

**EXPLORING THE EXPERIENCES AND OCCUPATIONS OF MEN WITH
CHRONIC FATIGUE SYNDROME/MYALGIC ENCEPHALOMYELITIS (CFS/ME)
USING A GADAMERIAN INTERPRETIVE PHENOMENOLOGICAL FRAMEWORK**

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Abstract

Background

Chronic fatigue syndrome (CFS) known interchangeably as myalgic encephalomyelitis or encephalomyelopathy (ME) is a contentious and often misunderstood condition of unknown cause. Associated symptoms may fluctuate and include post exertional mental and physical fatigue, sleep disturbance, generalised aches and pains and for some, hypersensitivities to alcohol, light and noise. The impact of having CFS/ME can result in disruption to all aspects of day to day life for children and adults regardless of ethnicity or socioeconomic factors. In adults, it is estimated that population prevalence is 0.2 – 0.4% which is higher than in children and that women are affected by the condition more than men by a ratio of 3:1. The vast majority of the literature linked to living with CFS/ME focuses on the experiences of women with the condition and as a consequence, there is a dearth of literature reporting on the experiences of men.

Objective

The focus of this study was to explore the experiences of men living with CFS/ME and its impact on their day to day lives and occupations.

Design

A qualitative design was employed underpinned by interpretive phenomenology. Eight men aged between 21 and 68 years old were recruited with a clinically confirmed diagnosis of CFS/ME and interviewed up to four times. Rich data were generated through dialogue, poetry and artworks. Interpretations were made using the hermeneutic work of Gadamer (2004) as a philosophical framework.

Analysis

Thematic analysis was employed. Unique and shared experiences were identified. Shared findings were synthesised into three themes to reflect the temporality of the men's experiences.

Findings

New knowledge generated included; distress experienced due to fearing life threatening causes of fatigue; difficulties with life transitions due to disruptive symptoms; feelings of

emasculatation and role loss; the need for social isolation to promote recovery and; the value of occupational adaptation in the form of pacing used to assist recovery and a return to health.

Conclusion

Occupational therapists need to explore how men's 'being-in-the-world' is disrupted due to the presence of CFS/ME, in order to better understand their 'doing/occupations'. By entering into the therapeutic relationship at this point, an understanding of 'disrupted-belonging and becoming' may also be achieved, enabling truly client-centred practice to be provided and support men's survival and health.

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Glossary

*All of the occupational terms have been taken from Christiansen and Townsend (2011) unless otherwise stated.

Being: Our existence in the world, also known as 'being-in-the-world' (Gadamer, 2004). The essence of someone, the inner person (Wilcock, 1998). See also Dasein.

Belonging: A connectedness to others, places and things (Wilcock and Hocking, 2015).

Becoming: A development or moving towards something a personal transformation (Wilcock and Hocking, 2015).

Dasein: Existence itself, 'being' known also as 'being-there' or 'being-in-the-world'. (Heidegger, 1962). See also Being.

Doing: Action, participation, accomplishments (Wilcock and Hocking, 2015). Referred to in this study inter-changeably as occupation and a dimension of 'being'.

Existentialism: Our human concerns relating to life, ageing and death, being and becoming, embodiment and identity, choice and meaningfulness, belonging and needs, sense of time and space, freedom and oppression, and, so on. (Finlay, 2011 p. 19).

Health: A condition of being involved, of 'being-in-the-world', of being together with one's fellow human beings, of active and rewarding engagement in one's everyday tasks and a state of harmonious being (Gadamer, 1996). Links closely with the notion of 'well-being' – see below.

Illness: A chaotic state of 'being' a moving away from harmonious health (Gadamer, 1996)

Lived body: The way we feel our body such as when we are sluggish, energized or have a bad hair day (Finlay, 2011 p. 20). An existentialist notion.

Lived time: Also defined as temporality; the subjective experience of time not objective clock time; an existentialist notion (Finlay, 2011).

Lived space: How a place is experienced. For example, home as comfortable as opposed to a dark alley as threatening. An existentialist notion (Finlay, 2011).

Occupation (McColl, 2003): Purposeful or meaningful activities in which humans engage as part of their normal daily lives. (McColl, 2003, p. 1).

Occupation (Wilcock, 2006): Doing, being, belonging and becoming. (Wilcock, 2006, p. 209).

Occupational adaptation: Adjustments and changes in the methods, tools, locations and other forces that determine participation in occupations by individuals, groups and communities.

Occupational alienation: Experiences devoid of meaning or purpose, a sense of isolation, powerlessness, frustration, loss of control, or estrangement from society or self that results from engagement in occupations that do not satisfy inner needs related to meaning and/or purpose.

Occupational deprivation: A term referring to a state for prolonged preclusion from engagement in occupations of necessity or meaning due to factors outside the control of an individual, such as geographic isolation, incarceration, or disability.

Occupational disruption: A transient or temporary condition of being restricted from participation in necessary or meaningful occupations, such as that caused by illness, temporary relocation, or temporary unemployment.

Occupational engagement: Full participation in occupations for purposes of doing what one needs and wants to do, being, becoming who one desires to be, and belonging through shared occupations in communities.

Occupational flow: Flow is a term attributed to the psychologist Mihaly Csikszentmihalyi (1997) to mean the experience of engagement that occurs when an individual is deeply interested in a task or occupation and his or her skills are at a level that matches or exceeds the challenges of the task.

Occupational identity: The socially constructed image of self as a participant in occupations.

Occupational justice/injustice: Term credited to Townsend and Wilcock (2000) referring to justice related to opportunities and resources required for occupational participation sufficient to satisfy personal needs and full citizenship.

Occupational marginalisation: Experiences of inequity from being outside the dominant or mainstream discourse and events of everyday occupations in a particular context; invisible, silent, on the edge of privilege and entitlement to occupational opportunities and resources.

Occupational mastery: Excelling in competence for participation in an occupation.

Occupational participation: The engagement of the individual's mind, body and soul in goal directed pursuits.

Occupational science: the study of the experiences and factors pertaining to human occupation.

Occupational therapy: A profession addressing human intrinsic needs and desires to explore the world and engage in occupational pursuits that are necessary, engaging, meaningful and purposeful, addressing the social, spiritual, physical and psychological benefits of occupational engagement and essential links to health well-being and equitable social inclusion.

Occupational well-being: Experiences of satisfaction and meaning derived from participation in occupation.

Reflection: Considering and reviewing thinking, actions and circumstances to develop new ideas (Howatson-Jones, 2016 p.171).

Reflective practice: Considering and reviewing the interplay between theory and practice and new ideas (Howatson-Jones, 2016 p.171).

Well-being: A complex phenomena encompassing physical, mental and social domains of life which considered collectively have the potential of enabling the individual to contemplate the subjective notion of living a 'good life'. A term sometimes referred to

interchangeably as 'wellness' (Wilcock and Hocking, 2015). Links closely with notions of health – see above.

Abbreviations

ABN: Association of British Neurologists

AfME: Action for ME

AIDS: Acquired Immune Deficiency Syndrome

BME: Black and Minority Ethnic

CASP: Critical Appraisal Skills Programme

CDC: Centers for Disease Control

CFIDS: Chronic Fatigue Immune Deficiency Syndrome

CFS: Chronic Fatigue Syndrome

DoH; Department of Health

FMS: Fibromyalgia Syndrome

FT: Foundation Trust

GCSE: General Certificate of Secondary Education

GP: General Practitioner

HC: Hermeneutic Circle

HMSO: Her Majesty's Stationary Office

ICD-10: International Classification of Diseases - 10

ICU: Intensive Care Unit

IOM: Institute of Medicine

IP: interpretive Phenomenology

IPA: interpretive Phenomenological Analysis

ISOS: International Society of Occupational Science

ME: Myalgic Encephalitis or Encephalopathy

MRC: Medical Research Council

NHS: National Health Service

NICE: National Institute for Health and Care Excellence, after April 2013. Prior to this was the National Institute for Health and Clinical Excellence

OU: Open University

PhD: In this study, an abbreviation used to mean ‘doctoral’

PIS: Participant Information Sheet

PRIME: Patients and Researchers in ME

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PTG: Post Traumatic Growth

PTSD: Post Traumatic Stress Disorder

PVFS: Post Viral Fatigue Syndrome

RA: Rheumatoid Arthritis

RNHRD: Royal National Hospital for Rheumatic Diseases

RUH: Royal United Hospital

SA: Severely Affected

SLE: Systemic Lupus Erythematosus

TA: Thematic Analysis

TATT: Tired All The Time – sometimes used by medics to describe chronic fatigue

UK: United Kingdom

UWE: University of the West of England

WFOT: World Federation of Occupational Therapists

WHO: World Health Organisation

“Man becomes what he is through what he does”

(Gadamer, 2004, p. 311).

Chapter 1:

Introduction to the study

1.0 Chapter overview

In this chapter I introduce the topic of the study, that is, the meaning of living with chronic fatigue syndrome/myalgic encephalomyelitis/encephalomyelopathy (CFS/ME) for men. A rationale for the study is given and the primary research question is stated. An outline of the study design, mention of the philosophical orientation and data collection methods employed are presented to illustrate how new knowledge was generated. The notion of experience as 'being-in-the-world' is introduced. Occupation is defined and situated within 'being-in-the-world' as 'doing'. The importance of attending to the meaning of occupation is highlighted. As an occupational therapist researcher, a description of occupational therapy is provided to situate the underpinning professional knowledge I bring to the study. Additionally, an introduction to the relatively new and emerging academic discipline of occupational science is included. The use of the term 'patient' in the study is also explained. The chapter concludes with an overview of the thesis construction and provides an outline of the contents of each of the seven chapters in the thesis.

1.1 Introducing the topic of the study: the experiences of men with CFS/ME

In this qualitative study I explored the illness experiences of eight men with a clinically confirmed diagnosis of Chronic Fatigue Syndrome (CFS). CFS is also known interchangeably as Myalgic Encephalomyelitis or Encephalomyelopathy (ME) and abbreviated throughout the study to CFS/ME. This condition has courted controversy in lay and scientific communities for many years. This is related to a lack of recognition or legitimacy as a health condition by many in the scientific community (Cohen, 1997; Prins, van der Meer and Bleijenbergh, 2006; Jarrett, 2011; Knudsen *et al.*, 2011; Hanlon, 2013). The lack of recognition is due largely to the absence of identifiable biological markers to support its existence as a recognised disease (Nettleton, *et al.*, 2005). Without these there has been a tendency for some clinicians to label the illness as a psychiatric disorder (Cohn, 1999; Prochalska, Gressier and Corruble, 2012). Currently, the condition is still the subject of ongoing academic research into its cause(s) and into effective treatments to manage symptomatology (ME Research UK, 2013). In light of this, the condition is often

referred to as an 'illness' rather than a 'disease', indicating the subjective rather than scientifically objective status of CFS/ME as a diagnostic entity (Prochalska, Gressier and Corruble, 2012). Despite acknowledged difficulties with its legitimacy, CFS/ME is taken seriously by the NHS in England and there are currently 49 centres specialising in providing treatments for those with the condition (McDermott *et al.*, 2014). Additionally, the condition has attracted some scientific legitimacy in recent years as currently the World Health Organisation (WHO) categorises ME as a neurological disorder. This is due in part to the nature of associated symptoms which include difficulties with body temperature regulation and cognitive impacts such as 'brain fog' (WHO, 2016).

1.2 Rationale for the study and formulation of the research question

In 1998, following public and professional lobbying at a national level, the Chief Medical Officer for England established an independent working group to review the health care needs and NHS service provision for adults and children with CFS/ME (CFS/ME Working Group, 2002). The consequences of this work led to the publication of guidelines for service design and delivery, and research recommendations being made to explore causation, diagnosis, effective treatments and the impact of living with the illness (*ibid*). Additionally, ring-fenced, central funding for the development of CFS/ME services was made available, accessed via a bidding process to the Department of Health (DoH). In the same year, the Medical Research Council (MRC, 2002) suggested that narratives should be collected from people with CFS/ME to better understand their illness experiences and its changing daily nature. Since this time however, numerous studies linked to women's experiences have been conducted but those focusing on men's experiences have not appeared in the literature.

The dearth of literature linked to men's experiences was of interest to me in my clinical role as a consultant occupational therapist and clinical lead of a specialist, inter-professional fatigue service for adults. The service was designed and established by myself and a fellow occupational therapist in 2004 following a successful bid for funding to the DoH. Since 2004, I have worked with thousands of adults with CFS/ME, more women than men however, and developed my clinical skills and knowledge about this contentious condition and its impact upon people's day to day lives and occupations. During this time I have been motivated to develop and provide evidenced-based services for adults with CFS/ME and this motivation has underpinned my clinical practise and led to this research being conducted in order to better understand the experiences of men.

