ramsay *et al*, 1978). Ramsay (1957; 1966) and his team had already ruled out psychiatric illness by stating that there was no abnormality. The psychiatrists had analysed the patient case notes and used the contact details of the patients to distribute a questionnaire assessing their levels of neuroticism. The ethics of their research were questionable because the hospital had provided the case notes without fully informed consent due to McEvedy (the lead researcher) failing to make his intentions clear from the outset. Debates over the nature of the Royal Free Disease continue. A recent study by Underhill and Baillod (2020) conducted interviews with former Royal Free Hospital staff who had been infected by the disease. Underhill and Baillod (2020) concluded that the epidemic was organic and psychogenic epidemic hysteria.

The portrayal of women with hysteria can be traced as far back as the Egyptians and Greeks, who believed that the wandering womb could travel around the body and disrupt its functioning, causing any symptoms, both mental and physical (Appignanesi, 2007; Showalter, 1998; Richmond, 1989). Until the last half of twentieth century there was little disagreement that hysteria was a disease that had characteristic symptoms and an underlying identifiable cause (Appignanesi, 2007). However, in the latter half of the twentieth century there was debate about whether hysteria could be regarded as a medically defined disease or if it was a socially constructed affliction – either a reaction to the social pressures of the world or a product of cultural stereotypes about women contained in medical knowledge (Hustevdt, 2011). The term hysterical has become pejorative as it dismisses patient experiences of suffering (Hustvedt, 2011). The nurses involved in the Royal Free Hospital Disease outbreak wrote a response to the British Medical Journal voicing their feelings of betrayal by the research. McEvedy and Beard (1970a; 1970b) had undermined the professionalism of nurses by suggesting that they could be affected by mass hysteria. The nurses felt their experiences were delegitimated both as patients and healthcare professionals and the breakdown in trust impacted on their willingness to respond to follow-up work on ME (Hyde and Bergmann, 1988).

McEvedy and Beard's (1970a; 1970b) theory of mass hysteria at the Royal Free hospital largely hinged on the basis that it had mostly been female staff members affected by outbreak. However, they failed to substantiate why women in particular were allegedly more likely to succumb to mass hysteria. In the foreword of Dr Melvin Ramsay's book which detailed the Royal Free Disease outbreak, Dr Behan (Consultant Neurologist at Glasgow University) mentions the word hysterical twice. He indicates that clinicians are trained to believe that no physical sign of disease means that the ME sufferer is

disregarded as having hysteria. Moreover, the "professional vision" (Goodwin, 1994, p. 606) of clinicians impacts on how ME is medically framed. Dr Behan further suggests that, although ME had recently been dismissed as a purely hysterical illness, he expected that ME would prove to be a new type of disease.

McEvedy and Beard's (1970a; 1970b) retrospective analyses of the Royal Free Disease had a profound effect on the interpretation of ME for nearly 50 years, as the condition became associated with being psychosomatic (Waters *et al.*, 2020). Conversely, once McEvedy and Beard (1970a; 1970b) had published their findings of hysteria, the advocacy behind ME also appeared to grow in momentum. In 1978 there was an ME symposium held by the Royal Society of Medicine and the meeting records[29] show that the two psychiatrists were not present. The CIBA symposium was established to discuss what was to be done about what the notes refer to as benign ME. The notes from the symposium state that Ramsay called for the benign part of the name to be dropped because of the devastating impact that the illness could have on patients. The lived experience of ME was therefore incorporated into the diagnostic label.

The significance and long-term effects of the psychologising of ME can be seen in a questionnaire from 1976 (see appendix C), which was found within the Wellcome Trust archives. The questionnaire was written and circulated by the Patients Association because they had identified how patients with ME were being told that their illness was in their minds. The minutes from the Patients Association meeting also state the intention of the Patients Association to distribute the questionnaire to those who had been affected by the Royal Free Disease in 1955. It is therefore possible to see another direct link between ME and the Royal Free Disease. Although the results of the questionnaire are under embargo until 2078, the questionnaire and meeting minutes were available in the Wellcome Trust archives. The questionnaire was used to inform my own interview schedule (see appendix B) and this provides continuity between the historical and contemporary elements of the thesis. The meeting minutes, which briefly discuss the questionnaire results, suggest that the patients had experienced their symptoms being dismissed as psychosomatic. The committee also point to the need for more scientific inquiry and treatments which are evidence-based rather than hearsay.

[29] The minutes are held in the Wellcome Trust archives. The notes contain an attendance list and the psychiatrists, McEvedy and Beard, were not present.

7.8 Conclusion

This chapter has provided biographies for both neurasthenia and the Royal Free Disease. By demonstrating how fatigue diagnoses have been framed historically, the chapter has attempted to offer a deeper understanding of how diagnoses are underpinned by social and cultural beliefs. Therefore, one of the key arguments of this chapter is that the popularity of neurasthenia was partly owed to its functional role and social significance. During its infancy the neurasthenia diagnosis had a functional role in the way that it enabled doctors and patients to address a range of perplexing symptoms which were underpinned by fatigue. From a contemporary perspective, the nervous disorder gave patients access to the sick role (Parsons, 1951), while preventing them from being stigmatised. For men in particular, the nervous disorder signified intellectualism elitism and a strong work ethic. The diagnosis also managed to navigate the epistemic privilege and authority of clinicians while validating and treating the suffering of individuals. Not only did neurasthenia attend to individual concerns but it was emblematic of wider social and cultural concerns, such as the speed of development and risks of new technologies. This is not to argue that neurasthenia is purely an intellectual construct. However, it can be suggested that the popularity of neurasthenia was owed to the disorder being framed as an intelligible, useful, and explanatory disease. Moreover, the "use of diagnosis and diagnostic labels infuses understandings of health, illness, disease, and social behaviour." (Jutel, 2019, p. 21).

The biography of the Royal Free Disease provided evidence to support the argument that the Royal Free was understood within the context of the fear and prevalence of polio. The epidemic in the Royal Free Hospital in 1955 was therefore framed being an organic, contagious, and serious condition. The discussion then turns to 1971, when the Royal Free Disease was retrospectively explained through mass hysteria by two psychiatrists, McEvedy and Beard (1970a; 1970b). The chapter has made direct links to contemporary ME and it has shown how the name evolved from being called the Royal Free Disease in 1955. However, psychogenic explanations have since lingered over ME and the nature of the condition remains contested.

One of the contributions of this chapter is how it shows the fluidity and fragility of diagnosis. Both neurasthenia and the Royal Free Disease emerged as organic diseases which legitimate the symptoms and suffering of the effected individuals. However, as those historical antecedents to ME ebb away, they become associated with mental illness and illegitimacy. The diagnoses gave differing opportunities for individuals to self-frame, interpret and present themselves. This is particularly salient in the case of neurasthenia, which was framed as being fashionable. The chapter has explored the issues of legitimacy and fashion with particular attention paid to gender and class. My findings broadly support some of Lian and Bondevik's (2015) findings from their research on 1970s ME and Victorian neurasthenia. They found that neurasthenia morphed from being a male-connoting high-status condition, to a female-

connoting low-status condition. In a similar way this chapter has shown how neurasthenia framed differing people in differing ways across its life course. In the early years of neurasthenia the condition was associated with men and it was popular. However, when neurasthenia was linked to women the nervous disorder became fashionable. A fashionable illness is not always the same as a legitimated condition. Without denying the physical and mental realities of neurasthenia, I claim that the understandings and explanations of neurasthenia were largely of a social-cultural nature and that they were frequently understood in gender and class specific terms (Rosenberg and Golden, 1992). Diagnoses are therefore socially and culturally contingent with variable consequences for particular groups of sufferers/patients.

Previous scholars have suggested that ME is a cultural illness, a fashionable illness or a post-modern phenomenon (Morris, 2000; Richmond, 1989; Showalter, 1998). Richmond (1989) queried whether ME will meet the same fate as neurasthenia and eventually fall out of fashion. The implication that ME is fashionable is a social imprint inherited from neurasthenia and the Royal Free Disease. The link between fashion and neurasthenia is more obvious but there are subtle commonalities with the Royal Free Disease, where the outbreak was explained by mass hysteria amongst female staff. Mass hysteria and fashion share the characteristic of being influenced by others or following a trend and they can also indicate a lack of agency and individuality.

Women's relationship to fashion and hysteria have historically had the ability to destabilise identity and morality (Lawlor, 2017). In the case of neurasthenia, the nervous disorder affected the apparently fragile minds of women. In a similar way, the alleged mass hysteria amongst female staff at the Royal Free Hospital pointed to an innate mental weakness amongst women. The pathologisation of femininity through psychiatric nosology has a long history, which is irrevocably tied to what it means to be a woman at a particular point in history (Ussher, 2013). Both, neurasthenia and the Royal Free Disease were marked with pathologised femininity, whether that was in the form excess of emotions, weakness, conforming to fashion or being affected by mass hysteria.