In lay terms, it is recognised that CFS/ME may commonly be assumed to be a female illness (Richman and Jason, 2001; Tseng and Natelson, 2004; Action for ME (AfME), 2007) with few accounts from men appearing in the media. Some evidence linking the possible cause of the illness to the role of female hormones may reinforce this assumption (Van Konynenburg, 2007). Additionally, but without fully understanding possible aetiology, the illness is usually reported as affecting more women than men in the academic literature (National Institute for Health and Clinical Excellence (NICE), 2007), meaning that men with the condition, it seemed to me, were a potentially hard to reach population in terms of research participation. Despite these factors, some indication of the impact of living with CFS/ME for men was provided via a membership survey by the national charity Action for ME (AfME) in 2007. AfME (ibid) gathered data via a questionnaire and telephone survey of 200 male members of the charity, all of whom considered they had CFS/ME. The survey highlighted a number of issues for the men including accounts by 95.3% (n = 190) of negative impacts on their lives, in terms of roles and identity. Additionally, the survey also revealed that over half of these men (n = 101) had lost male friends as male bonding was identified as often being linked to sport or physical activity which had been disrupted by the presence of fatigue. It was also reported that many had experienced severe economic losses as a result of their illness. Whilst I considered that the findings from the survey provided some insight into men's experiences, I had some concerns that participants may have had other contentious or undiagnosed conditions and/or other co-morbidities that were not mentioned, as all participated on a self-selected basis. Furthermore, these data did not provide contextualised accounts or arguably, trustworthy research evidence to inform possible improvements to future clinical practice. The opportunity to explore the survey data further however, might have been useful in informing the formulation of my research question. I therefore contacted AfME to request permission to access the raw data. This request was however, turned down by the charity on data protection grounds preventing any further scrutiny of the context, the reported findings or a critical appraisal of the survey methodology.

Before commencing this study I was also aware that a group of researchers from the University of Warwick had conducted 40 interviews with adults to capture the lived experience of having CFS/ME (Staniszewska *et al.*, 2010). This study was called the PRIME (Patients and Researchers in ME) project and was designed to establish an open access database for patient and researcher use. The rationale for publishing patient contributions was to emphasise the need for "*patient-based evidence*" (Staniszewska *et al.*, 2010 p. 313) to complement studies linked to CFS/ME clinical outcomes and economic evaluations. The PRIME project included qualitative data from 16 men of

unspecified ages and seemed to be a potential source of secondary data to provide background to or refute the need for my own study. Trying to access these data however was problematic and I was informed by personal email communication from the author that the database had not been maintained and was therefore no longer available for patient or researcher use.

Noticing the lack of literature linked to men's experiences led me to explore the gender of adults referred to the specialist fatigue service in which I worked by conducting an audit of referral data. Audit findings from a five year period between August 2007 and May 2011 were reflective of an increased prevalence in women, as reported in the literature, with only 120 men being referred to the service as opposed to over 800 women during this period. I considered therefore that as a specialist fatigue team we had probably become very experienced in identifying and meeting the needs of women with CFS/ME, but had some concerns that men's needs may not be being met and therefore required some exploration. With these concerns in mind, I began to search the literature and it soon became evident to me that research studies linked purely to men's experiences of living with a clinically confirmed diagnosis of CFS/ME were difficult to find. Furthermore, some authors had focussed exclusively on the experiences of women considering they were easier to recruit due to a higher reported prevalence in this demographic.

Adding to the rationale for conducting this study, I had noticed through clinical practice that men's anecdotal accounts of living with CFS/ME differed to women's in terms of perceived risks to personal safety. Risks included fear of physical attack by other men when out alone at night and were experienced due to a perceived inability to defend oneself because of a lack of energy and reduced levels of physical fitness. Such fears had prevented access to evening social events. Other differences reported were linked to concerns about not being the able to be the main income generator in their families as fatigue symptoms began to threaten their work performance and productivity. The importance of being a good father was also reported and had been brought into question for some men as available energy had to be used to address personal care and work tasks leaving little or no energy for spending 'quality time' with their children.

Considering the above factors collectively, I subsequently began to review the academic literature and was unable to identify any studies focusing exclusively on the experiences of men with the condition. The outcome of my fact-finding endeavours provided a rationale for an investigation into the experiences of men with CFS/ME and how this impacted on

their day to day lives and occupations. Researching this topic therefore, had the potential to address a gap in the literature and inform client-centred practice for men with CFS/ME. The principal research question posed in order to address the gap in the existing literature was therefore:

‘How is CFS/ME experienced by men living with this condition?’

1.3 Introduction to the study design, philosophical orientation and how new knowledge was generated

To address the research question, an interpretive phenomenological approach was employed. This enabled me to capture in-depth accounts of the meaning of living with CFS/ME for the men involved. This meant that I was able to better understand how this impacted upon their ‘being-in-the-world’, an existentialist concept first coined by the contemporary German philosopher Heidegger (1962). Finlay (2011) expands this definition and states that ‘being’ is *“the experience of existence; our human condition”* (Finlay, 2011 p. 19). The concept is also considered as our daily experiences or the *“everydayness”* of our life (Dahlstrom, 2013 p. 37) a matter therefore, of importance to occupational therapists. Additionally, ‘being’ is acknowledged in the occupational therapy literature as a concept linked to the notions of living authentically in the world and self-identity:

“To know one’s self is to know one’s being. One way that my self becomes known to me is through occupation and one way that my self expresses itself in the world is through occupation.” (Hasselkus, 2011, p. 25).

Finlay (2011), who is an occupational therapist, describes how interpretive phenomenological research can be used to explore existential issues in the following quote:

“It engages our human concerns relating to life, ageing and death, being and becoming, embodiment and identity, choice and meaningfulness, belonging and needs, sense of time and space, freedom and oppression, and so on.” (Finlay, 2011 p. 19).

This methodology therefore, held particular resonance with me as an occupational therapist in terms of how the meaning of occupation might be situated in the broader concept of ‘being-in-the-world’ for men with CFS/ME. Paying attention therefore to the

resonance between philosophical and occupational therapy frameworks, new knowledge was generated about the experiences of the participants in the study.

Data were generated from individual interviews with men of varying ages. Meanings were analysed using an interpretive approach and the metaphor of the hermeneutic circle. This is a concept of Heidegger's (1962) which was adopted by his student and fellow philosopher Hans-Georg Gadamer (Gadamer, 2004). Use of the metaphor enables attention to be paid to the smallest parts of the data and linked to the broader collective data in cyclical fashion in order to interpret experiences in context. Gadamer's work was used as the philosophical orientation to the study and is explored in greater depth in Chapter 3. Additionally, thematic analysis based on the work of Braun and Clarke (2006) was employed to organise the interpretations, and the uniqueness and similarities in the men's experiences were identified. The data were interpreted and discussed in relation to the existing literature. Additionally, new insights were provided linked to the meaning of the men's experiences of living with CFS/ME, conceptualised broadly as their 'being', which included the impact of this upon their day to day occupations, conceptualised generally as their 'doing'.

1.4 Defining occupation for the purposes of this study

The need to define occupation is intrinsic to this study but is not without difficulty. Historically, the origins of occupation lie in the Latin verb 'occupatio' which translates as "*to occupy or seize*" (Christiansen and Townsend, 2011 p. 2). In lay terms, occupation may be defined as; a job or work; some other task that may occupy one's time or attention such as a hobby (Hodder Educational, 2011); or as a collective noun referring to the occupation of a given physical space, such as occupying a property or specified geographical area (Chambers, 2011).

Over the last century, definitions of occupation have evolved within the occupational therapy profession to make sense of the meaning of what people do in their everyday lives and how they occupy their time. Ongoing attempts to provide a consistent and satisfactory definition of occupation has been driven by various occupational therapy theorists predominantly for research purposes. Definitions frequently include those that split occupation into specific task domains of everyday activity to explore and in some way measure. Examples include those from the USA by Kielhofner (2008) whose definition suggested occupation to be a combination of the activity domains of self-care, work and

play. Or the definition provided by Canadian based occupational therapy theorists which encompasses productivity (including paid and voluntary work and other activities such as childcare and household work), self-care and leisure domains (Law *et al.*, 1998). The use of such models is acknowledged as enabling an explanation of how occupation is identified. Conversely however, such models have been criticised for theoretically driving the meaning of occupation for individuals and therefore, of being at odds with the claimed client-centeredness of the profession (Hammell, 2004). Additionally, Hammell (*ibid*) suggested that the use of task orientated models to understand the meaning of occupation were limiting, simplistic and lacking in cultural context. She also suggested that their use may result in important contextual information being overlooked. In addition, Jonsson (2008) suggested that the use of categorical domains linked to the definition of occupation, including for example 'productivity' were formulated to address social policy and contemporary political drivers rather than being client-centred and were therefore paradoxical to what occupational therapists aim to achieve as a client-centred, caring profession. Like Hammell (2004) these definitions do not, she suggested, concentrate on the needs, aspirations, fears and lives of the individual. Neither do they enable exploration of possible links between engagement in occupation and health and well-being; the focus of practice for the occupational therapy profession and more broadly, and inter-professionally, the interests of occupational scientists.

Occupation is assumed by occupational therapists to be a socially constructed concept (Iwama, 2006) and as such, culturally contextualised for the individual. This means that occupation is considered as being much more than simply a task that occupies one's time (Wilcock, 2006). Occupational therapists therefore, acknowledge that the construct of occupation is embedded in theoretical and philosophical assumptions and these are listed in Box 1 below:

Box 1: Underpinning assumptions linked to the construct of occupation

- Occupation can broadly be defined as:
'All the things that people do in their everyday life'.
- Human beings are by nature occupational.
- People engage in occupation all the time.
- Through participation and engagement in occupations people understand cultural contexts.
- An individual's occupations contribute to their identity.
- Meaningful occupation draws from the individual's beliefs and values.
- Meaningful occupations may be personally or socially derived from the past experiences, an anticipated future and from the dynamics of the present.
- The meaning of occupation is often unspoken.
- Meaning of mundane occupations is diminished until the person is no longer able to accomplish them.

(Adapted from Reed, Hocking and Smythe, 2010).

Considering the underpinning assumptions as stated above, it is clear that the construct of 'occupation' or 'doing' is more difficult to define than it may at first seem. It is complex and multi-dimensional in nature, relates to the occupying of space and time and reflects motivational components in terms of purpose and meaning (Christiansen and Townsend, 2011). Additionally, it is suggested that to understand meaningful 'doing', attention to an individual's 'being' is also required based on their values and beliefs (Christiansen and Townsend, 2011).

In order to address the lack of meaning for the individual in definitions of occupation Wilcock (1998) expanded this from simply 'doing' to: *"a synthesis of doing, being and becoming"* (Wilcock, 1998 p. 249). Wilcock (ibid) considered that this definition better reflected the client-centred philosophy and essence of occupational therapy. Hasselkus (2011) summarises the meaning of Wilcock's definition as follows:

"Our sense of who we are as human beings and who we are becoming contributes to the intelligibility of our lives. Our being and our becoming are part of our life stories as they are lived and created anew each day; being and becoming emanate from the everyday doing of our lives". (Hasselkus, 2011 p. 24).

Leading on from this in 2000, Rebeiro *et al.* further expanded Wilcock's 1998 definition of occupation by adding the notion of 'belonging' to 'doing, being and becoming'. These elements of occupation were considered by Hammell (2004) to usefully reflect *"dimensions of meaning"* (Hammell, 2004 p. 296). Additionally, Hammell (2009a) argued that occupation should be defined as experience as opposed to task in order to capture the uniqueness of clients' perspectives encountered in occupational therapy practice. Hammell (2009b) also suggested that: *"if occupational therapists enabled diverse clients' perspectives to inform occupational categories, perhaps the relationship between occupations and well-being might more easily be identified in theory and addressed in practice"* (Hammell, 2009b p. 107). This suggestion sits well with the ontology and epistemology of interpretive phenomenological researchers interested in exploring the diverse perspectives of human beings' life experiences and the meaning of their subjective sense of well-being.

1.4.1 The definition of occupation adopted for the study

For the purposes of this study the overarching definition of occupation adopted is that stated by McColl (2003) as:

“Purposeful or meaningful activities in which humans engage as part of their normal daily lives.” (McColl, 2003, p. 1).

In order to understand the notion of meaningful activities however, occupation was explored more specifically in terms of *“doing, being, belonging and becoming”* (Wilcock and Hocking, 2015, p. xi). In this study ‘doing’ therefore, was situated within the philosophical concept of ‘being-in-the-world’. This exploration of occupation and its resonance with the Gadamerian philosophical orientation of the study are discussed in greater depth in Chapter 3 which focuses on the ontological and epistemological frameworks underpinning the enquiry.

1.5 An introduction to the profession of occupational therapy

In order to understand the role of occupational therapy in any setting it is useful to define what the profession is. The World Federation of Occupational Therapists (WFOT) defines occupational therapy as:

“Occupational therapy is a client-centred health profession concerned with promoting health and well-being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by working with people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or the environment to better support their occupational engagement” (WFOT, 2012).