Conceptualising diseases and illnesses as fashionable or modish can signify a perverse form of popularity with superficial connotations of being contrived. To be in vogue, is also suggestive of an illness having been stringently either "in" or "out" of favour (Gilman 2010, p. 12), but diagnoses are more complex than the term "fashionability" (Andrews and Lawlor, 2017, p. 241) allows for. The framings of neurasthenia and the Royal Free Disease captured broader cultural and social concerns, rather than being what Abbey and Garfinkel (1991, p. 1638) refer to as "culturally sanctioned illnesses". Support for the conditions being emblematic of societal anxieties can be found in the aetiology of Beard's conceptualisation of neurasthenia, which reflected anxieties over the speed of development and industry. In the case of the Royal Free Disease, concern over polio outbreaks framed the emergence of

the Royal Free Disease and the search for an aetiological agent. This is not to say that the diagnoses were caused or created by social anxieties, but rather that the diagnoses were understood through societal concerns.

Therefore, in a broader sense this research of fatigue dominated diagnoses reflects how "medicine is part of general culture and the general culture is shaped by medicine" (Gilman 2010, p. 23). By focusing upon two fatigue dominated illnesses, neurasthenia and The Royal Free Disease, this chapter has demonstrated how the emergence of diagnostic labels frame social and cultural values and vice-versa. This is not to say that diagnoses are purely intellectual constructs, but rather that diagnostic categories are historically located and culturally specific, while being fluid and unfixed. As the organicity of neurasthenia and the Royal Free Disease appear to ebb, so did the legitimacy of the conditions, creating a vacuum for alternative explanations. We can see how "the less knowledge we have, the larger the space for the cultural imprint becomes" (Lian and Bondevik, 2015, p. 920). The space therefore provides room for psychological, moral and social inscriptions.

While this chapter has sought to offer an analysis into the framings of historical fatigue dominated illnesses, the next chapter concludes the overall thesis and it will offer a critical analysis on how historical understandings of neurasthenia and the Royal Free Disease affect how people experience contemporary ME. The thesis conclusion will therefore consider how there are evident continuities between historical diagnoses underpinned by fatigue and the interview participants' contemporary experiences of ME.

Chapter 8
Conclusion
Developing An Understanding of a Contested Diagnosis

8.1 Introduction

The thesis has contributed to the sociology of diagnosis through a cultural and social exploration of the ME diagnosis. It does so both historically and contemporaneously combining semi-structured interviews with historical archival research, employing a methodological approach that is under-utilised in the sociology of diagnosis. Through analysing the histories of neurasthenia and the Royal Free Disease, the thesis has contributed to the sociology of health and illness by showing how diagnoses can gain and lose prominence. The contemporary interviews highlighted how the diagnostic process of ME is psychologised. Exploring historical fatigue dominated illnesses has contributed to a deepened understanding of how ME has become associated with psychological causes. The research has demonstrated the significance of the ME label, highlighting how it is viewed as the best possible shorthand for a confusing and contested illness. In doing so it adds to current approaches in the sociology of health and illness by showing how labelling multiple unexplained symptoms with a diagnosis has a functional value, even when a diagnosis is not particularly explanatory. This research also contributes the novel concept of necessitated loneliness to the sociology of health and illness. Extant research on loneliness has often focussed upon how loneliness impacts on our health but this research has shown how our sense of loneliness is affected by chronic illness and disability. Necessitated loneliness is neither sought-after nor unwanted, but it is an integral part of living with ME. Accordingly, one of the key contributions of the thesis is that necessitated loneliness challenges the way in which loneliness is conceptualised as being negative, while social isolation bears the potential to be desirable.

This thesis originated from a realisation, during my own search for a diagnosis, that labels do matter. After a misdiagnosis of ME, I was relabelled with a more biomedically recognised disease. Same symptoms, same person, but a different label. From a personal perspective, I experienced how diagnosis can affect our self-identity, health trajectory, and relationships. While personal experience initiated my research journey, a review of the substantive literature revealed that the clinical diagnosis of ME as a specific focus had not yet been sociologically explored. Further, ME has not previously been conceptually investigated through a framework underpinned by the sociology of diagnosis. The

literature pointed to how ME is a contested condition, and this thesis demonstrates how the diagnosis is especially contested. The ME diagnosis poses significant challenges and social consequences for those negotiating living with ME. The academic rationale for exploring the diagnosis of ME consisted of the following three main points:

- Firstly, ME and diagnosis were both understudied areas within sociology. The sociology of diagnosis is now a prominent field within sociology but contributing literature has been more sparse in recent years.
- Secondly, ME is a contested illness where there are tensions between the patient and clinicians' perspective on the condition. Moreover, ME is an illness, "you have fight to get" (Dumit, 2006, p. 579) and the diagnosis involves a process which is often fraught with tension. There is much that is unknown about ME, including the pathology, prevalence, and aetiology.[30] There are multiple explanations and theories about the cause of ME, but it was unclear how patients interpret the illness. Brown (1995, p. 39) who originally called for a sociology of diagnosis, suggested that contested illnesses are fruitful areas of study because they provide an insight into some of the most "pressing issues of power in medical diagnosis".
- Thirdly, Looper and Kirmayer (2004) found that ME was more psychologised and stigmatised than other contested illnesses. Looper and Kirmayer (2004) proposed that ME is more stigmatised because the cause of ME is unknown and attributed to emotional disorders. Yet, why should ME be more stigmatised and associated with mental illness than other biomedically unexplained contested illnesses?

One of the key contributions of my research is its use of an underused methodology. The methodology uses two different qualitative methods and datasets. 42 in-depth and semi-structured qualitative interviews were conducted with people who had been clinically diagnosed with ME. Alongside the interviews, an archival analysis was undertaken at the Wellcome Trust and the Metropolitan Archives in London. The archival research explored the history of neurasthenia and the Royal Free Disease, which are what Aronowitz (1992, p. 173) refers to as "borderland antecedents" to ME. Uniting the two methods was a questionnaire from 1976 (see appendix C) which was uncovered in the Wellcome Trust archives. By using the questionnaire to inform the interview guide (see appendix B), I was able to ask some of the same questions that had concerned researchers from the Patients' Association who had investigated what they referred to as the Royal Free Disease/Icelandic Disease/Myalgic Encephalomyeltitis. This study offers more than a contemporaneous snapshot of social life by asking what continuities exist between the experiences of the possible antecedents of ME and the contemporary experiences of ME. Moreover, what historical legacies has ME inherited?

[30] The prevalence rates for the United Kingdom are estimated and extrapolated from other countries (NICE, 2007).

To conclude this thesis, final reflections are offered on four key research questions:

- RQ1: How do people with CFS/ME interpret and make sense of their diagnosis?
- RQ2: What is the diagnostic process for someone who has been clinically diagnosed with CFS/ME?
- RQ3: How does CFS/ME impact on the lives of those who have been diagnosed?
- RQ4: How have the fatigue dominated illnesses, neurasthenia and the Royal Free Disease, been historically framed?

In exploring each question, I am taken back to the overarching aim of this thesis, which was to investigate how people who have been clinically diagnosed with ME, experience their diagnosis. The participants' recounted their experiences through their diagnostic journey, detailing their first onset of symptoms to the initial diagnostic "utterance" (Fleischman, 1999, p. 10) of ME, and the subsequent impact on their lives of receiving an ME diagnosis. In classifying and diagnosing, medicine often fails to recognise that the boundaries of categorisation are socially agreed upon according to the dictates, conventions and abilities of the field, rather than already existing objects awaiting discovery (Jutel, 2009). The thesis has therefore challenged this supposition by emphasising the social and historical aspects of diagnosis. It highlights the social consequences of labelling and classifying diseases, illnesses and people, while considering how the ME diagnosis fits within the wider power relations of medicine.

This thesis is loosely structured around Blaxter's (1978) suggestion that a diagnosis can be understood as a label and a process. The label is the available category for assignment, and the process is the way in which the diagnosis is designated. The thesis also incorporates the social consequences of an ME diagnosis (Jutel and Nettleton, 2011). Approaching the structuring in this way reflects how the thesis is underpinned by a sociology of diagnosis framework, but the three lenses/focal points (label, process, social consequences) overlap and interrelate across the thesis.

In concluding the thesis, a summary of each data chapter is detailed, along with some additional analysis. The continuities between the historical antecedents of ME and contemporary ME will be emphasised with a focus upon mental illness, legitimacy and responsibility. Through the dual lenses of the contemporary and the historical, a unique insight is offered into how people with ME experience and interpret their condition. I provide an analysis of why ME is contested by looking to historical fatigue dominated illnesses, neurasthenia and the Royal Free Disease. As with any study, the research has its limitations and these will be reflected upon. Reflections for future research are suggested which offer potential considerations for clinical practice. This conclusion will then offer some final reflections

which relate to the forthcoming NICE guidelines for ME and to the implications of long Covid for conceptualising how ME is framed.

Chapter Summaries

The main findings from the data chapters are summarised below. The summaries not only describe the contents of each chapter, but they also provide more general answers to the research questions listed above.

8.2 Labelling ME: Epistemic Injustice and Uncertainty (Chapter Four)

8.2.1 Which Label? CFS or ME?

Chapter four draws attention to how the diagnostic label was experienced and interpreted by the interview participants, illustrating how people diagnosed with ME make sense of their illness. Chapter four is the first empirical chapter, and it addresses research question one, "how do people with ME interpret and make sense of their diagnosis?" I began by showing how the interview respondents understood their diagnosis with a preference for the term ME over CFS. CFS persisted in being regarded as a stigmatising diagnostic label instead of mirroring the lived experience of what most of the participants referred to as ME. The emphasis on fatigue in CFS (chronic *fatigue* syndrome), appeared to undermine both the severity and the multisystemic nature of the symptoms that the participants experienced. Such alienation from the diagnostic label occurs when the medical model takes inadequate account of the illness problems (such as how a patient has actually lived, explained, and accounted for their symptoms) and is unable to incorporate them in its narrative via the diagnostic label (Jutel, 2011b). The preference for the ME label over CFS can therefore be seen as an act of resistance by respondents when faced with the medical preference for CFS. However, the favouring of ME over CFS also reflects a broader cultural awareness of the term ME, being a label that is more readily understood by others. The participants acknowledged that there were limitations to the term ME because the category failed to be particularly explanatory. This finding suggests that even if a diagnosis is not always understood or illuminating, a diagnosis does hold meaning because "classification does indeed have its consequences perceived as real, it has real effect" (Bowker and Starr 1999, p. 137).

8.2.2 The Social Consequences of Having a Diagnosis Withheld

The chapter applies Fricker's (2007, p. 10) concept of "epistemic injustice" to explore the asymmetrical power and knowledge dynamics between patient and clinician. Fricker (2007, p. 10) suggested that "epistemic injustice", is where someone is wronged specifically in their capacity as a knower, wronged therefore in a capacity essential to human value. According to Fricker (2007, p. 10) there are two types

of epistemic injustice, which are "testimonial injustice" and "hermeneutical injustice" (Fricker, 2007, p. 10). Testimonial injustice occurs when a speaker is unfairly accorded a lower level of credibility because of prejudice (such as the stigma attached to ME). The participants suffered testimonial injustice when they were denied knowledge of themselves through having the diagnosis of ME knowingly withheld from them. The participants were prevented from being participants in their diagnosis and their patient narratives were often dismissed and discredited. Doctors have it in their gift to withhold or bestow a diagnosis. The epistemic injustices experienced by the participants highlight medicine's authority over diagnosis. Unequal power dynamics between patient and doctor persist in the diagnosis of ME. This finding is especially salient when we consider the rise of the empowered patient (Hardey, 1999; 2001), expert patient programmes (Lorig, 2002) and a policy focus on patient choice (Dixon *et al*, 2010). Applying Fricker's (2007) concepts moves beyond recognising stigma to show how stigma is enacted and experienced. Applying the concepts provides a deeper level of analysis into the relationships between patients and clinicians. Competing epistemologies between the participants and healthcare professionals are a consistent theme of this chapter. However, epistemic tensions run throughout the overall thesis and this observation will be discussed further in section 8.6 of this chapter.

Chapter four highlights the significant social consequences of having a diagnosis withheld. The social implications of denying patients knowledge of their diagnosis can be seen where the participants were unable to access the sick role (Parsons, 1951). Being prevented from accessing the sick role (Parsons, 1951) prevents a person from accessing an "infrastructure – into a set of work practice, beliefs, narratives, and organisational routines" (Bowker and Starr 1999, p. 137). Having a diagnosis withheld by clinicians also left the interview participants in the state of heightened uncertainty that is "diagnostic limbo**"** (Corbin and Strauss, 1988, p. 22). Without a label, the participants were left without medical, social and institutional acknowledgement of their suffering and symptoms. Diagnostic limbo feeds into a social limbo, leaving patients without a shorthand/label to denote their symptoms and health status to others. My findings echo Nettleton's (2006, p. 1176) research which found that "one is not allowed to be anomalously 'ill'. Society does not readily give people permission to be ill in the absence of an 'accepted' abnormal pathology or physiology". In the absence of a diagnosis, the participants were unable to have a chance of accessing the sick role (Parsons, 1951) and its benefits, including treatment and exemption from their social roles. Chapter four shows how diagnostic limbo is a form of liminality because the person finds themselves "betwixt and between" (Turner, 1969, p. 94) states, where the individual is regarded as neither well nor legitimately ill. There also remains a sense of liminality and diagnostic limbo after receiving an ME diagnosis because the diagnosis remains contested.

8.2.3 Diagnostic Uncertainty

Uncertainty does not disappear with an ME diagnosis and doubt is a sustained feature of living with ME. Nettleton (2006) has also suggested that diagnostic categories can form a sense stability in our

identities and understanding but, at the same time, a diagnosis can create ambivalence. When the ME diagnosis was eventually assigned to the participants, the label gave them an anchor around which they could consider their patient narrative(s), their identity/identities, and their future. The diagnosis of ME also ruled out illnesses which the participants feared more than ME. However, there was often a lingering fear that a disease might have been overlooked. The contested nature of ME was reflected in the participants' experience of "epistemological purgatory" (Barker, 2005, p. 106). This is when an individual is left to process the subjective feelings of their illness when medicine is unable to objectively verify its existence, leaving the patient in an "epistemological crisis" (Barker, 2005, p. 106). The participants felt that their symptoms were real and physical with an organic cause, but there were no medical signs to medically validate their embodied experience. Moreover, within clinical consultations the participants commonly experienced their ME diagnosis being regarded as a mental illness. Chapter four explores the social consequences of labelling ME from the perspective of those who have been clinically diagnosed with the condition. The themes of mental illness and morality re-emerge in the next summary of chapter five, which addresses the diagnostic process of ME.

8.3 The Diagnostic Process: Mental Illness and Morality (Chapter Five)

8.3.1 Caught in an Iterative Loop

Chapter five focuses upon the diagnostic process of ME while demonstrating how psychiatry dominated the diagnosis experience. The chapter answers research question two "What is the diagnostic process for someone who has been clinically diagnosed with ME?" The chapter shows how participants experienced their symptoms being attributed to a mental disorder, when healthcare professionals suggested that ME was imaginary or depression. This opinion was also reflected in the participants' social networks , demonstrating how values and beliefs within medicine and society can permeate one another. Horton Salway (2004) found that the emphasis on ME being veiled depression suppressed personal experience as a fact-constructing device. However, my research built upon this insight by finding that the clinical emphasis on the imaginary and psychological sometimes led to depression which had previously been absent. The social consequences of this can be seen in the iterative loop (catch 22) whereby there was a medical emphasis on the participants' symptoms being part of a psychological illness. Yet the participants often later developed depression because of their subjective experience being discredited and dismissed. This is an additional example of the social ramifications of testimonial injustice because the participants' illness experiences were medically discredited.

8.3.2 The Psychologisation of ME

A key finding within chapter five was that the psychologisation of ME is particularly notable when the participants' experiences of the treatments are considered. One of the identified approaches to treating ME was the offer by clinicians of antidepressants to help alleviate the symptoms. The use of

antidepressants is, however, not recommended in the NICE guidelines (2007) treatments for ME. Further, my research found there to be two types of psychological therapies which approached ME in differing ways. The coping approach emphasised how the participants could adapt to living with what can be a chronic and disabling illness. The behavioural approach concentrated on how the participants' behaviour and thought processes caused their illness. The participants found the coping approach helpful while the behavioural approach was stigmatising, because the locus of responsibility was fixed upon the individual. Attributing the cause of ME to the personality of an individual implies a social and moral deviance, it being inferred that the individual 'chooses' to be unwell. There is currently no conclusive evidence to suggest that ME is a psychological condition and the debate over the cause of ME remains contested. However, the psychiatric and psychological approaches to treating ME appear to define the aetiology with harmful social consequences. This perhaps reflects the western approach to health and disease, which considers unexplained condition as being psychological and therefore less real (Jutel, 2011).

8.3.3 Misaligned Classification and Diagnostic Process

The diagnostic process and treatments of ME are misaligned with how the condition is medically categorised. The World Health Organisation[31] classifies CFS/ME as a somatic neuro-immunological condition (ICD-10, code G93.3) and in the United Kingdom the NICE (2007) guidelines state that CFS/ME is a real illness with unknown origins. However, this study has shown how the participants' diagnostic journey is largely concentrated within general medicine and psychiatry. Diagnosis allegedly defines which specialty should assume responsibility for specific diseases and disorders; diagnosis might therefore be considered a roadmap (Jutel, 2009) or a patient pathway. In the first instance the participants were usually diagnosed with ME within primary care by their General Practitioner. However, further confirmation of the ME diagnosis took place at either an ME clinic or at a hospital, by a secondary care consultant. The care and diagnosis at ME clinics were largely managed by psychiatrists and occupational therapists. The hospital based secondary care specialists tended to be psychiatrists, but the participants also saw consultants in specialisms which included tropical disease, haematology, rheumatology and neurology. However, upon confirmation of an ME diagnosis the patient was either treated at an ME clinic or referred back to their General Practitioner for treatment. In some cases, the participants were left with a diagnosis but no follow-up or treatment plan. The emphasis on psychological causes and treatments were misaligned with the categorisation of ME, as well as the lived and embodied experiences of the participants.

[31] The ICD-11 has now been approved and will be put into effect on 1st January 2022. It lists CFS/ME as a neurological disease in 'other disorders of the nervous system', section 8E49.