This definition provides a comprehensive summary of what we do and why, and underpinning this definition, are the epistemological roots of the profession which are based in humanism and existentialism. That is, the profession adopts the stance that all humans are unique beings in the world and cannot simply be explained in reductionist physiological terms (Wilcock, 2006). Rather, the individual’s existence comprises thoughts, moods, feelings, relationships and conscious experiences, all of which contribute to their unique sense of being.

Occupational therapists consider that occupation is a naturally occurring phenomenon through which life experience is gained during transition over the life course, via:

“Doing [occupation], [which enables] being, becoming and belonging [which are a means to] ‘survival and health’” (Wilcock, 2006 p. 209).

Wilcock abbreviates this statement into the following equation: $d+b3 = sh$. With this equation in mind, occupation is acknowledged as a therapeutic modality possessing the potential to impact positively on health and well-being (Yerxa, 1990; Law *et al.*, 1998; Wilcock, 2006). This acknowledgment underpins therapeutic interventions provided by occupational therapists such as myself. In terms of this study, the role of the occupational therapist in services specifically for people with CFS/ME is detailed in Chapter 2 which provides a more contextualised background to the enquiry. Christiansen and Townsend (2011) however, summarise how client-centred occupational therapy services can provide positive outcomes in terms of health and well-being for service users:

“Occupational therapy services that address the client priorities and needs for occupation will also influence overall health, well-being and just or unjust participation in society.” (Christiansen and Townsend, 2011 p. 28).

In this quotation the notion of occupational justice/injustice is introduced which is defined as being: *“related to opportunities and resources required for occupational participation sufficient to satisfy personal needs and full citizenship.”* (Christiansen and Townsend, 2011 p. 421). This is a notion not always easily applicable to people with CFS/ME due to the stigma of having a medically unexplained illness and consequently, being treated negatively by others in day to day life (Wojcik, Armstrong and Kanaan, 2011; Grue, 2014). The notion of occupational justice/injustice originates in the occupational science literature, a relatively new and emerging academic discipline which will now be introduced.

1.6 An introduction to occupational science

The importance of systematically researching the notion of occupation and its impact on the lives of human beings is the concern of occupational science (Yerxa, 1990). As an academic discipline, occupational science is considered as new and emerging as it was first conceptualised and developed by occupational therapists across the world in the 1990s. Responsibility for its development is due in part to Wilcock who at the WFOT Conference in 1998 it is stated: *“highlighted the occupational foundations of the 1996 World Health Organisations Ottawa Charter for Health Promotion”* (Whiteford and Hocking, 2012 p. 167). Wilcock’s statement clearly linked the Charter to the possibility of health and well-being through occupation. Additionally, the impetus to develop occupational science was based on global trends at the time which Yerxa (2000) summarised as follows:

1. The increasing number of the population with chronic impairments impacting upon occupational participation in the daily life of their cultures.
2. Public policy debates about the needs and rights of people with impairments including the need for equality of capability.
3. The decreasing role of governments in providing resources for people with impairments.
4. New approaches to studying human beings in real-life contexts.
5. The growth in complexity of daily life resulting in problems in organising and using one's time, orchestrating activities, balancing roles and achieving competence and satisfaction through occupation.
6. A readiness for the occupational therapy profession to explore new concepts because of the worldwide maturation of the profession.

(Adapted from Yerxa, 2000 pp. 87-98).

Since the early days of its development occupational science has concerned itself with individual and collective explorations of the meaning of occupation for people globally and in a variety of cultures and contexts to enquire how social discourse shapes engagement in occupation and how political and socio-economic factors impact on occupational choices and opportunities (Whiteford and Hocking, 2012). In 2000, the International Society of Occupational Science (ISOS) was formed and their mission statement was formulated as follows:

“ISOS aims to advance world health, well-being and justice by energizing a worldwide network of individuals, groups and organizations to research, debate and activate for equity of opportunity for people, according to an understanding of their occupational nature.” (Whiteford and Hocking, 2012 p. 168).

Since 2000, the Journal of Occupational Science has come into being and three European Occupational Science Conferences have been held, the last of which I attended in 2015 to present emerging findings from the present study. This growth, I consider, demonstrates the increasing recognition of the importance of the role of occupation or ‘doing’ as intrinsic to our ‘being-in-the-world’.

1.6.1 The links between occupational science and other disciplines

Occupational science has clear links with the occupational therapy profession in terms of building a body of knowledge to support evidenced-based practice. However, the science also resonates with other health and social care practitioners such as psychologists and academics from disciplines such as sociology and anthropology, as one of the key beliefs of occupational scientists is that the discipline is naturally multi-professional in nature. This is a belief I support, as following the mission statement of ISOS (2000) in practice led to a successful multi-professional submission to the 2015 conference mentioned above, in collaboration with psychologists from the fatigue team in which I work. Furthermore, I consider that using the framework of occupational science in my practice has the potential for future academic enquiry of a multi-professional nature, enabling the meaning of 'doing' to be translated across and into inter-professional academia and practice.

1.7 The use of the term 'patient' in the study

Throughout the study the term 'patient' is used to describe people who access health and social care services. This is not used in any pejorative way but instead to provide context to their experiences and make clear the settings where they have received treatment. Additionally, in my experience the people with CFS/ME who access National Health Service (NHS) fatigue services do not usually have any issue with being referred to as a patient as long as they are treated with dignity and respect. This is in part, I consider, because they are generally pleased to have some support from NHS services and welcome the opportunity of being treated as a legitimate patient just as any other patient with a better understood health condition such as cancer or diabetes would usually be. For the patients I see however, this has sadly not always been the case.

1.8 Thesis construction

The thesis is largely written in the first person. Where appropriate contents are presented in tables or lists to clarify and summarise information. Links are given to relevant documents included in the appendices where appropriate.

Reflexive statements appear periodically and are headed as such and typed in italics, to illustrate reflection and critical thinking about my actions throughout the research process demonstrating an iterative, self-questioning approach to decision-making that contributes to the trustworthiness of the study (Bailey, 2007).

The thesis is arranged into seven chapters which include this first introductory chapter, **Chapter 1**, which provides a broad overview of the subject area, a rationale for the study, an introduction to the concepts included and mention of how new knowledge was generated. Additionally, a summary of each of the remaining six chapters is provided below.

Chapter 2 provides the background to the study. This includes the body of literature linked to how CFS/ME is currently understood, or not, by the medical world and a brief history of the condition. The potential causes of CFS/ME are explored. Difficulties and controversies linked with diagnosing the condition are included and the most commonly used diagnostic criteria are stated. The contentious nature of CFS/ME and issues linked to its status as a legitimate condition are addressed, and commonality with other misunderstood medical conditions is mentioned. The current recommended evidenced-based and informed guidelines for treatment appear. Additionally, the role of the occupational therapist in fatigue services is introduced. The chapter concludes with a critical review of the existing literature linked to the experiences of men with CFS/ME and identifies where gaps exist, demonstrating the need for this study.

Chapter 3 focuses on the ontological and epistemological considerations and assumptions underpinning the study. Definitions of the key terms ontology and epistemology are considered and their influence on the research process is discussed. The concept of truth is considered and how this is known. My ontology and epistemology as an occupational therapist are stated to situate myself and my pre-judgements within the enquiry. The selected philosophical orientation of Gadamer is introduced and a rationale for adopting a Gadamerian framework is also presented. The importance of Gadamer's attention to genuine dialogue and its role in facilitating an understanding of human experience is introduced. The chapter concludes by identifying the resonance between the philosophical orientation to the study and the selected methodology which is then presented in Chapter 4.

Chapter 4 includes a presentation of the chosen methodology with supporting rationale for selection. The sampling strategy for participant recruitment to the study is presented. The ethical considerations of the study appear in this chapter and two substantial amendments to ethics approvals are reported. The process of obtaining written, informed consent appears and signposting to the appendices containing the Participant Information

Sheet and other documents of relevance is included. Participant, researcher, transcriber and data safety issues are addressed. Additionally, participant demographics and the relationship between the participants and I are described. Data collection methods appear and are critiqued. An introduction to the hermeneutic circle appears which was employed during data collection and analysis. The location of the interviews is included and contrasts between differing locations are made. The practical management of the interviews is also discussed and the number of interviews conducted with each participant, their locations, duration and initial data codes generated are summarised in tabular form.

The importance of achieving genuine dialogue during interviewing is situated within a Gadamerian framework. The rejection of member checking in interpretive phenomenological enquiry is addressed.

How the data were thematically analysed using the work of Braun and Clarke (2006) appears in this chapter. This includes a critique of this process and mention of its usefulness in interpretive phenomenological studies. The six phases of the selected thematic analysis are described and illustrated in a flow diagram. The chapter concludes with a consideration of the importance of addressing trustworthiness in qualitative studies and provides examples of this from the study itself.

In **Chapter 5** the findings are presented in three sections. Section one details the uniqueness of each of the eight men's experiences which are summarised into themes. Section two includes a thematic map for each participant and is accompanied by co-created data from their interviews. The data are supported by verbatim quotes to add to the credibility and confirmability of the study and an accompanying narrative. In section three, a thematic map of similarities in experiences, referred to as 'shared experiences', appears in four themes. The four themes and sub-themes identified are presented and are also supported with verbatim quotes from the data and an accompanying narrative which provides the basis for the discussion chapter which follows.

In **Chapter 6** I explain how I understood the meaning of living with CFS/ME for the men involved in the study. A critical discussion of the findings is presented in relation to the literature review, and new and original contributions to the knowledge-base linked to men with CFS/ME are included. The findings support or refute the background literature as

appropriate. Reference to the wider literature is also made and implications for practice are addressed. The Chapter concludes with a consideration of the strengths and limitations of the study and suggestions for further research are made.

In the final chapter, **Chapter 7** the aim of the research enquiry is revisited. The implications of the findings for occupational therapy practice are considered. The limitations and strengths of the study are addressed and suggestions for future research enquiries are made. I provide a conclusion to the study which addresses what the study adds to the knowledge-base and how this may be of use in practice.

1.9 Chapter summary

In this chapter I have introduced the research topic and situated the rationale for my study within the current landscape of debates around the nature of CFS/ME. An introduction to key concepts such as 'being-in-the-world' and occupation are introduced. Additionally, an overview of the thesis construction and chapter contents were provided to demonstrate the direction of the enquiry and add to the flow of the report. Chapter 2 will now provide a more in-depth background to the study and a critical review of the existing literature linked to the experiences of men with CFS/ME.

Chapter 2:

The background to the study and critical review of the existing literature

2.0 Chapter overview

In this chapter an introduction to CFS/ME is provided which includes a brief history of the illness, potential causes, difficulties with how the illness is defined and therefore diagnosed, and current recommended treatment interventions. Additionally, the impact of having CFS/ME and the consequences of this on day to day life and occupations is discussed. The role of the occupational therapist in fatigue services is summarised and my own experiences of working with men with CFS/ME are acknowledged. The commonality of CFS/ME with other long-term conditions is also discussed. The chapter includes a critical review of the literature performed in a systematic manner to identify what is known about men's experiences of living with CFS/ME and a synthesis of the findings from the review are presented in three inter-related themes. Additionally, gaps in the existing literature linked to men's experiences of living with CFS/ME are identified to demonstrate the need for this study to be conducted.

2.1 An introduction to CFS/ME

Chronic Fatigue Syndrome (CFS), known more commonly in the past as ME (Myalgic Encephalopathy or Encephalomyelitis), is classified as a neurological condition by the WHO (2016). CFS/ME is a debilitating, fluctuating, long-term condition characterised by intolerance of physical and mental exertion, with delayed impact on both physical and mental functioning, that is not significantly alleviated by rest (NICE, 2007). Most people with the condition experience sleep disturbance and many experience significant muscle pain. Other symptoms may also be experienced such as headaches; nausea; digestive problems (for example constipation or diarrhoea); flu-like malaise; wildly fluctuating body temperature; and/or allergies and sensitivities to noise, medications, food (including typically alcohol), chemicals, light, or touch (Fukuda *et al.*, 1994). Additionally, the Medical Research Council (2011) considers CFS/ME to be a medical condition that is both complex and seriously debilitating and imposes a substantial burden on the health of the United Kingdom (UK) population. Furthermore, it is claimed that CFS/ME has a greater

impact on well-being and functional abilities than other chronic conditions including cancer (Nacul, *et al.*, 2011).

2.2 Collecting epidemiological data about CFS/ME

Collecting epidemiological data about CFS/ME is acknowledged as challenging due to the variability of case definitions potentially employed and Prins, van der Meer and Bleijenberg (2006) suggested that more research was needed to address this issue. Prevalence is however, estimated as being 0.4% - 2% of the population, with a ratio of 3:1 women to men with the condition (NICE, 2007; Reid *et al.*, 2008; Prochalska, Gressier and Corruble, 2012). Currently it is estimated that approximately 250,000 men, women and children in the UK live with the illness (AfME, 2014). Three levels of severity are recognised which are; mild, moderate and severe CFS/ME, dependant on the person's abilities to do activities for themselves and carry out daily tasks (NICE, 2007). The severity levels are defined in Box 2 below:

Box 2: Severity levels of CFS/ME

Mild CFS/ME:

People are mobile, can care for themselves, and can do light domestic tasks with difficulty. Most are still working or in education, but to do so have probably stopped all leisure and social pursuits and have often taken days off from work/education.