8.4 Loneliness and Liminality: "It's Like Being on the Other Side of a Mirror, Just Looking In" (Chapter Six)

8.4.1 Necessitated Loneliness

Chapter six discusses the social consequences of the ME diagnosis, which pertains to the sociology of diagnosis framework (Jutel and Nettleton, 2011). Chapter six addresses research question three, "How does ME impact on the lives of the participants?" Attention was drawn to how living with ME can significantly impact on relationships and social networks and especially friendships. Moreover, the contested and conflicted nature of ME filters into the loneliness experienced by people living with the condition. Loneliness was an unanticipated theme which emerged from the interview data. By asking how ME had changed the lives of the participants, descriptions of their everyday lives were elicited and loneliness and social isolation were revealed as key themes within the research.

This penultimate empirical chapter addresses how the symptoms of ME make it difficult to create new relationships and maintain existing social connections. All of the interview participants saw dramatic "biographical disruption" as a result of living with ME, including the surrender of their working roles, changes in family dynamics and negotiating their everyday routines. Tasks such as getting dressed, washing and eating were often balanced with whether the physical exertion would make the participant feel worse. There was a sense of restrictedness or what Little *et al*. (1998, p. 1486) refers to as boundedness, being a persistent "awareness of limits to space, empowerment and available time." As the symptoms of ME worsened, boundedness could be seen when the social worlds of the participants became increasingly contracted and their social contacts progressively reduced. The loneliness involved in the experience of living with ME might be referred to as necessitated loneliness because, although the respondents desired company, they did not always feel well enough to engage with others.

8.4.2 Normality Talk

Chapter six also highlights how the participants compared their own lives to those of "normal" lives, which created an emotional distance between themselves (us) and people who did not have ME (them). A 'normal' life appeared to have a linear progression without disruptions, obstacles or negativity (Hockey and James, 1993), which contrasted with the participants' lives being marked with uncertainty and restrictiveness. The respondents therefore found themselves on the peripheries of social life, feeling left behind by the seemingly normal world and living a liminal existence. For Little *et al.* (1998 p. 1486) "communicative alienation" was an integral part of living with liminality and "expresses a state of variable alienation from social familiars brought about by the inability to communicate and share the nature of the experience of illness, its diagnosis and treatment". The participants in my research experienced communicative alienation. However, the struggle to communicate their illness also extended to difficulties communicating their daily experiences. Their everyday lives were starkly

dissimilar to apparently normal lives, bounded by a different impression of time, space and sociality. This was neatly illustrated by Alex, who felt at a literal loss for words because she was no longer able to perform the activities others commonly do. Activities such as reading, focusing on a newspaper or computer, washing daily or pottering in the garden, all felt unachievable at the time of the interview.

8.4.3 Self Preservation

Social withdrawal was sometimes necessitated by the symptoms of ME, but it was also often necessary in order to preserve a positive sense of self. The participants experienced the stigma associated with ME when they were accused of being mentally ill, malingering or imagining their illness. Disbelief was perpetuated by the participants being largely invisible from social and public life, which links to how the illness is also biomedically imperceptible. The participants were therefore neither literally nor metaphorically seen to be ill, which only served to propagate negative accusations from those within their social network. Loneliness was not only caused by the participants socially withdrawing from negativity, but it was also triggered by friends ending their relationships. The participants experienced "sustained liminality" and they were constantly aware of having ME, even when they felt that they were in remission. The sustained liminality made it difficult to plan and prepare for the future and the participants felt that this made them appear fickle or unreliable. It uncertainty placed a strain on relationships, as did differing expectations. Expectations also played a role in the breakdown of friendships, with the participants expecting better support from friends and friends overestimating the capabilities of the participants.

8.4.4 Conceptualising Loneliness

The participants not only experienced a decline in their number of social connections, but they also found a decline in the quality of existing relationships (Perlman and Peplau, 1981). Social isolation and loneliness are two interrelated concepts which are conceptually distinct. The key difference between the two concepts can be summarised as loneliness being undesirable, whereas social isolation bears the potential to be wanted. However, I contend that the participants in this research experienced loneliness and social isolation as the same state of being, meaning that the two distinct concepts are not always experienced as such. Neither loneliness nor social isolation were desired by the participants, but they were nevertheless necessary for the purposes managing the symptoms and social ramifications of ME. The participants' loneliness was necessitated by their health condition and the stigma attached to the contested interpretations of ME.

8.5 Biographies of Fatigue Dominated Illnesses: Neurasthenia and the Royal Free Disease (Chapter Seven)

While the previous empirical chapters offered a contemporary analysis of the ME diagnosis, chapter seven answers the fourth question, "how have the fatigue dominated illnesses, neurasthenia and the Royal Free Disease, been historically framed?" It was therefore necessary to look to the past to see how fatigue dominated illnesses have been historically framed and interpreted. This final data chapter draws from my data collection conducted at the Wellcome Trust library and archives and the London Metropolitan archives. It discusses how two fatigue dominated illnesses – neurasthenia and the Royal Free Disease - have been interpreted within different historical periods. This is not to say that the Royal Free Disease and neurasthenia are the same as ME, but they might be better regarded as distant ancestors which share some of the same characteristics as contemporary ME.

8.5.1 Neurasthenia: A Legitimate or Fashionable Diagnosis?

The biography of neurasthenia details how neurasthenia ascended to become a popular diagnosis in the late Victorian era and early Edwardian era. Neurasthenia flourished because Beard (1869; 1880) conceptualised the nervous disorder as an organic and legitimate illness, which was caused and framed by societal anxieties over new technologies and the speed of development. Beard's (1880; 1884) aetiology of neurasthenia was therefore a combination of a social commentary and medical theory which reflected the prevailing societal anxieties. The theory that a patient's nervous system was functioning at less than full capacity seemed sensible (Bynum, 2003). The diagnosis of neurasthenia also flourished because neurasthenia made good sense within the specific historical and cultural context. The contemporary sociologist Stockl (2007) suggests that a diagnosis needs to make sense for it to be useful. Beard (1884) made neurasthenia intelligible by drawing from the intellectual and popular repertoire available to him, making the condition comprehensible to both patients and physicians alike.

The chapter shows how neurasthenia held more legitimacy when it had an element of exclusivity, applying to male members of the intellectual and upper classes. The issues of legitimacy and fashion are highlighted with particular attention paid to the nuances of gender and class. Part of the early success of neurasthenia was derived from its association with a refined character, which was only available to the upper classes. When neurasthenia was associated with men the disorder was both credible and popular. However, when neurasthenia was related to women the illness was regarded as being fashionable and illegitimate. I contend that a fashionable illness is not always the same as a credible one. Without denying the physical and mental realities of neurasthenia, the understandings and explanations of neurasthenia were largely of a social-cultural nature, and they were frequently understood in gender and class specific terms (Rosenberg and Golden, 1992). Moreover, the chapter

shows how diagnoses are socially and culturally contingent, with variable consequences for different groups of sufferers.

Attention was drawn in this chapter to how the diagnostic category of neurasthenia held social value for both physicians and patients. For physicians, neurasthenia offered a diagnostic label for a confusing group of symptoms which required treatment. From the perspective of the patient, a neurasthenia diagnosis conferred the benefits of treatment and an association with moral superiority, with few liabilities. Neurasthenia navigated a fine balance between maintaining the epistemic authority of medicine while incorporating the subjective experience of the patient. However, the social value of neurasthenia ebbed as the explanatory merit of the diagnosis deteriorated. The diagnostic label of neurasthenia became progressively less useful as it encompassed too much and explained very little. Thereafter, patients (and consumers) who were diagnosed with neurasthenia saw the legitimacy of their diagnosis wane. After addressing the possible reasons for why neurasthenia declined, the chapter moved on to the Royal Free Disease (1955), which had a similar pattern of symptoms, with fatigue being an integral characteristic.

8.5.2 The Royal Free Disease: Viral Disease or Mass Hysteria?

The biography of the Royal Free Disease details the emergence of an epidemic in the Royal Free Hospital, London in 1955. The chapter provides evidence of how the epidemiological research team at the Royal Free Hospital suspected that the outbreak was caused by polio. The prevalence and fear of poliomyelitis framed how the Royal Free Disease was regarded as a viral disease. However, once the outbreak at the hospital became connected to mental illness and mass hysteria, the legitimacy of the Royal Free Disease ebbed. McEvedy and Beard's (1970a; 1970b) theory of mass hysteria at the Royal Free hospital largely hinged on the basis that it had mostly been female staff members effected by the outbreak. However, they failed to substantiate why women were allegedly more likely to succumb to mass hysteria. McEvedy and Beard's (1970a; 1970b) suggested that when women lived in close proximity to one another, as they did in the nurses' quarters, there was a tendency towards mass hysteria. McEvedy and Beard's (1970a; 1970b) retrospective analyses of the Royal Free Disease had a profound effect on the interpretation of ME for nearly 50 years, as it came to be associated with being psychosomatic (Waters *et al.*, 2020). While the term psychosomatic appears to blur the boundaries between the psychological and the physical, the term might also denote an embodied mental health problem. The chapter highlights some of the more transparent and direct connections that the Royal Free Disease has to contemporary ME, including how the name myalgic encephalomyelitis developed from the Royal Free Disease.

Chapter seven, which concentrates on two fatigue dominated illnesses, neurasthenia and The Royal Free Disease, demonstrates how the emergence of diagnostic labels can be framed by, and in turn frame,

social and cultural values. It shows how diagnostic categories are historically located and culturally specific, while being fluid and unfixed. As the organicity of both neurasthenia and the Royal Free Disease appeared to ebb, so did the perceived legitimacy of the conditions, creating a vacuum for alternative explanations.

8.6 The Continuities Between Historical Fatigue Dominated Illnesses and Contemporary ME

A holistic overview of the thesis points to continuities between the possible historical antecendents of ME and the contemporary experiences of ME. The first of these connections is how neurasthenia and the Royal Free Disease waned in legitimacy as both illnesses became associated with mental illness. This would appear to indicate that there is some continuity with the contemporary experiences of ME. Chapter five explored how psychiatry and mental illness dominated the participants' experiences of being diagnosed with ME. The participants had their symptoms and their illness psychologised and discredited through being told that the illness was unreal, psychological or a vase of malingering. The participants reported that the process of being diagnosed with ME tended to involve psychologists and psychiatrists. The treatments also placed an emphasis on ME being a mental illness. It is unclear why ME should be more psychologised and stigmatised that other contested illnesses, including irritable bowel syndrome and fibromyalgia. However, by looking to the past, we can see why people with ME experience their diagnosis being repeatedly psychologised. Contemporary ME has potentially inherited from potential antecedent illnesses dominated by fatigue, neurasthenia and the Royal Free Disease, the relationship between mental illness and (il)legitimacy.

The nature of ME and whether it is psychogenic, somatic, or a combination of both, is still fiercely disputed (Banks and Prior, 2001; Lian and Nettleton, 2015; Spandler and Allen, 2018; Underhill and Baillod, 2020). There is plentiful research (Ware, 1992; Dummit, 2006; Spandler and Allen, 2018) on ME which has shown how the mental state of the patient is often questioned. Even now, there is debate over whether ME is a modern manifestation of hysteria (Showalter, 1997) and a question mark hangs over whether it is a genuine illness (Scull, 2011) or a reincarnation of neurasthenia (Wessley, 1990). The issue of legitimacy persisted for the interview participants, whose subjective experience of ME was incompatible with medical discourse. The illegitimacy of ME was usually expressed in competing physical and psychological explanations for the condition. This finding possibly reflects how, in western societies, the values and concepts of medicine dominate, and less physical tends to mean less real (Cohn, 1999; Jutel, 2011c; Kirmayer, 1988; Ware 1992). Consequently, it is possible to see the recurring unresolved contests and dichotomies between biology and culture, mind and body, real or fake, and moral or deviant.

The dichotomy between illness and disease also emerges throughout the histories of the fatigue dominated illnesses. Chapter seven has referred to the Royal Free Disease and neurasthenia as illnesses. However, during their infancy, the Royal Free Disease and neurasthenia might have been better regarded as diseases. Within the sociology of health and illness, the concept of disease is treated as the knowledge domain of scientists and medical experts, while the 'illness' refers to the lived experience of sufferers (Balint, 1964; Kleinman, 1973; Eisenberg, 1977). Both neurasthenia and the Royal Free Disease emerged and began as legitimate diseases, despite an unclear and ambiguous organicity. However, diagnosing neurasthenia and the Royal Free Disease initially struck a balance between maintaining medical epistemic authority while incorporating the subjective experience of patients. McGann (2011) distinguishes between medical and social discourses, claiming that they have varying dominance during the diagnostic process. From an historical perspective, the medical and social discourses also had varying contributions along the life courses of neurasthenia and the Royal Free Disease. Social and psychological explanations became more apparent as the illnesses declined in perceived legitimacy and organicity. The contemporary experiences of ME have shown the unevenness in epistemic rights and power dynamics between patients and their clinicians. However, the histories of neurasthenia and the Royal Free Disease demonstrate that an improved weighting between clinicians and patients can be achieved. During the infancy of both diagnoses there was a lack of scientific evidence for the illnesses, but patients were taken seriously and their concerns were addressed.

The biographies of neurasthenia and the Royal Free Disease also highlight how the locus of responsibility for an illness is related to blame and morality. Chapter seven showed how neurasthenia shifted from being an organic illness caused by societal stressors to be regarded as a mental disorder, with the alleged cause lying with the individual. Similarly, the Royal Free Disease emerged as an epidemic when it was believed to have been caused by a virus simulating poliomyelitis. The cause of the Royal Free became contested when McEvedy and Beard (1970a; 1970b), two psychiatrists, retrospectively claimed the 1955 epidemic was a case of mass hysteria caused by mental illness. The locus of responsibility again shifts from being societal to thereafter being located within the individual. There are clear historical continuities with chapter five, which elucidated the diagnostic process of contemporary ME. The findings in chapter five pointed to how psychological treatments of ME implied that the patients were held responsible for their illness, with a treatment emphasis on a personality or behavioral flaw. However, the interview participants found themselves in a double bind; they were held responsible for their illness, yet not always entrusted with holding a diagnosis (see chapter four). The shift in responsibility found in historical and contemporary accounts are illustrative of the medical custodianship of diagnosis. Medical professionals have the power to define disease and deviance, thereby perpetuating and reinforcing the authority of the medical profession. It has been shown how ME is a contested illness which is biomedically ambiguous, and it might be argued that the condition highlights the limits of medical knowledge. However, in making the patient accountable for ME, the

threat to biomedical authority posed by unexplained and uncontrollable illness is defused (Jackson, 2005). The participants' experience of diagnosis appears to reinforce the fallibility of medicine. Securing a diagnosis is needed to medically legitimate suffering and to try to access elements of the sick role (Parsons, 1951). The drive for a diagnosis is stimulated by a need to overcome diagnostic and social limbo and stabilise uncertainty. However, it appears that "our desire to palliate uncertainty via diagnosis may lead to, rather than remedy, its powerful impact" (Jutel, 2016, p. 97).

8.7 Sociological and Methodological Contributions

The thesis has contributed to the sociology of diagnosis by exploring how ME has been socially framed and understood both historically and contemporaneously. A key contribution of the research is the exploration of the historical framing of ME and how there are longstanding continuities with how contemporary ME is experienced. An historical analysis of fatigue dominated illnesses enables some distance to explore how diagnoses have been socially and culturally framed. It allows the researcher to ask, "How do we know what we know?" The research therefore goes beyond exploring diagnosis as one eureka cognitive moment in which a patient receives the "diagnostic utterance" (Fleischmann, 1999, p. 10) by analysing the diagnostic process and potential antecedents of ME. In addition to this, the respondents' interviews included narratives about their relationships, their clinical encounters, and their everyday lives, accounting for the impact of diagnosis beyond the clinic in order to comprehensively explore the diagnostic experience. By focusing on one specific contested illness and historical representations of fatigue diagnoses, the research is able to elucidate broader areas of interest to sociologists of health and illness. The study demonstrates how diagnoses are historically and socially contingent (Brown, 1995; Cohn, 1998; Jutel, 2011a; Rosenberg and Golden, 1992). Diagnoses have been shown to rise and ebb in legitimacy, offering different groups of people varying opportunities to interpret their condition and frame their identities. More broadly, the research offers an insight into the authority and power of medicine and how diagnosis manages boundaries and categories between health and disease.

This thesis also has significant reach beyond the field of the sociology of diagnosis. The research contributes to further areas of sociological concern as it is the first to specifically explore the social isolation and loneliness experienced when living with a clinical diagnosis of ME. The study therefore has the potential to illuminate the relationships and social loss involved in other contested conditions. Before the Covid-19 pandemic, loneliness was an understudied area within sociology, being more prevalent as a topic within gerontology. Chapter six provided an explicitly sociological approach to loneliness, reflecting how loneliness is affected by structural and social factors, including living arrangements (Neve *et al.*, 2019), stigma and chronic illness/disability. There is plentiful research on how loneliness effects our health, but less attention has been focused on how our health (or lack of

health) impacts on how lonely and socially isolated we feel. The research was undertaken from a perspective which incorporates chronic illness and disability, which both have the potential to affect anyone of any age. The research therefore diverges from a stereotype which associates loneliness with ageing. Furthermore, sociological insights are offered into what can be a private and taboo issue and the research has sought to bring loneliness to the forefront of the sociology of health and illness. This research on the loneliness experienced with ME provides an insight into the broader social problem of an alleged "loneliness epidemic" (Bound Alberti, 2019, p. 242).

One of the principal contributions of the study lies in the methodology. The research approach is one that engages the historical and the contemporary, through a sociological lens. It does this by combining in-depth semi-structured interviews with archival research of possible historical antecedents to ME. The value of conducting interviews can be found when they elucidate the diagnostic process and daily experiences of living with a contested illness. The embodied experience of living with what can be a chronic and disabling illness unfolded from the interviews. An historical analysis of fatigue dominated illnesses offers a pathway to understanding why the experience of ME is fraught with stigma and contest. Conducting an historical exploration in tandem with contemporary interviews enabled a deeper insight into the contemporary experiences of ME by enabling continuities to be identified.

The archival research highlighted how neurasthenia and the Royal Free Disease have been historically and culturally framed. Framing is a tool which is used for historical research, and it is possible that there is not enough distance from current diagnoses to be able to effectively explore how they are framed. Framing enables us to understand historical diagnoses, whereas interpretation assists in comparing the present with the past. Jutel and Nettleton (2011) proposed a third rubric to studying diagnosis, suggesting that we consider the consequences, in addition to the label and process. However, a conceivable fourth rubric is adding interpretation to the framework underpinning the sociology of diagnosis. Moss (2008, p. 156) has referred to interpretation as the most "flexible aspect of diagnosis, and it is also the most sensitive to the cultural shifts and social understandings of medicalised knowledge". This fourth rubric of interpretation has the potential to encapsulate framing, but interpretation also allows for greater scope with which to also explore contemporary understandings of diagnosis, health and disease.