Moderate CFS/ME:

People have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work or education and need rest periods. Their sleep at night is generally of poor quality and disturbed.

Severe CFS/ME:

People are unable to do any activity for themselves, or can carry out minimal daily tasks only (such as face washing, cleaning teeth). They have severe cognitive difficulties and depend on a wheelchair for mobility. They are often unable to leave the house, or have a severe or prolonged after-effect if they do so. They may also spend most of their time in bed, and are often extremely sensitive to light and noise.

Adapted from NICE, 2007.

The condition affects all racial, ethnic and socioeconomic groups (Burns, Bennett and McGough, 2012). However, recent research suggests that the prevalence of CFS/ME in England is higher in minority ethnic groups with risk factors for CFS/ME being lack of physical activity, anxiety, depression and negative aspects of social support (Bhui, *et al.*, 2011).

2.3 A brief history of CFS/ME

Historically, illnesses with similar symptoms to that currently defined as CFS/ME are discussed in the literature dating back as far as the 16th century and are referred to as 'the English sweats' (Cox, 2000). Over the twentieth century reported outbreaks across the world of fatigue-like conditions have been reported without establishing any definitive cause. The labelling of similar illnesses has been the subject of much debate over time (Nettleton, *et al.*, 2005). Labelling therefore, has varied and been attributed to symptoms experienced, location of outbreaks or in one instance to a social stereotype and has included; 'neurasthenia' in the 1860s, 'fibrositis' in the 1890s, 'Icelandic disease' in the 1940s, 'encephalomyelitis/Royal Free disease' in the 1950s, 'myalgic encephalomyelitis' (ME) in the 1970s, 'post-viral fatigue syndrome' (PVFS) and 'yuppie flu' in the 1980s, 'chronic fatigue and immune deficiency syndrome' (CFIDS) in the 1980s and worldwide, 'chronic fatigue syndrome' (CFS) in the 1990s (Cox, 2000). Over time these definitions have evolved, some building on others or contesting or modifying suggested criteria for definitional purposes, reflecting ongoing diagnostic debates (Christley, Duffy and Martin, 2012). Additionally, Prochalska, Gressier and Corruble (2012) suggested that the more general term of CFS rather than ME has been used for many years to reflect the lack of knowledge regarding aetiology and disease process. More recently the Institute of Medicine (IOM) in the United States of America has controversially suggested a further name change for the illness to systemic exertion intolerance disease or SEID for short (IOM, 2015). For UK health professionals currently however, the NICE Guidelines (2007) recommend adopting a label of CFS/ME when referring to the illness to aid collective understanding.

2.4 Investigating the potential causes of CFS/ME

There is growing evidence that inflammatory factors acting upon the central nervous system may contribute to CFS/ME (Arnett and Clarke, 2012). Other possible causes of CFS/ME have been explored in terms of: links to genetics; physical inactivity; sleep disturbance; neurobiological abnormalities involving serotonin metabolism; central

nervous system changes such as reduced grey matter volume and lower than average cerebral blood flow; relationships with anxiety and depression; personality disorders; co-morbidities with conditions such as Irritable Bowel Syndrome (Prochalska, Gressier and Corruble, 2012); complex interactions operating between physiology, cognition, emotion and behaviour (Moss-Morris, Spence and Hou 2011); and enhanced interoception, a concept where activity is perceived as being more of an effort than in healthy controls and where cognitive and physical abilities are under-estimated with a heightened awareness of one's internal physiological state (White, 2004). Common viruses including upper respiratory tract infections have been excluded as a possible cause. However, viruses causing glandular fever, hepatitis, viral meningitis, Q fever and Ross River virus have been linked to a possible causative role (Moss-Morris, Spence and Hou, 2011). Additionally, studies into the role of enzymes on female hormones have been conducted to explore the higher incidence rates in women (Van Konynenburg, 2007) and further investigation is suggested to explore gender bias (Moss-Morris, Spence and Hou, 2011). Despite these investigations none of these potential agents has been conclusively proven to cause CFS/ME although all are acknowledged and suggested as potential risks or triggering factors for the development of this complex, multifactoral condition, or as possible predisposing, precipitating or perpetuating elements (Afari and Buchwald, 2003). At this time therefore, the cause of CFS/ME is still unknown and consequently, no known cure for the illness exists. However, a degree of legitimacy has been afforded to the label of CFS/ME as it is recognised by the World Health Organisation as a neurological condition (WHO, 2016). In summary, despite 30 years of research into the causes of CFS/ME (Prins, van der Meer and Bleijenberg, 2006) it is suggested that further work is still needed which includes the search for specific markers to distinguish between CFS/ME and any associated co-morbid psychiatric conditions (Christley, Duffy and Martin 2012).

2.5 Difficulties with diagnosing CFS/ME

In addition to the debates linked to how the illness should be labelled, inconsistency exists regarding which diagnostic criteria should be most frequently adopted in clinical practice and for research purposes (Christley, Duffy and Martin 2012). In 2011, Carruthers *et al.* made an attempt to reach an international definitional consensus via a Delphi-type process which involved an independent patient advocate, clinicians, researchers and teaching faculty across thirteen countries including the UK. The participants were stated as having approximately 400 years of clinical and teaching experience collectively and of diagnosing or treating approximately 50,000 patients with CFS/ME. The researchers

chose to adopt the Canadian Criteria which excludes symptoms of mental illness and is one of five published diagnostic criteria available in the literature (Prochalska, Gressier and Corruble 2012). The Canadian criteria are consistent with the literature acknowledging that whilst CFS/ME and clinical depression share some common symptomatology, the conditions can be distinguished separately by the individual adopting unique coping styles (Moss-Morris and Petrie, 2001). It is suggested that people with CFS/ME cope by reducing physical activity, trying to avoid stress and believing in external attributions for their illness; whilst people with depression are distinguished by exhibiting low self-esteem in terms of coping and by attributing their illness to internal/psychological factors (Moss-Morris and Petrie, 2001).

Other attempts have been made to reach a worldwide consensus for case definitions which link both physical and psychiatric symptoms in CFS/ME, potentially strengthening associations which may not exist. These case definitions have however, been considered as too broad for CFS/ME diagnostic purposes (Christley, Duffy and Martin 2012) and are not therefore adopted consistently in research or clinical practice.

Additional attempts to add to the body of knowledge linked to case definitions of CFS/ME include the work of Wojcik (2011) and Wojcik, Armstrong and Kanaan (2011). These authors conducted a survey of consultant neurologists registered with the Association of British Neurologists (ABN) and asked 591 participants two questions related to CFS:

- Question 1. *“Did you know that chronic fatigue syndrome (CFS) is classed as a neurological condition in ICD-10?”*
- Question 2. *“Do you believe that CFS is a neurological condition, in the ‘usual sense of neurological’?”*

(Wojcik, 2011, p. 573).

A response rate of 59% (n = 351) was achieved after two rounds. In response to question one, 229 (65%) responded ‘yes’ they did know, 116 (33%) responded ‘no’ and 6 (2%) gave no answer. In response to question two, 42 (12%) responded ‘yes’ that they did believe CFS to be a neurological condition ‘in the usual sense of neurological’, 295 (84%) responded ‘no’ and 14 (4%) gave no answer. Two respondents (0.6%) said ‘no’ to the first question and ‘yes’ to the second and 38 (11%) answered ‘yes’ to both questions. This study would seem to support the notion that a majority of consultant neurologists

registered with ABN at the time did not believe CFS to be a neurological condition 'in the usual sense'. What criteria were used to define 'in the usual sense' however was not clear. There would also seem to be some discrepancy over the definition of 'the usual sense' between consultant neurologists as 38 of them answered 'yes' to both questions leaving the reader in some doubt about consensus between their professional opinions. This survey reinforces doubt around the issues of what CFS/ME is and how it should be defined. In terms of patient experience of gaining a diagnosis, it is interesting to consider perhaps the consequences and potentially variable outcome for the patient in an encounter with one or more of the neurologists involved in this study.

2.6 When a diagnosis of CFS/ME may be made

It is clear from the literature that no one common definition currently satisfies the collective clinical and academic population of those working in the field of CFS/ME and it is suggested that minimum data elements need to be collected when conducting research studies for comparative research purposes (Jason, *et al.*, 2012b). Additionally, it is suggested by many that the Fukuda *et al.* (1994) criteria devised by the Centers for Disease Control (CDC) in the USA and summarised in Table 1 below, are the most prominent and widely used of several that are available (Devanur and Kerr 2006, Prins, van der Meer and Bleijenberg, 2006; Browne and Chalder 2009; Christley, Duffy and Martin 2012). These criteria however, were devised in order to further CFS/ME research rather than as a diagnostic tool for clinicians. It is not therefore, without criticism, as the criteria were formulated through consensus of opinion of those working in the field rather than as a result of research findings. It is stated in the literature however, that their adoption has assisted in terms of unifying starting points in academic research in this contentious field of study (Christley, Duffy and Martin 2012). Also, the use of these criteria, importantly to the patient, facilitate a diagnosis of CFS/ME to be considered after excluding other serious illnesses first such as Lyme's Disease, multiple sclerosis, coeliac disease, anaemia and hypothyroidism. Despite acknowledged variability in case definitions confirmation of a clinical diagnosis of CFS/ME may then be made after the exclusion of other conditions associated with fatigue (Harvey and Wessely, 2009; Prochalska, Gressier and Corruble, 2012). A positive diagnosis is therefore, known as a diagnosis by exclusion (NICE, 2007). For the patient this means that it is only after a variety of sometimes invasive and exhaustive medical tests have been conducted to exclude other conditions that may mimic its symptoms (Afari and Buchwald, 2003), that a diagnosis of CFS/ME should be made (NICE 2007). Additionally, and in order to make a diagnosis, it is suggested that "A (case) *formulation that identifies predisposing,*

precipitating and perpetuating factors is valuable for providing an explanation to the patient and for planning management” (Sharpe, 2008 p. 453).

Table 1: The most prominent and widely used diagnostic criteria for CFS/ME.

CDC case definition of CFS/ME (Fukuda Criteria <i>et al.</i>, 1994) summary.
Clinically evaluated, medically unexplained, persistent or relapsing fatigue of at least 6 months duration that is:
<ul style="list-style-type: none"> • New onset (not life-long) • Not result of ongoing exertion • Not substantially alleviated by rest • A substantial reduction in previous level of activities
Plus the occurrence of 4 or more of the following symptoms:
<ul style="list-style-type: none"> • Impaired memory and or concentration • Sore throat • Tender lymph nodes • Muscle pain • Joint pain • New headache • Unrefreshing sleep • Post exertional malaise
Exclusion criteria:
<ul style="list-style-type: none"> • Medical condition explaining fatigue (e.g. untreated hypothyroidism, sleep apnoea, narcolepsy) • Any previously diagnosed medical condition whose resolution has not been documented • Any past or current diagnosis of major depressive disorder or bipolar disorder, schizophrenia, dementia, or delusional disorder, anorexia nervosa, bulimia nervosa, alcohol or substance abuse • Severe obesity (Body Mass Index of > 45) • Any unexplained physical examination finding or laboratory or imaging test abnormality that strongly suggests the presence of an exclusionary condition

(Adapted from Fukuda *et al.*, 1994).

2.7 General Practitioners’ (GPs) experiences of diagnosing CFS/ME

In 2010, Chew-Graham *et al.* conducted a survey in England of twenty-two GPs’ experiences of diagnosing and managing CFS/ME. Study participants reported feeling unconfident in diagnosing such a complex condition, being uncertain of its existence and additionally concerned about their inability to access any fatigue management services. Despite these findings the authors claimed that CFS/ME was being increasingly

recognised in primary care as an entity in its own right (Chew-Graham *et al.* 2010). In my own experience this seems to be the case as since the fatigue service in which I work was set up in 2004, a consistent annual increase to date of approximately 20% in referral rates has been evident from primary care referrers for adults with CFS/ME.

Despite ongoing controversies and reported concerns of GPs, the NICE Guidelines (2007) encourage GPs to consider making a diagnosis of CFS/ME when a patient presents with enduring fatigue of four months duration or more, a change from the 1994 Fukuda Criteria of six months as appears in Table 1 above, in the absence of any other medical cause and to take a needs-led, patient-centred approach which should be delivered locally by suitably trained teams of professionals. However, evidence of conflict between GPs and patients about the nature of the condition can be problematic, preventing or delaying a timely diagnosis (Chew-Graham *et al.*, 2010).

2.8 Recommending that CFS/ME is recognised as a legitimate condition

Due to the lack of a definitive diagnostic test to biologically confirm the existence of CFS/ME the nature of the illness is still not necessarily recognised as a legitimate health condition by some health practitioners (Lingard and Court, 2014). According to expert opinion however, this has become less of a problem in the last ten years or so due in part to an influential political lobbying campaign launched at the start of the millennium by health professionals, patients and their families demanding that Government action be given to address the ongoing and debilitating nature of CFS/ME. As a consequence of this campaign, the Chief Medical Officer for England published a report recommending that CFS/ME be recognised as a legitimate condition (CFS/ME Working Group, 2002).

Following two decades of “*heated debate*” (Fry and Martin, 1996 p. 424; Prins, van der Meer and Bleijenberg, 2006, p. 346; Prochalska, Gressier and Corruble, 2012, p. 40) the existence of CFS/ME is still in question. Against this shifting and contentious background people with this condition, or where this condition is suspected, are at times left in a position of uncertainty regarding their health and well-being and what to do about the fatigue-related issues they are experiencing (Gilje, Soderlund and Malterud, 2008). Additionally, the use of a diagnostic label has been considered as being potentially disabling or enabling depending on what the label implies (Huibers and Wessely, 2006).

For example, using the term 'fatigue' exclusively in its diagnostic labelling, can add to confusion when significant pain and other symptoms, such as brain fog, or word-finding difficulties are also likely to be experienced (Caruthers *et al.*, 2011). In order to address these symptoms in clinical practice NICE Guidelines (2007) are employed.

2.9 Recommended treatment interventions for CFS/ME

The current evidenced-based UK guidelines for CFS/ME published originally by NICE in 2004 and updated in 2007, emphasise the need for primary care clinicians to make an early and accurate diagnosis with appropriate referral to specialist services for management of the condition. However, research demonstrates that this is not necessarily happening in the recommended timeframe (Chew-Graham *et al.*, 2010). Ongoing debates in primary care linked to defining the condition can cause difficulties in obtaining a diagnosis, leading to uncertainty and stigma for patients (Clarke and James, 2003; Whitehead, 2005).

The NICE Guidelines (2007) were based on the limited amount of research findings available, collective expert opinion and anecdotal, contemporary patient experiences, gathered by the UK charity Action for ME (AfME) in a survey of members in 2006 (AfME, 2006). This survey was based on the response of approximately 2000 members, regarding their opinions on the best ways to cope with their condition on a day to day basis. The results of this survey fed into the NICE Guidelines to form the current evidence base for treatments, which comprises a combination of life-style management (including self-help education and advice regarding energy management and pacing of daily activities) and help to better control symptoms (for example, through the prescribing of analgesics to manage associated pain) (NICE, 2007). These Guidelines are still used in clinical practice despite the recent PACE randomised controlled trial (White *et al.*, 2011) which has caused worldwide controversy linked to protocol design (Smith, 2015).

2.10 The impact of CFS/ME on day to day life and occupations

What occupies our time across the life span are issues which are often taken for granted and may not be given our full attention due to being considered as everyday occurrences. The everyday is something that goes unnoticed until something happens in our lives that disrupts and disturbs the everyday. Becoming ill may be considered as one such disruption. The everyday occupations of people at the onset of CFS/ME, during their

illness and during the time leading up to gaining a diagnosis, may become inaccessible. This can leave people with a sense of loss akin to bereavement, as exclusion and alienation from their usual lives, roles routines and activities/occupations results in reduced control and agency over their 'being', 'doing', 'becoming' and 'belonging'.

In order to understand what it means to live with CFS/ME it is necessary to acknowledge the lack of a consistent diagnostic or case definition for the condition and the consequences of this for the individual in terms of their subjective sense of health and well-being (Christley, Duffy and Martin, 2012). As the cause of CFS/ME remains unknown and no definitive, diagnostic test is currently available (Browne and Chalder, 2009; Carruthers *et al.*, 2011; Wojcik, Armstrong and Kanaan, 2011; Jason *et al.*, 2012a; Christley, Duffy and Martin, 2012), a definitive prognosis for people who are diagnosed with CFS/ME is also uncertain (NICE, 2007). However, accounts of recovery do appear in the associated literature claiming that people may improve to a lesser or greater degree (Soderlund, Skoge and Malterud, 2000). Additionally, it is recognised that different stages in the natural course of CFS/ME exist they are; acute illness, experienced at onset or during a relapse; maintenance or stabilisation, living with the symptoms to a greater or lesser degree and; recovery, considered as an absence of the illness (NICE, 2007).

The impact of living with a condition that courts diagnostic controversy can be confusing and detrimental for the individual concerned (Jarrett, 2011). CFS/ME has been described in the literature as "*an orphan illness*" (Prochalska, Gressier and Corruble 2012, pp. 46) as with its mix of physical and psychological symptomatology, it has been considered to sit on the borders of medicine and psychiatry and therefore is un-adopted by either clinical field. Furthermore, the condition is one of the most common reasons for children being absent from school for protracted periods of time (Royal College of Paediatrics and Child Health, 2004), and in adults and children, can be the cause of severe life disruption.

Given the unpredictable and fluctuating nature of CFS/ME (NICE, 2007), it is easy to imagine how day to day lives, roles, routines and occupations can no longer be followed. For example, when someone with the condition experiences a set-back in their energy levels this might lead to occupational disruption, defined as "*a transient state of being restricted from participation in necessary or meaningful occupations*" (Christiansen and Townsend, 2011 p. 420). If following the set-back they are able to return to necessary or meaningful occupations, occupational potential may be re-established. If however, the set-

back becomes prolonged they may then experience occupational deprivation defined as “*prolonged preclusion from engagement in occupations of necessity or meaning due to factors outside the control of an individual, such as through geographical isolation, incarceration, or disability*” (Christiansen and Townsend, 2011 p. 420). Living with the impact of CFS/ME it is argued can be detrimental to the person’s subjective sense of health and well-being, defined here as “*a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*” (World Health Organisation, 1948).

2.11 Occupational therapy for people with CFS/ME and introduction to my clinical role

As an occupational therapist working in a fatigue service I am aware that members of the profession can and do play an important role in the delivery of client-centred, evidenced-based interventions for people with CFS/ME in a variety of settings (Moore, 2000; Gray and Fossey, 2003; McDermott *et al.*, 2014). This includes a potential role within primary care which is acknowledged in the literature in terms of assisting people with the condition when the short term transient state of occupational disruption is experienced (Hughes, 2009). In my experience however, a significant number of people I see have had their lives and occupations disrupted for so long that they are experiencing ongoing occupational deprivation due to the chronic nature of CFS/ME.

As the cause of CFS/ME is currently unknown occupational therapy interventions cannot offer a cure. Rather, our aim is to alleviate symptoms and ensure occupational justice for all. This is achieved by empowering the person to self-manage their CFS/ME using various adaptive strategies to cope with the condition despite the presence of fluctuating and disabling symptoms of a mild, moderate or severe nature as defined earlier in the chapter in Box 2. Patients I see may have tried a variety of alternative treatments to cope with their condition. This may include alternative or complementary therapies such as dietary supplements, Lightning Process, Reiki, homeopathy or acupuncture. Currently however, the evidence base linked to such therapies for CFS/ME is unsubstantiated (Reid *et al.*, 2008; Knudsen *et al.*, 2011; Burns, Bennett and McGough, 2012). My advice therefore to people who have tried these or wish to do so, is that as long as they can be afforded and essentially ‘do no harm’ they may be worth trying, but do not guarantee a cure.

In line with the current NICE Guidelines (2007) occupational therapists work in partnership with people with CFS/ME to identify how the condition impacts upon their everyday life and activities/occupations. This is achieved through individual assessment of those referred to specialist fatigue services such as the one in which I work. My role includes performing a holistic assessment of the occupational needs of the person through gathering an account of how the illness has developed for them and how their illness beliefs (Pemberton and Cox, 2013) have impacted upon all they want, need and have to do in daily life, whilst also addressing contextual social and environmental factors. Following assessment, a tailored and jointly negotiated treatment plan is formulated taking a shared decision-making approach (NICE, 2007). This enables provision of evidenced-based interventions to address identified and often fluctuating needs. The formulation of this plan facilitates a returning to, or maintenance of, participation in their day to day lives and occupations and therefore, impacts positively on their individual sense of health and well-being.

The importance of the links between occupation, health and well-being are identifiable in the stories people with CFS/ME bring to their assessment and treatment encounters with me. Their losses in terms of occupations, roles, routines and identities trouble them and prevent them from engaging in the everyday things they used to like to do and those they need to do. Their expectations, and those of significant others, are commonly a source of guilt and anxiety. In-depth accounts are openly shared by them. These accounts are used to help us to understand a person's needs, values, beliefs and motivations. Once these are identified we can then offer interventions that may help them to cope more easily with their day to day lives and occupations despite the presence of CFS/ME. Without these accounts we would arguably not be able to help as much as we do. We are led by the needs and aspirations of those referred to our service and actively seek out their subjective stories in order to impact positively on their experiences of living with the condition in the absence of a known cure.

2.12 CFS/ME and commonalities with other misunderstood long-term conditions

Whilst CFS/ME might be considered to be a contentious condition in terms of its diagnosis, it is interesting to acknowledge that it shares commonalities with other long-term conditions where fatigue is a feature such as Systemic Lupus Erythematosus (SLE) and Rheumatoid Arthritis (RA) (Holmes, 1988). Historically, these conditions were also

linked to the efforts of academics and healthcare professionals to establish effective symptom identification, diagnostic criteria and possible causal factors (Christley, Duffy and Martin, 2012). However, whilst the causes of these conditions still remain inconclusive, both SLE and RA are now recognised worldwide in the field of rheumatology and have therefore been legitimised in healthcare practice (Klippel and Dieppe, 1995). Why this is the case is unclear, but it may be that as both conditions are usually associated with some visible and therefore objective symptom manifestations, such as skin rashes or joint swelling, they have therefore been afforded a legitimised status. However in CFS/ME, fatigue and associated symptoms are not necessarily observable to the clinician or others, further adding to the contentious nature of the condition from a biomedical perspective.

Non-visible health issues can create a dilemma for those with CFS/ME and other conditions such as chronic headaches or Fibromyalgia Syndrome (FMS); a chronic pain condition of contested origins and legitimacy (Wolfe *et al.*, 1990). This issue was explored by Lonardi (2007) in her study of what she termed “*socially invisible disease*” (Lonardi, 2007, p. 1619) to refer to a condition where “*people who are affected look exactly the same as physically healthy people and adopt outwardly normal behaviour in public*” (ibid, p. 1620), which is commonly the case for people with CFS/ME. Her study focused on the life stories of 31 participants (24 women and 7 men) all of whom experienced chronic headaches and had been attending a specialised pain centre in Northern Italy. Using a grounded theory approach, Lonardi explored how people became aware of objective, subjective and socially constructed aspects of living with chronic pain. She asked participants about their experiences of ‘disease’ (considered as objective), ‘illness’ (considered as subjective) and ‘sickness’ (considered as socially constructed aspects of experience), and whether, as their experiences were non-visible, they disclosed their experiences, or concealed them and dealt with them alone. Her findings captured reports of illness trajectories, a notion defined by Glaser and Strauss (1965), as stories of biographical disruption consistent with Bury’s work (1982). These were concerned with the impact of living with chronic pain and how it interfered with participants’ daily lives, identities, self-reliance and social relationships.

Lonardi (ibid) also discovered the need for participants to stabilise this disruption and negotiate its representation in social situations. In this part of her study she linked her work to the theories of Goffman (1963) on stigma in terms of people disclosing their experiences, risking living with stigma and the alternative notion of passing; which means living in secrecy with the burden of their experience being kept to themselves. She

suggested that whichever option is decided upon, there may be success or failure, in terms of the person managing or not, the reconstruction of their social identity. The importance of social identity negotiation for people with contested conditions was a key finding in this paper. She argued that if a condition cannot be seen it potentially has no socially recognised representation, which leaves the person with the condition in a discredited state that she refers to as “*social death*” (Lonardi, 2007, p. 1625). The Lonardi study concluded that “*as long as people believe that a headache is normal and that it goes away with a tablet, there is not much hope for building understanding social networks*” (Lonardi, 2007, p. 1629).

Lonardi’s findings (2007) about assumptions that chronic headaches are normal to experience and easy to alleviate resonate with assumptions about fatigue experienced by those with CFS/ME. In clinical practice the acronym TATT is familiar to me and others as a medic’s shorthand for ‘Tired All The Time’. To the lay person, everyone gets tired; this subjective experience cannot necessarily be objectively observed and in most people’s understanding will go away after a short period of rest. In CFS/ME however, this is not the case, as the fatigue experienced is not necessarily alleviated by short periods of rest and is classically experienced some time after the event as post exertional fatigue, rather than as an immediate consequence of relative energy expenditure (NICE, 2007). Additionally, and because their health issues are generally non-visible, people with CFS/ME or chronic pain, may have been through a process of diagnostic uncertainty possibly having visited various specialists on a number of occasions to gain a legitimate diagnosis (Clarke and James, 2003).