8.8 Limitations of the Study

The key limitations of the research mainly pertain to the methodology. Firstly, this small-scale study does not and cannot claim to represent all individuals who have been diagnosed with ME. It would be fruitful to explore cross cultural differences in how ME is perceived, named and experienced but this was beyond the scope of the current research. It would also be challenging to offer a cross-cultural study

because the label of ME alters geographically. Further, people from ethnic minorities are regrettably underrepresented within this study, as they are in wider ME research. Further research is needed to reflect the diverse experiences of people living with ME. Although this study has provided insights into the diagnosis of CFS/ME, its focus was restricted to those who received their diagnosis through recourse to medical attention. The experiences of those who do not choose to access a clinical diagnosis are yet to be explored.

Secondly, the archival research explored materials which were largely from the clinicians' perspective. There were regrettably few materials from the patients' viewpoint. The sources tended to have been written by elite, educated men and there were few materials either written by, or relating to, people of different classes and ethnicities. Comparisons between historical medical perspectives and contemporary patient perspectives have the potential to be methodologically incongruous. However, some of the archival materials were written by authors who were patients and clinicians. This shows how positions (medical and patient) which might be part of two distinct groups, do not necessarily belong to only one group. Nor do they necessarily have the same values or similar understandings of the condition that is being researched (Cohn, 1999).

8.9 Informing Future Practice

This research has offered an insight into the diagnostic process of ME, highlighting how it is fraught with uncertainty and "epistemological purgatory" (Barker, 2005, p. 7). The diagnosis of ME eliminates a degree of uncertainty but the diagnosis remains ambiguous because it is not fully explanatory or conclusive. This finding might be regarded as an example of "diagnostic illusory" (Nettleton, Kitzinger and Kitzinger, 2014, p. 134), which captures "the ambiguities and nuanced complexities associated with the biomedical imperative to name and classify" (Nettleton, Kitzinger and Kitzinger, 2014, p. 134). The interview participants in my study felt that it was crucial to receive a diagnostic label. However, Nettleton, Kitzinger and Kitzinger (2014, p. 134) have questioned whether diagnoses raise false hopes with the expectation of certainty and intelligibility. In a similar vein, Joyce and Jeske (2020) found that broad diagnostic classification of autoimmune disease can help doctors to support patients. It is common amongst those with autoimmune conditions to meet criteria for different autoimmune disorders, to be on the borderline of a diagnosis or for the diagnosis to change to another autoimmune disease. Joyce and Jeske (2020) found that beginning the diagnostic process with an umbrella diagnosis helped to mitigate the discomforting feelings of uncertainty. Joyce and Jeske (2020) show how the diagnostic process can be improved for those who face ambivalence and uncertainties as they journey through their diagnostic experience.

I therefore propose that clinicians and patients are better informed of the ambivalence that can be experienced as part of the ME diagnosis. In addition to this, rather than withholding a diagnosis of ME, a suspected diagnosis might help patients to navigate the inconsistencies and uncertainties involved in a withheld or unconfirmed diagnosis. By clarifying what medicine is unable to explain, patients and clinicians can begin to have a more open and receptive dialogue, when each brings their own knowledge and experience to the diagnostic process. My study shows how classifying people and diagnoses has very real social consequences for patients and medical practice. Consequently, I would suggest that more attention needs to be paid to how we "lump and split" (Zerubavel, 1996, p. 421) people and diagnostic categories, because this can improve how the diagnosis is experienced and communicated.

8.10 Final Reflections

As I write this conclusion, an article has appeared in The Telegraph titled, "There's Currently No Cure For Long Covid or ME – But Only One Has a Stigma Attached" (Turner, 2021). The article has been written with a patient who has ME. The article suggests that long-Covid and ME are both illnesses with overlapping symptoms which have been caused by a virus. What is poignant about this piece is how, much like polio in the 1955 Royal Free Disease outbreak, the Covid-19 virus is framing ME. My research has shown how the framing of fatigue illnesses has been susceptible to cultural and social changes. It has also demonstrated how the framings of neurasthenia and the Royal Free Disease reflected societal concerns as those illnesses emerged.

The emergence of long Covid could have positive implications for the medical approach to ME. Like ME, long Covid is multi-systemic with similar overlapping symptoms dominated by fatigue. The longer-term impact of Covid-19 will require the NHS to reconsider the way that services are organised and delivered in order to care and treat people with long Covid. The diagnostic process of ME was mainly based within psychiatry, which reflects how the NHS has long been organised on a single specialty referral model, with primary care as the gatekeeper. A movement away from single specialisms could have positive implications for the ways in which people with ME are supported. There is the potential for an approach which is more holistic and less focussed upon the psychogenic. The histories of the neurasthenia and the Royal Free Disease show how fatigue dominated illnesses do not have to be psychologised or illegitimate. In Beard's (1869; 1880) conceptualisation of neurasthenia, a more holistic view of the body was incorporated into his vision. Beard (1869; 1880) had an approach which addressed the somatic issues of the body and the mind, without stigma or reference to what we might now refer to as mental disorder. The NICE guidelines (2007) for ME are currently being revised and this creates an opportunity to rethink the patient pathway, consider the patient voice and realign the clinical process with patient experience.

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Appendix A

Assessing historical Documents (Wood, 2011, p. 27)

Criteria	*Critique*
Provenance	What kind of document is it? Who created the document? Why was the document created? What does the preservation suggest about its authenticity?
Purpose	What was the writer's purpose in creating the document? Who was the document written for? How did the writer's purpose influence the way the document was written?
Context	How does the document relate to its temporal, geographic, social, political, cultural and professional contexts? How representative is the document of other documents in the field? How representative is the writer of other people in the field?
Veracity	How credible is the writer? How might the writer's purpose in creating the document have introduced bias? What values and assumptions are evident in the document? How important is it that evidence in this document is accurate? How does the information differ from others?
Usefulness	How useful is the document for the research purpose? How does the document offer information not available from other sources?

Appendix B

Interview Schedule

Name:

Gender:

Age:

Ethnicity:

Current hometown:

Current Occupation:

Previous Occupation (if applicable):

When diagnosed:

Date of interview

Interview type:

Experiencing the illness

1. What are your first memories of becoming ill?
2. How has your life changed since becoming ill?
3. What do you think caused your illness?
4. Do you have any theories about what might have caused your illness?
5. What tend to be your main symptoms?
6. How do you manage your illness? Does anything help to alleviate the symptoms? Have you found anything makes you feel worse?
7. What does a typical day look like for you now?
8. Have you ever had any periods of remission?
9. How do you feel about your illness?

Relationships with clinicians

1. How many doctors did you see before receiving a diagnosis?
2. How long did it take to receive a diagnosis?
3. Did you have any tests before being diagnosed? If so, which?
4. Did you encounter any difficulties during the process of being diagnosed?
5. How did you feel when you were diagnosed with the illness?
6. How would you describe your relationship with your doctor?
7. Do you feel that your doctor is well informed about ME?
8. How regularly do you see your doctor? Do you tend to see the same person?

9. Have you seen any other healthcare professionals? If so, which and why? Was the referral helpful?
10. Has your doctor recommended any other treatments?
11. Have you ever tried any alternative therapies or medicines? If so, which? Did they help?

Relationships

1. Has your illness had any impact on your relationships?
2. Is there anyone who helps or cares for you when you're ill? What is your relationship to this person? How do you find this relationship?
3. Do you feel that family and/or friends understand ME?
4. Do you know other people with ME? How did you meet these people/this person? Are you a member of any patient groups?
5. Is there someone you talk to about your illness?
6. How do you think the public perceive ME?
7. Did/do you find your workplace supportive? In what ways?

Naming the illness

1. What do you tend to call your illness?
2. Do you remember what your doctor/ HCP called the illness when you were first diagnosed?
3. Where do you first hear about ME?
4. Did you research ME before you were diagnosed? And after? If so, what were your main resources? Were they helpful?
5. Do you feel well informed about the illness?

Accessing Resources

1. Has your financial situation changed as a result of the illness?
2. How do you think you could have been better supported?
3. How do you think that people with ME could be better supported?

Appendix C

Wellcome Trust Questionnaire, 1976

ICELAND DISEASE (Myalgic Encephalomyelitis)

QUESTIONNAIRE

Name

Address

Age

Sex

Occupation

Name & address of doctor

Telephone No.