The consequences of having a contested condition for the participants in the Lonardi (2007) study and also for people with CFS/ME is the risk of loss on many levels including the loss of their ability to be, do and become who they wish, as self-identity, occupations, social agency, relationships, roles and responsibilities are all potentially negatively affected. Additionally, their sense of inter-connectedness with others and belonging to society may also be impacted upon by their illness.

A qualitative study by Asbring (2000) explored identity transformation as a consequence of chronic illness for twenty-five women, twelve diagnosed with CFS/ME and thirteen with the chronic pain condition Fibromyalgia Syndrome (FMS), two contentious diagnoses with overlapping symptom profiles (Norregaard *et al.*, 1993). Findings indicated that radical life

disruption is experienced, impacting negatively particularly on work and social activities and on the expected life course. As activities became difficult or impossible to engage in, the concept of 'self' was disrupted in terms of past, present and future possible self-identity. A minority of the participants were able to maintain activities which were important to their identity while others were not. The impact of this, Asbring (2000) claims, is that, with a partial maintenance of self-identifying activities, only a partial transformation of identity was needed. For others a greater transformation was needed, as activities had to be given up or adapted in order to come to terms with their new identity. Furthermore, reconciliation to a new identity was more established for those who had lived with their diagnosis longer. For those who had been ill for a significant period of time but received a diagnosis late however, reconciliation seemed less well established and may have been prolonged. The participant's "*horizon of planning*" (Asbring, 2000, p. 316) was reported as lost due to the fluctuating and unpredictable nature of CFS/ME and also FMS. This study provides examples of how a person's activities or occupations, can impact upon their identity and the need for occupational adaptation to facilitate reconciliation with changed self.

In addition to the negatively reported consequences of having CFS/ME or FMS, Asbring (2000) also mentioned that positive gains were made by some. These included an opportunity for a re-evaluation of needs and habits and a re-prioritisation of obligations and social relationships, which were linked to increased self-respect and personal integrity. However, whilst these findings were interesting, the views of men with CFS/ME were not captured in the study.

2.13 Building on the rationale for the study

The rationale for this study is presented in chapter 1 in sub-section 1.2 and supported by the lack of literature linked specifically to the experiences of men with CFS/ME at the start of this study in 2010. Once the rationale for the study was established a critical review of the existing literature was conducted which is now presented as part of this chapter.

2.14 The Literature Review

2.14.1 Introduction to the review and the research question posed

In this section of the chapter I summarise the evidence available to address the research questions posed by this study. The principal question was:

‘How is CFS/ME experienced by men living with this condition?’

A review of the literature was commenced in December 2010 and completed in April 2014 to address the principal research question and the following sub questions:

- What is already known about the experiences of men living with CFS/ME and how the condition might impact upon their occupations?
- Where are the gaps in the current literature relating to men living with CFS/ME?

2.14.2 The search strategy

A search strategy was devised linked to the research topic and scope which included key terms such as ‘CFS’, ‘ME’, ‘PVFS’, ‘men’ and ‘experiences’ and the Boolean operators ‘AND’ and ‘*’ were employed as appropriate, to combine and/or extend key search terms. Electronic databases were searched including ASSIA, BNI, Social Services Abstracts, Sociological Abstracts, AMED, CINAHL Plus, MEDLINE, PsychARTICLES, PsychINFO, and SocINDEX, accessed via the library website at UWE (See Appendix A for an audit trail of literature search). No date limits were set in order to capture literature from as wide a time period as possible. The search was completed in April 2014 to address the research questions and situate the study in the available published literature at that time. In order to identify high quality literature, only published peer reviewed studies were included. In June 2016 and updated search of the literature was performed and two papers of relevance published later in 2014 were identified these were; Brooks, King and Wearden (2014) and Lingard and Court (2014). Both papers focused on the experiences of couples relationships with each other, where one of the partners had a diagnosis of CFS/ME. Uniquely, the Brooks, King and Wearden (2014) paper focused on two men in their mid-fifties with a diagnosis of CFS/ME. Additionally, the authors explored positive and negative interactions with healthcare professionals. The findings from both papers highlighted the importance of the role of ‘significant others’ and the potential for

relationships to be strengthened as a result of having CFS/ME. The findings identified from the updated search however, were not unique. Similar findings were identified in the literature review completed in April 2014 and therefore, as the literature review, analysis and synthesis had been completed earlier these papers were included in the discussion chapter of this thesis in section

2.14.3 Identifying existing knowledge and gaps in the literature

During initial searches, it was consistently reported in the literature, that men were less likely to be affected by or diagnosed with CFS/ME than women (Prochalska, Gressier and Corruble, 2012) and that men with CFS/ME were considered to be relatively scarce in the general population, making their inclusion in research studies uncommon (Ciccone, Weissman and Natelson, 2008). This claim was supported by the lack of identifiable literature available following my own searches.

From the searches conducted between October 2010 and April 2014, only five papers were identified which specifically focused on the subject of men and chronic fatigue or CFS/ME. Four of the five studies were biomedical in nature and one reported on the outcomes of a graded physical activity programme for one male participant. None of the studies focused on the experiences of living with CFS/ME. The studies were;

- Sharpe *et al.* (1997), who investigated neuroendocrine control in men with CFS/ME and concluded, without experimental evidence, that hormonal change may be due to prolonged inactivity or a disrupted sleep-wake cycle.
- Unwin *et al.* (1999), who focused on fatigue experienced as a consequence of Gulf War Syndrome and the need for vaccination against biological warfare.
- Friedberg (2002) who investigated via a single case study, the impact of a twenty-six session Cognitive Behavioural Therapy-based graded activity programme and reported improved walking time and weight lifting intensity.
- Shor (2007) who reported on the similarities between CFS/ME and Lyme Disease and the importance of testing for this, in a case study, focusing on one man who was reported as being undiagnosed with the treatable condition of Lyme Disease for two years.
- Ciccone, Weissman and Natelson (2008) which focused on the aetiology of fatigue between samples of male Gulf war veterans and civilian men, to establish whether sub-types of the condition existed through experimental blood sample analysis.

The aim of the researchers was to establish whether conditions of a medically unexplained nature could be attributed to a single syndrome hypothesis and for these reasons the study was not included in this review, as it did not relate to men's experiences of living with CFS/ME. The four other studies mentioned were also rejected from this review for the same reason.

2.14.4 Inclusion and exclusion criteria for the literature review

Originally, in October 2010, the inclusion criteria for the literature review were limited to research linked to men's experiences only. However, due to the lack of available published qualitative literature available, the original inclusion criteria were broadened in January 2012 in order to explore experiences of 'adults' with CFS/ME. This resulted in some literature being identified linked to the experiences of men, but noticeably and predominantly, all studies also included data linked to women. It was anticipated however, that specific examples of men's experiences could be extrapolated from the data, to illustrate their experiences. The criteria appear in Table 2 below:

Table 2: Inclusion and exclusion criteria used to identify literature of relevance

Inclusion Criteria	Exclusion Criteria
<p>October 2010: initial searches. Experiences of men of any age with CFS/ME/PVFS/CFIDS.</p> <p>January 2012: criteria broadened. Experiences of adults with CFS/ME/PVFS/CFIDS. (Studies including both men and women).</p>	Literature related exclusively to experiences of women with CFS/ME/ PVFS/CFIDS.
English language papers.	Non English language papers.
Qualitative, published, peer reviewed literature including primary studies and systematic reviews of qualitative studies/meta-ethnographies.	Unpublished/grey literature.
No date limit.	

2.14.5 The papers included in the review

A total of eleven papers were eventually selected for inclusion in this review and a critical appraisal and synthesis of findings can be found in this chapter. All studies appropriately employed qualitative methodologies to explore experiences of living with CFS/ME. Nine of these were primary studies and two were qualitative, meta-ethnographies, also known as meta-syntheses (Anderson *et al.*, 2012). A list of the included studies appears below in chronological order:

1. **Ware N. C. (1992) primary data study.** Suffering and the Social Construction of Illness: The deligitimation of Illness Experience Chronic Fatigue Syndrome.
2. **Cooper (1997) primary data study.** Myalgic Encephalomyelitis and the medical encounter.
3. **Tuck and Human (1998) primary data study.** The Experience of Living with Chronic Fatigue Syndrome.
4. **Dickson, Knussen and Flowers (2007) primary data study.** Stigma and the deligitimation of experience: An interpretative phenomenological analysis of people living with chronic fatigue syndrome.
5. **Larun and Malterud (2007) a meta-synthesis of twenty-one qualitative studies.** Identity and coping experiences in Chronic Fatigue Syndrome: A synthesis of qualitative studies.
6. **Arroll and Senior (2008) primary data study.** Individuals' experience of chronic fatigue syndrome/myalgic encephalomyelitis: An interpretative phenomenological analysis.
7. **Dickson, Knussen and Flowers (2008) primary data study.** 'That was my old life; it's almost like a past-life now': Identity crisis, loss and adjustment amongst people living with Chronic Fatigue Syndrome.
8. **de Carvalho Leite *et al.* (2011) primary data study.** Social support needs for equity in health and social care: a thematic analysis of experiences of people with chronic fatigue syndrome/myalgic encephalomyelitis.
9. **Anderson *et al.* (2012) a meta-synthesis of thirty-four qualitative studies.** A review and meta-synthesis of qualitative studies on Myalgic Encephalomyelitis/chronic fatigue syndrome.
10. **Arroll and Howard (2013) primary data study.** 'The letting go, the building up, [and] the gradual process of rebuilding': Identity change and post-traumatic growth in myalgic encephalomyelitis/chronic fatigue syndrome.

11. **Anderson, Jason and Hlavety (2014) primary data study.** A Qualitative Natural History Study of ME/CFS in the Community.

2.14.6 How the papers in the review were critically appraised

All papers were critically appraised using a recognised critical appraisal tool (Crowe and Sheppard, 2011). The qualitative, primary studies were appraised using the McMaster University School of Rehabilitation Science Critical Review Form – Qualitative Studies (Version 2.0) (Letts *et al.*, 2007). I felt this was particularly appropriate as questions are included which enable the appraiser to consider whether the research has implications for occupational therapy practice and research. The two meta-syntheses were appraised using a combination of the Critical Appraisal Skills Programme (CASP) Systematic Reviews Checklist (CASP, 2013) and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Checklist (Moher *et al.*, 2009). A combination of both CASP (2013) and PRISMA (2009) was used as both were originally designed for reviews of quantitative studies so neither is tailored specifically to qualitative reviews. By combining the two tools however, a more comprehensive critique was possible. For example, CASP contains tick boxes which enable a summary of the review to be recorded and easily reviewed and PRISMA includes a section linked to the funding of research, enabling conflicts of interest to be easily identified, whereas CASP does not.

A summary of the critical appraisals for the eleven papers included in the literature review is presented in Table 3 below:

Table 3 Critical appraisal summaries of the articles in the review

Author/Date Theoretical Underpinnings and Aim	Methodology and Methods	Main Findings and Conclusion	Strengths and Limitations	Relevance to My Study
<p><u>1. Ware (1992).</u></p> <p>Author field: Medical Anthropology.</p> <p>Major theoretical stance: Social constructionism of cultural concepts e.g. 'suffering' Kleinman (1992) & 'illness reality' defined by Good (1977).</p> <p>Aim of Study/Paper: Elicitation of accounts of illness experiences and 'illness reality'.</p>	<p>Qualitative: Life History.</p> <p>Interviews n = 50. Women n = 40. Men n = 10.</p>	<p>'Illness reality' difficult for those with a contested/delegitimate 'not real' non-visible condition leads to trivialisation of symptoms by medics and others and experiences of stigma, shame, alienation & blame. As 'illness' is socially constructed currently delegitimation leads to illness not being real, but an exaggeration of the everyday = malingering or imagined symptoms = "crazy". Struggle over definition of reality in CFS & status of persons with the condition not same as those 'genuinely ill' = no access to catharsis. Medicine needs to reframe thinking.</p>	<p>One off interviews with n = 50 adults. Rich data illustrated in verbatim quotes. Definitions of concepts used to frame analysis included. Rationale for sample size not stated. No mention of where interviews took place. Pre-defined concepts used as framework may have limited analysis of data and meaning of experiences.</p>	<p>Men's accounts of living with CFS/ME included: n = 10. However, gender not reported for quotes male voice therefore not identifiable. Claim that tendency for medics to discount women's accounts. (Female author).</p>

Author/Date Theoretical Underpinnings and Aim	Methodology and Methods	Main Findings and Conclusion	Strengths and Limitations	Relevance to My Study
<p><u>2. Cooper (1997).</u></p> <p>Author field: Sociology</p> <p>Major theoretical stance: Social Constructivist.</p> <p>Disease as objective (Doctor's subjective) and illness as subjective and culturally bound.</p> <p>Aim of Study/Paper: Explores consequences of the medical encounter for those with CFS/ME over time from pre to post diagnosis.</p>	<p>Qualitative: Biographical/ Narrative.</p> <p>Interviews n = 10.</p> <p>Women n = 7 (One woman's mother provided data on her behalf).</p> <p>Men n = 3.</p>	<p>Disease ontology prioritised over illness ontology by medics (Kleinman, 1980).</p> <p>Difficulties in gaining a diagnosis as subjective/illegitimate condition. No access to sick role. No common language.</p> <p>Altered perceptions of role of medics & challenge to symbolic authority if not diagnosed due to delegitimate nature of CFS/ME.</p> <p>Shifting power & myth challenging patients who know more than GP. Desire to be acknowledged by mainstream health systems/culturally valued. Diagnosis assists rapport.</p> <p>No diagnosis leads to alternative therapies being sought including support groups. Double disruption of: 1. Day to day life 2. Deconstruction of social personality. GP sexism: bored housewife syndrome.</p>	<p>Claims to have included people who were 'severely affected' (SA)/hard to reach participants.</p> <p>Descriptions of those with SA: did not fit clinical picture of SA how this was assessed is not included but threatens credibility of data.</p> <p>Participants may not have met any criteria for CFS/ME as recruited via support group.</p> <p>Ethics & informed consent not addressed.</p> <p>Analysis not explained threatening dependability.</p>	<p>Men's accounts of living with CFS/ME included: n = 3.</p> <p>n = 2 quotes appear in data to identify male voice: 1 man positive re GP and diagnosis 1 negative.</p> <p>Mention GPs more accepting of men's illness n = 2 but acknowledged can't generalise. (Female author).</p>

Author/Date Theoretical Underpinnings and Aim	Methodology and Methods	Main Findings and Conclusion	Strengths and Limitations	Relevance to My Study
<p>3. <u>Tuck and Human (1998)</u>.</p> <p>Author field: Nursing.</p> <p>Major theoretical stance: Phenomenological.</p> <p>Aim of Study/Paper: To explore the physical & emotional components of experience of CFS.</p>	<p>Qualitative: Interpretive Phenomenology.</p> <p>Questionnaires with open ended questions: responses ranged from a single paragraph to several pages, n = 22.</p> <p>Women n = 19 Men n = 3</p>	<p>Three categories of experiences included:</p> <ol style="list-style-type: none"> 1. Being in the illness. 2. Life before and after CFS. 3. Living with CFS. <p>Acknowledged need for a holistic approach (mind, body and spirit) in nursing, showing empathy & compassion.</p> <p>Temporal nature of experiences emphasised. Changes in life & perceptions of self following illness.</p>	<p>One of the only studies to include mention of a clear audit trail which increases trustworthiness.</p> <p>Main limitation is use of questionnaires for an interpretive phenomenological study and lack of opportunity to clarify during data collection to reach shared understandings of meanings.</p> <p>Also chose to use image of a woman in the journal where published (stereotypical).</p>	<p>Men's accounts of living with CFS/ME included: n = 3.</p> <p>Gender not reported for quotes male voice not identifiable.</p>

Author/Date Theoretical Underpinnings and Aim	Methodology and Methods	Main Findings and Conclusion	Strengths and Limitations	Relevance to My Study
<p>4. <u>Dickson, Knussen and Flowers (2007)</u>.</p> <p>Author field: Health Psychology.</p> <p>Major theoretical stance: Phenomenological.</p> <p>Aim of Study/Paper: To explore experiences of living with CFS.</p>	<p>Qualitative: Interpretative Phenomenological Analysis (IPA).</p> <p>Interviews n = 14.</p> <p>Women n = 8. Men n = 6.</p>	<p>Two inter-related themes presented:</p> <p>1. Negotiating a diagnosis & negative delimiting experiences: GPs commonly attributed CFS to depression. Deception employed to 'kid' GP re tablets secretly not taken to legitimise condition. Frustration, hatred & disappointment with GPs. Diagnosis = legitimacy. Delay => distress. Anomie.</p> <p>2. Negotiating CFS with loved ones & finding this more difficult than attitudes of GPs. Seen as personal rejection/loss as much a burden as illness itself. Stigma. Support = well-being.</p>	<p>Claim re unique focus on partners' and friends' attitudes and deligitimation not been conducted before.</p> <p>Recruitment via an alternative health clinic that provided a list of n = 7 client names: Ethical data protection issues? n = 7 were friends or colleagues of the first author – Bias and pressure to participate?</p> <p>Plus self-reported diagnosis issues.</p>	<p>Men's accounts of living with CFS/ME included: n = 6</p> <p>n = 3 quotes appear in data to identify male voice: re depression v CFS, trivialisation & intolerance of friends, well versus unwell & work attendance.</p> <p>Authors claim men well represented in this study unlike others.</p> <p>Acknowledged other studies report women being treated differently to men by GPs but <u>not</u> found in this study.</p>

Author/Date Theoretical Underpinnings and Aim	Methodology and Methods	Main Findings and Conclusion	Strengths and Limitations	Relevance to My Study
<p><u>5. Larun and Malterud (2007).</u></p> <p>Author field: Public health & primary health care backgrounds.</p> <p>Major theoretical stance: Medicine.</p> <p>Aim of Study/Paper: To provide insights into how patients & doctors experience CFS.</p>	<p>Systematic review of qualitative data: n = 20 qualitative studies to identify & translate across studies to access understandings & organise the increasing body of knowledge about CFS experiences & therefore create access to processes possibly influencing the progress & impact of CFS. Literature: 1993 – 2005 & multidisciplinary: Anthropology Sociology Psychiatry General Practice Occupational Therapy Epidemiology.</p>	<p>Papers analysed to provide interpretation of original findings & developed constructs from line of arguments: 1. Symptoms experienced & impact on everyday life: 3 common = extreme fatigue, debilitating pain & cognitive problems. Enigmatic & serious impact on day to day life. 2. Illness beliefs & causal attributions: infection, bodily collapse, not psychosomatic, weak character. 3. Doctor patient interaction: Lack of confidence in GPs, physician scepticism, stigma & trivialisation. Identities of CFS patients challenged when legitimacy of illness is questioned. Doctors struggle to maintain professional authority. Patients expect science will supply the answer. Identity challenged when legitimacy questioned burden adds to loss = vulnerability additional to symptom suffering.</p>	<p>Use of Noblit & Hares's (1998) guidelines for meta-ethnography studies & quality checklist to identify "empirical studies".</p> <p>Clear trail for selection and rejection of papers.</p> <p>Extends the level of interpretation of primary studies.</p> <p>n = 3 of the included papers did not specify gender mix of participants.</p> <p>Many papers included recruited from support groups – may be issues with self-diagnosis.</p>	<p>Out of n = 20 papers: n = 0 studies focused on just men's experiences; n = 9 studies focused on just women's experiences; n = 2 studies did not state gender of participants; n = 2 studies focused on GPs experiences; n = 7 studies included both men & women. Gender not reported for quotes male voice not identifiable.</p>

Author/Date Theoretical Underpinnings and Aim	Methodology and Methods	Main Findings and Conclusion	Strengths and Limitations	Relevance to My Study
<p><u>G. Arroll and Senior (2008).</u></p> <p>Author field: Health Psychology.</p> <p>Major theoretical stance: Phenomenological.</p> <p>Aim of Study/Paper: To explore experiences of conceptualising symptoms and experiences of trying to obtain a diagnosis.</p>	<p>Qualitative: Interpretative Phenomenological Analysis (IPA).</p> <p>Interviews n = 10.</p> <p>Women n = 8. Men n = 2.</p>	<p>6 themes linked to journey from pre diagnosis through illness course & symptom perceptions:</p> <ol style="list-style-type: none"> 1. Recognising symptomatology. 2. Illness course. 3. Impact on daily and working life/occupations. 4. Frequency of symptoms. 5. External information. 6. Diagnosis & treatment. <p>Gaining a diagnosis likened to 'quest' but stated as not the end of "the journey" but may have been the beginning re search for help & restoration of health.</p>	<p>Acknowledged people who are severely affected are hard to reach & could not therefore include in study.</p> <p>Good analytical rigour demonstrated.</p> <p>Procedural rigour could have been better e.g. no mention of where telephone interview calls took place.</p> <p>Not necessarily best data collection method i.e. use of telephone interviews for a phenomenological study.</p>	<p>Men's accounts of living with CFS/ME included: n = 2. n = 1 man commented glad he was not female as GP encounter could be more difficult (myth?)</p> <p>n = 2 quotes appear in data to identify male voice: fluctuating lack of stamina & unpredictable nature of feeling ill & weakness as getting older not illness.</p> <p>Makes mention of occupational impact of having CFS/ME & cites occupational therapy academic literature in support.</p>

Author/Date Theoretical Underpinnings and Aim	Methodology and Methods	Main Findings and Conclusion	Strengths and Limitations	Relevance to My Study
<p><u>7. Dickson, Knussen and Flowers (2008).</u></p> <p>Author field: Health Psychology.</p> <p>Major theoretical stance: Phenomenological.</p> <p>Aim of Study/Paper: To gather experiential accounts from adults living with CFS/ME.</p>	<p>Qualitative: Interpretative Phenomenological Analysis (IPA).</p> <p>Interviews n = 14.</p> <p>Women n = 8. Men n = 6.</p>	<p>3 inter-related themes identified:</p> <ol style="list-style-type: none"> 1. Identity crisis: agency & embodiment. 2. Scepticism & the self. 3. Acceptance, adjustment & coping. <p>An ongoing sense of personal loss with reduced agency & control.</p> <p>Identity, agency and control regained via adapting activities to ensure degree of success. Importance of psychosocial environment emphasised.</p>	<p>Questionnaire employed to check participants met Fukuda (1994) diagnostic criteria.</p> <p>Recruitment via an alternative health clinic that provided a list of n = 7 client names: Ethics & data protection? n = 7 were friends or colleagues of the first author: undue influence/pressure to participate?</p> <p>1 interview in researcher's home - not necessarily best place for a phenomenological study or for researcher safety.</p>	<p>Men's accounts of living with CFS/ME included: n = 6.</p> <p>n = 4 quotes appear in data to identify male voice: 1 x death trap as no life; 1 x felt useless & illness taking control; 1 x hopeless & helpless empty shell a fragment of who they used to be; 1 x life in tatters can't do what want to do.</p> <p>Adaptation of daily activities to match abilities = core skills of occupational therapists and achievable tasks = acceptance of self, illness & improved self-worth.</p>

Author/Date Theoretical Underpinnings and Aim	Methodology and Methods	Main Findings and Conclusion	Strengths and Limitations	Relevance to My Study
<p><u>S. de Carvalho Leite et al. (2011).</u></p> <p>Author field: Multi-disciplinary: medicine, occupational therapy and social sciences, took a health equity perspective, based on previous studies of inequity of access to services for people with CFS/ME.</p> <p>Major theoretical stance: Variety as multi-disciplinary team.</p> <p>Aim of Study/Paper Report on need for equity in health and social care services for adults with CFS/ME.</p>	<p>Qualitative: Interpretive Phenomenology. Data led thematic analysis.</p> <p>1. Focus group n = 6 (? gender).</p> <p>Then follow up:</p> <p>2. Interviews n = 35.</p> <p>Women n = 27. Men n = 8.</p>	<p>Needs for personalised, timely & sustained support to alleviate impact & regain life control grouped into 3 themes:</p> <ol style="list-style-type: none"> 1. Symptoms, functional limitations & illness management. 2. Practical support and social care 3. Financial support. <p>Experiences of those with CFS can usefully inform/educate health practitioners, policy makers & general public & promote shared decision making, co-ordinated action & promote human rights for those with CFS/ME.</p> <p>Changes in attitudes of those above & more flexibly organised health & social care provision & advocacy are needed.</p>	<p>Overall rigour demonstrated well. Evidence of 4 elements of trustworthiness: i.e. credibility, transferability, dependability & confirmability.</p> <p>Data collected over time, multiple methods, multiple interviews, triangulation of data & researchers.</p> <p>Made mention of including participants from ethnic minorities.</p> <p>Claim sample was diverse & participants acknowledged as belonging to a heterogeneous group.</p>	<p>Men's accounts of living with CFS/ME included: n = 8.</p> <p>n = 1 quote appears in data to identify male voice: 1 x needed complete care.</p> <p>Role of occupational therapy specifically mentioned in terms of enabling equity in terms of access to work and educational roles.</p>

Author/Date Theoretical Underpinnings and Aim	Methodology and Methods	Main Findings and Conclusion	Strengths and Limitations	Relevance to My Study
<p>9. <u>Anderson et al. (2012).</u></p> <p>Author field: All authors from psychology background.</p> <p>Major theoretical stance: Constructivist.</p> <p>Aim of Study/Paper: To review & synthesise findings across qualitative studies on ME/CFS.</p>	<p>Systematic review of qualitative data: Analysed within a meta-analytic framework. Included a multi-perspective examination of ME/CFS plus a comparative analysis of ME/CFS versus other chronic conditions.</p> <p>Review comprised n = 34 qualitative studies.</p>	<p>Failure of medical label reinforces social & psychiatric explanations. Stereotyping of patients continues & includes stigma from professionals, families & friends. Variability in symptoms, identity changes, reductions across physical, social & economic domains, efforts to cope & balance activity. Need for education to help with diagnosis & therefore legitimise. Patients and health care professionals struggle to understand & manage the illness.</p> <p>Future research: recommended community based samples & to integrate various components within ME/CFS experience including the sociocultural environment; plus challenge clinicians' dominant assumptions & account for victim-blaming tendencies to move research & practice forward. Also recommended need for increased qualitative studies to capture self-perceptions of people with CFS/ME to better understand experiences of marginalisation.</p>	<p>Provides structured summary & situates the study in what is already known & builds on the meta-analysis of Larun and Malterud (2007).</p> <p>Methods explained, synthesis of results explained.</p> <p>Acknowledges potential bias due to selection of participants from those with access to some form of support services.</p> <p>Limitations included & funders acknowledged.</p>	<p>All 34 studies scrutinised. Those of relevance n = 21. Less relevant n = 13, reasons: just women, or medic/GP experiences. Claims that tendency for medics to take men more seriously than women are included. No quotes from participants included, male voice not specifically identifiable.</p>

As this review by Anderson et al. (2012) was first submitted to publishers in November 2010, it is suggested that this is probably the reason for The de Carvalho Leite et al. (2011) study not being included in the meta-synthesis.