Date of onset

Place of onset

Activity at time of onset

Connection with similar cases

Connection with children

Any recent vaccinations/ immunizations

Please indicate by a tick if you have experienced any of the following symptoms since you became ill:-

Column 1

1) Headache
2) Pain in back of neck
3) Muscle pain in back, arms or legs
4) Sore eyes
5) Sensitivity to light
6) Excessive fatigue
7) Physical weakness
8) Legs feeling heavy
9) Difficulty in standing
10) Pins and needles in arms or legs
11) Difficulty in carrying heavy weights or lifting arms above head
12) Numbness
13) Clumsiness
14) Giddiness/dizziness
15) Muscle twitching
16) Shivering attacks
17) Feeling 'awful'
18) Loss of appetite
19) Nausea
20) Looking pale or 'grey'
21) Cold hands and feet
22) Loss of memory
23) Loss of concentration
24) Insomnia
25) Depression
26) Difficulty in passing water

Column 2

1) Stiffness of neck
2) Pain in abdomen
3) Fainting
4) Vomiting
5) Diarrhoea
6) Constipation
7) Palpitations
8) Abdominal distention
9) Vaginal discharge

Column 3

1) Sore throat
2) Pain in chest
3) Tremor
4) Noises in ears
5) Sensitivity to noise
6) 'Indigestion'
7) Frequent crying
8) Nightmares
9) Shortness of breath

P.T.O.

Column 4

1) 'Cold in head'
2) Raised temperature
3) Rash
4) Painful joints
5) Earache
6) Deafness
7) Seeing double
8) Blurred vision
9) Cough
10) Frequency in passing water
11) Dry mouth
12) Flushing
13) Increased thirst
14) Sweating unduly
15) Panic feelings
16) Guilt feelings
17) Bad taste in mouth

Have your symptoms varied from day to day? or during the day?

Are they worse in morning/afternoon/at night?

Are they worse lying down?

Did you become ill suddenly/gradually?

Was your health previously good?

Were any other members of your family affected?

Have you any family history of allergy, e.g. hay fever, asthma, eczema, skin rashes, reactions to drugs or foods?

Are you improving/getting worse/about the same?

Do you have any permanent muscle weakness such as difficulty in standing, lifting arms above the head or carrying heavy weights?

Do climatic conditions, e.g. sunlight, have any effect on your symptoms?

Have you had any blood or electrical tests or other investigations, e.g. lumbar puncture?

If so, did they show anything?

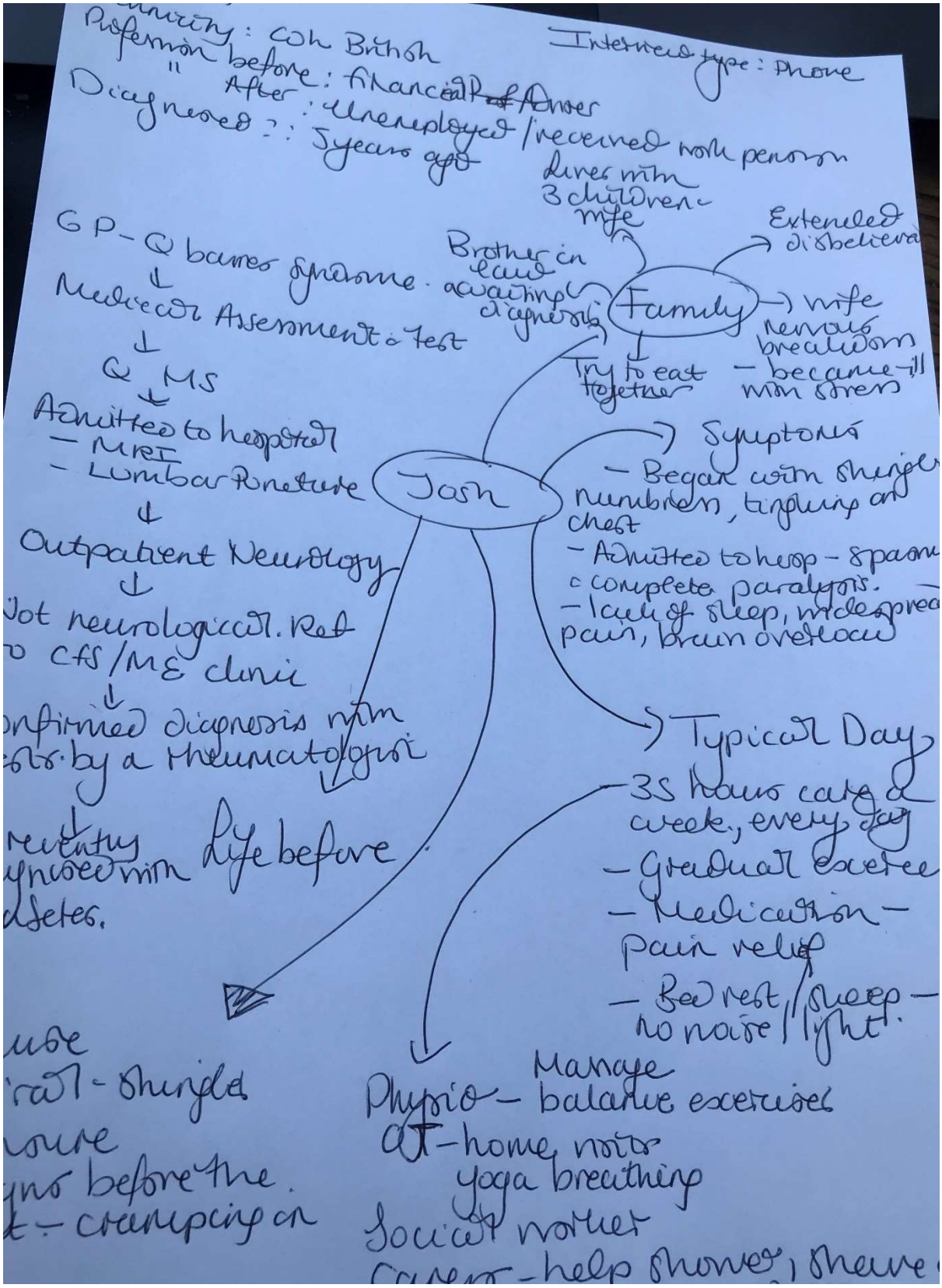
What diagnosis, if any, have you been given?

Would you be prepared if selected to go to a hospital and possibly be admitted for a short time for tests which will further research into this illness but not necessarily result in any new treatment for you?

Will you give your permission for us to contact your doctor if necessary

Appendix D

OSOP Example



Appendix E

Consent Form

The University Of Sheffield.

Consent form

Exploring how people with chronic fatigue syndrome/ myalgic encephalomyelitis (CFS/ME) experience their diagnosis

Name of researcher: Please initial box

1. I agree that I have read and that I understand the information sheet dated [insert date] for the CFS/ME project. ☐
2. I have had sufficient opportunities to ask questions about the project. ☐
3. I understand that it is up to me whether or not I take part and that I can stop at any time without needing to say why. ☐

Name of participating person	Date	Signature
Natalie Wotherspoon Name of researcher	Date	Signature

Copies: One for each participating person, one for researcher, one to be kept with project site file.
Consent form [Version 1 April 2014]

Appendix F

Information Sheet

The University Of Sheffield.

The Diagnosis of Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis

How do people with CFS/ME experience their diagnosis?

What do you think and feel?

I would like to invite people with CFS/ME to take part in this research project. I am interested in hearing about your experiences of having been diagnosed with CFS/ME. Before you decide whether or not you want to be involved, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like further information. Take time to decide whether or not you would like to be involved.

Thank you for taking the time to read this information.

What is the aim of this project?

This project will take place over twelve months from September 2014 to May 2015. The project aims to find out about how people experience their diagnosis of CFS. The results of the study will help service providers to improve their knowledge of CFS/ME and to reduce the time it takes to be diagnosed.

Why have I been chosen to take part?

You have been chosen because you have shown an interest in participating in this research. You will also have been diagnosed with CFS/ME by a doctor in the UK.

I would like to speak with people with CFS/ME to find out how they feel about their diagnosis and how they have experienced being diagnosed.

Do I have to take part?

It is up to you whether or not you would like to take part. If you do decide to take part, you will be given this information sheet to keep and also be asked to sign a consent form. If you decide that you would like to take part, you are still free to change your mind and withdraw at any time.

What will happen if I do wish to take part?

If you are happy to join the study you will be involved in a one to one discussion with myself, a doctoral researcher.

During the interview, I will sit down with you in a comfortable place of your choosing. You will be asked questions about your feelings and experiences around your diagnosis and illness. If you do not wish to answer any of the questions during the interview, you may say so and I will move on to the next question.

I expect that talking to you will take approximately one hour. I will ensure that the interview process inconveniences you as little as possible.

What should I do next?

If you would like to join the study, please complete the slip at the bottom of this information sheet and post it in the stamped addressed envelope provided or phone me on 07864845848 or email me at nwotherspoon1@sheffield.ac.uk. Once you have decided to take part you will be asked to sign a consent form. You will receive a copy of this to keep, along with this information sheet.

What are the possible disadvantages?

I do not foresee any disadvantages to you from taking part in this study. In the unlikely event that either of you become upset or distressed you may choose to withdraw from the study at any time. I may wish to quote some of the things you say in my discussion of the findings that will be produced from the study, but no one will be able to identify these as your words.

Whatever you tell us will be treated as confidential and, if necessary, we will disguise your identity. You will have the right to stop the recorder at any point, and have the recording wiped clean, without any reason. Nothing recorded from our conversation will be traceable back to you.

What are the possible advantages of taking part in this study?

You will not benefit immediately or directly from taking part in this study but your experiences of being diagnosed with CFS/ME will help improve our understanding of CFS/ME.

Will my taking part in this study be kept confidential?

All information collected during this study will be kept strictly confidential. The discussion with you will be typed up and all names and identifiable information will be removed so that you cannot be recognized. Once this has all happened, the recording will be wiped.

What if something goes wrong?

If you wish to complain about any issue relating to your involvement in this research study, please voice your concerns to myself. Alternatively you may complain to my supervisor, Dr Kate Reed (0114 222 6478).

What will happen to the results of the research project?

The results of this study will form part of my PhD. It is likely that the results will be published in journal articles and presented at conferences, so that the results can become widely known. No one will be able to identify you in my PhD or anything else that is produced out of this research.

After the study has been completed, the anonymised transcripts (the typed up interviews) will be destroyed.

If when the project has ended, you would like to know about the findings, you can contact me on 07864845848 or nwotherspoon1@sheffield.ac.uk and I will send a summary of the findings to you.

Who is organising and funding the research?

The research is funded by the department of Sociological Studies at the University of Sheffield.

Who reviewed the project?

The University of Sheffield sociological studies research ethics committee approved this study on 16th June 2014.

Contact for further information

Natalie Wotherspoon, Doctoral Researcher, Department of sociological studies, Elmfield building, Northumberland Road, Sheffield S10 2TU.
Tel: 07864845848
Email: nwotherspoon1@sheffield.ac.uk

If you would like to take part in this research project, either contact us at the above address (use the stamped addressed envelope if you wish) or phone me on the above telephone number.

Name ----------

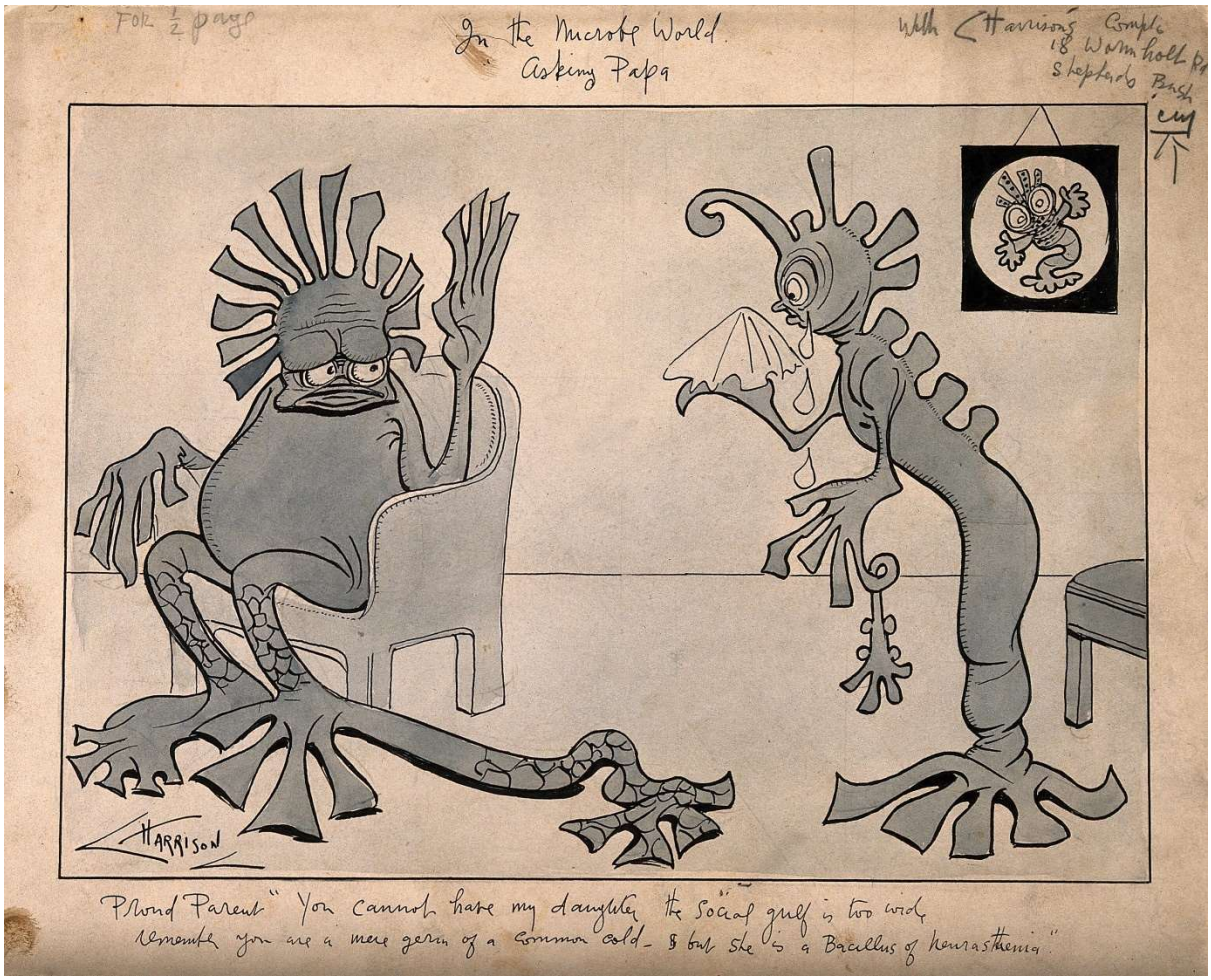
Contact Details ----------

[Version 1: April 2014]

Appendix G

Neurasthenia Cartoon

A common cold germ asking the father of a neurasthenia bacillus if he can marry her; he is refused on account of the social gap between them. A pen drawing by C. Harrison (1913) entitled “In the Microbe World, Asking Papa”.



Appendix H

Table of Interview Participants' Information

Pseudonym	Age	Gender	Ethnicity	Previous Occupation	Full time/Part-time work (after ME)	Current Occupation	Interview Type
Alex	60	F	White	Social Worker	Not applicable	Unemployed	Face to face
Amy	32	F	White	Student	Not applicable	Unemployed	Face to face
Becky	40	F	White	Administrator	Part-time	Receptionist	Phone
Cara	40	F	White	Studying for postgraduate degree	Not applicable	Unemployed	Skype
Clare	42	F	White	Teacher	Not applicable	Unemployed	Face to face
Dave	Decline	M	White	Student	Not applicable	Unemployed	Phone
Dawn	21	F	White	Student	Part-time	Student	Face to face
Donna	30	F	White	Gap year student	Part-time	Charity Admin	Face to face
Emma	27	F	White	Administrator	Part-time	Student	Face to face
Emily	43	F	White	Teacher	Part-time	Teacher	Face to face
Erica	57	F	White	Nurse	Not applicable	Unemployed	Phone
Evelyn	37	F	White	Dental nurse	Not applicable	Unemployed	Phone
Fiona	50	F	White	Nurse	Not applicable	Unemployed	Phone
Fran	55	F	White	Police Officer	Not applicable	Unemployed	Phone
Georgia	46	F	White	Teaching Assistant	Not applicable	Unemployed	Face to face
Gill	57	F	White	Administrator	Temp-work	Administrator	Skype

Pseudonym	Age	Gender	Ethnicity	Previous Occupation	Full time/Part-time work (after ME)	Current Occupation	Interview Type
Gina	31	F	White	Marketing Manager	Part-time	Marketing Manager	Phone
Grace	27	F	White	Teacher	Part-time	Teaching Assistant	Face to face
Harriet	57	F	White	Teacher	Not applicable	Unemployed	Face to face
Heather	37	F	White	Nurse	Not applicable	Unemployed	Face to face
Jenny	47	F	White	Occupational Therapist	Not applicable	Unemployed	Skype
Josh	37	M	White	Financial advisor	Not applicable	Unemployed	Phone
June	27	F	White	Administrator	Not applicable	Unemployed	Phone
Katie	40	F	White	Teacher	Part-time	Teacher	Skype
Kirsty	30	F	White	Nurse	Not applicable	Unemployed	Phone
Laura	45	F	White	Project Manager	Not applicable	Unemployed	Face to face
Lauren	48	F	White	Nurse	Not applicable	Unemployed	Skype
Leanne	30	F	White	Architect	Part-time	Architect	Phone
Libby	19	F	White	Student	Full-time	Student - university	Face to face
Louise	55	F	White	Financial Systems Analyst	Not applicable	Unemployed	Face to face
Lucy	50	F	White	Community Service Health Manager	Not applicable	Unemployed	Face to face
Marjorie	45	F	White	Teacher	Part-time	Teacher	Skype
Martin	36	M	White	Teacher	Not applicable	Unemployed	Skype
Melissa	45	F	White	Barrister	Not applicable	Unemployed	Phone
Mike	43	M	White	Engineer	Part-time	Engineer	Face to face
Miriam	41	F	White	Student at College	Not applicable	Unemployed	Face to face

Pseudonym	Age	Gender	Ethnicity	Previous Occupation	Full time/Part-time work (after ME)	Current Occupation	Interview Type
Peggy	30	F	White	Nursery Practitioner	Not applicable	Unemployed	Face to face
Phil	31	M	White	Charity Fundraiser	Not applicable	Unemployed and retraining	Face to face
Rachael	36	F	White	Had childhood ME	Part-time	Volunteer	Skype
Rosie	31	F	White	Gap year student	Not applicable	Unemployed	Face to face
Serena	59	F	White	Administrator	Part-time temp work	Administrator	Phone
Simon	43	M	White	Engineer	Part-time	Engineer	Face to face