Author/Date Theoretical Underpinnings and Aim	Methodology and Methods	Main Findings and Conclusion	Strengths and Limitations	Relevance to My Study
<p><u>10. Arroll and Howard (2013).</u></p> <p>Author field: Health Psychology.</p> <p>Major theoretical stance: Phenomenological.</p> <p>Aim of Study/Paper: To explore the lived experiences for those with CFS/ME. Focus on data analysis re positive aspects of identity change & notion of 'post traumatic growth' (PTG) viewed as positive.</p>	<p>Qualitative: Interpretative phenomenological analysis (IPA).</p> <p>Interviews n = 10.</p> <p>Women n = 7. Men n = 3.</p>	<p>4 main themes:</p> <ol style="list-style-type: none"> 1. Comparisons of past to present self. 2. Effects of social isolation on identity. 3. Subsequent insights of others. 4. PTG gradual process of letting go, building up & rebuilding (not necessarily sequential). <p>Reported difficulties with more understood conditions e.g. cancer & identity & there fore increased difficulties for those with CFS/ME.</p> <p>Some will experience PTG n = 2, some will not n = 8. Mention of "yo-yo health" & life "in limbo" & impermanence of life plans. Suggest psychological interventions can assist with PTG.</p>	<p>Overall rigour: 4 elements of trustworthiness: i.e. credibility, transferability, dependability & confirmability.</p> <p>Both authors had personal experience of CFS/ME & included reflexive accounts of this.</p> <p>Both claimed to be "recovered" paper may have provided catharsis for them? Additionally, both work for a private clinic providing treatments for those with CFS/ME - marketing? Background identity literature appears to be related to women only.</p>	<p>Men's accounts of living with CFS/ME included: n = 3.</p> <p>n = 3 quotes appear in data to identify male voice: 1 x loss on many levels; 1 x career shapes who you are; 1 x like the old me.</p> <p>Mention of how restoration or discovery of meaningful occupations impacts on/have a vital role to play in influencing subjective well-being & identity & reference to occupational therapy academic literature.</p>

Author/Date Theoretical Underpinnings	Methodology and Methods	Main Findings and Conclusion	Strengths and Limitations	Relevance to My Study
<p>11. <u>Anderson, Jason and Hlavaty (2014)</u>.</p> <p>Author field: Psychology.</p> <p>Major theoretical stance: Feminist constructivist.</p> <p>Aim of Study/Paper: To examine the experiences of a community based sample of people with CFS/ME to explore events that may lead to identifying course & progression of illness overtime.</p>	<p>Qualitative: Grounded Theory</p> <p>Wave 2 of a 2 stage study, Wave 1 (n = 213) having occurred 10 years earlier.</p> <p>Participants recruited from those included in Wave 1 of the study.</p> <p>Interviews n = 19.</p> <p>Women n = 16. Men n = 3.</p>	<p>3 major inter-related categories established:</p> <ol style="list-style-type: none"> 1. Importance of understanding context in which illness is experienced. 2. The physical construction of the illness. 3. Coping & illness management strategies. <p>Medical & social inequity still exists for people with CFS/ME especially women.</p> <p>Future research needed to ensure patients' voices are heard & conduct longitudinal studies.</p>	<p>Fatigue screening conducted. Procedural rigour demonstrated e.g. researchers trained & flexibility evident: a choice of face to face or telephone interviews offered This could have been considered a strength or a limitation.</p> <p>Analytical rigour also demonstrated.</p> <p>Trustworthiness evidenced: rich data, team of researchers & triangulation of data.</p> <p>Study published in <i>Healthcare for Women Int.</i> but includes men meaning study could have been missed due to readership demographic - query choice of publication? Possibly also published results elsewhere.</p> <p>Some of the physical changes could have been age-related e.g. weight gain & hormonal issues but all attributed to CFS/ME.</p>	<p>Men's accounts of living with CFS/ME included: n = 3.</p> <p>n = 2 quotes appear in data to identify male voice: 1 x death in family as cause; 1 x coming out as gay identity stress & cause.</p> <p>Notions of "occupational identity" & "occupational reduction" mentioned in lay terms & need to balance activities & develop adaptive strategies.</p> <p>Reported that historically literature includes tendency for medics to discount women's accounts. (Feminist authors).</p>

2.14.7 Research designs and epistemologies of authors included in the review

Qualitative data were generated from all eleven studies included in this review however; research designs and the epistemological stance of the authors were variable. Whilst it is acknowledged as problematic to attempt to synthesise the findings of studies with a variance in design, theoretical stance and epistemology (Creswell and Plano Clark, 2011), I considered that as all studies claimed to include qualitative reports of men's experiences, that all findings potentially had some importance to my study. Additionally and regardless of major theoretical stances adopted, many similarities in findings across the studies were identified.

2.15 Papers

2.15.1 Paper 1: Ware (1992)

The earliest study identified, from the USA, by Ware (1992), explored cultural concepts of suffering, due to deligitimation of CFS/ME and the notion of illness reality, as defined by Good (1977). Fifty participants, ten of whom were men were included, all of whom were part of a general physician's case load, having sought help for debilitating fatigue. It was however, unclear if all fifty met any recognised diagnostic criteria and the author makes no mention of how the participants were recruited or ethical considerations of the study. The participants were all interviewed once. No mention was made of where the interviews took place or their duration and the experiences of men are not specifically reported. It would seem that data collection was theoretically driven and analysed narrowly linking to the two concepts mentioned above, as opposed to reporting on the wider experiences of adults living with CFS/ME.

The author found that delegitimation encounters were reported with both physicians and others, including friends. Mention of legitimation was linked to visible symptoms such as swollen glands. Self-doubt was linked to people being repeatedly disbelieved and their illness reality was therefore threatened. As a consequence, a retreat into secrecy and a hidden existence was reported, leading to alienation, feelings of shame and stigma and an inability to access catharsis or coping. Depression was also reported as a part of the illness rather than a cause. The intractability of the medical model was discussed and the need for medicine to reform its thinking about CFS/ME was suggested. These findings were important to me as they held resonance with my pre-understandings of the impact of CFS/ME on day to day life, based on anecdotal experiences gained through clinical practice.

Suggestions for future gender specific research were made by the female author. These were not however, linked to men's experiences (the minority of participants included in her research) but instead, those of women. Ware's (1992) rationale for this, was that women were more readily discounted by the medical profession than men. As the majority of participants in this study were female, it could be argued that basing this assumption on this study alone could be misleading. Additionally, these findings may not be easily generalisable to assist with understanding men's experiences, as their accounts are not explicitly reported in the data. Some caution therefore, needs to be observed and credibility questioned.

2.15.2 Paper 2: Cooper (1997)

The second study in the review was based on the experiences of ten adults, seven women and three men. The mother of one of the women provided data on behalf of her adult daughter. Participants were recruited by the author via a community-based, voluntary self-help group, either by phone or newsletter. This was however, only after the group organiser was allowed to decide whether she considered potential participants would be suitable for inclusion in the study. This may be considered as a major limitation of the study as selection criteria were unclear. This may have resulted in people with other unexplained/undiagnosed conditions being included, in addition to or opposed to, those with a confirmed diagnosis of CFS/ME. Additionally, the demographic details of participants were not comprehensively included which would have been interesting to consider in terms of potentially different experiences reported at various points in the life span.

The author used interviews as a data collection method, conducted in participants' own homes to reduce the burden of needing to travel to the researcher's location. Whilst this, I felt, demonstrated some understanding of the impact of CFS/ME on her participants, I had some suspicion regarding the author's understanding of the illness, as she reported she had interviewed people who were bedridden, but who were "*extremely active*" (Cooper, 1997 p. 191) from a functional perspective, being able to run and attend the support group. Whilst the fluctuating nature of CFS/ME is acknowledged, this description threatened the credibility of the findings of this study, as it is not my clinical experience/my prejudgement, that this would be possible for those who were experiencing severe CFS/ME. A sense of naiveté therefore seemed to surround this researcher's claims and her perceptions of someone who was severely affected, which was inconsistent with published literature (Cox and Findley, 1998; NICE, 2007) and my extensive clinical

experience. The social constructionist concept of an 'illness career framework' was used to guide data analysis, although an audit trail of the process was not included, making analysis difficult to replicate and threatening dependability.

The main findings reported were linked to difficulties with obtaining a diagnosis and therefore, alternative therapies, including support groups being sought for help; altered perceptions of the symbolic authority of medics and challenges to this; and disease ontology being prioritised over illness ontology by medics. These findings uniquely report on the ontological issues around illness and disease when compared with the other studies included in this review. Caution needs to be observed however, due to the limitations linked to recruitment, researcher's assumptions and lack of understandings and the lack of identifiable data linked to men's experiences of living with CFS/ME. Two verbatim quotes from men do however, appear in the study findings, one being from a forty seven year old, who had self-diagnosed his ME due to reluctance from his GP to do so. This had led to him providing his GP with some CFS/ME literature, which he reported, had provoked a negative response in his doctor and made him feel like a bad patient. The other quote was from a man whose age was not stated, who had experienced a very supportive response from his GP to his illness. Not only did his GP tell him he could see he was ill, thus legitimising his illness, he was also apologetic when he could not do anything to help during a domiciliary visit to the patient. This is an interesting piece of data, as it illustrates that a genuine partnership encounter occurred between the patient and his GP, with the GP letting go of his symbolic authority by admitting the failure of modern medicine in not being able to help.

In summary, whilst there are some significant limitations to this study, a degree of relevance to my own study was acknowledged, as the presence of men's experiences are reported. It is worth remembering however, that only one of them had a medically confirmed diagnosis of CFS/ME and the other may possibly have been experiencing some other illness or disease, threatening the credibility of these data, but not necessarily so.

2.15.3 Paper 3: Tuck and Human (1998)

Tuck and Human (1998), sought to collect in-depth, rich data from adults to explore the physical and emotional components of having CFS/ME. The sampling process for this study was described in detail and an audit trail for data analysis was designed strengthening its dependability and analytical rigour. Twenty two participants were

recruited either from a CFS/ME support group, or from participants at a CFS/ME tele-conference. Participants volunteered to take part and were between 19 and 74 years of age. Nineteen women and three men were included; twelve were married, three were single and seven were divorced; and only three participants were in employment. Ethics and consent were addressed. Data were collected through questionnaire completion and the authors acknowledge this as a limitation of the study, as they were unable to explore and clarify the data with participants, to strengthen the confirmability of the data. Nevertheless, they considered their findings provided valuable insights into living with CFS/ME. The authors suggested that future research into the experiences of people with CFS/ME should include face to face contact and in-depth interviews, rather than collecting data via postal questionnaires.

Data were presented as three themes or units of meaning for the participants, these were; 1. Being in the illness; 2. Life's contrasts before and after CFS; and 3. Living with symptoms of CFS. The key findings from this study were that CFS is an holistic condition affecting mind, body and spirit and people with CFS ground their experiences in a temporal way, reporting being in the illness first, recounting life before the illness, and living with symptoms. They also suggest that empathy and compassion are essential components of practice for nurses working with people with CFS/ME. Whilst valuable insights were gained from this study in terms of 'being' and 'doing' over time, experiences of men are not identifiable in the data, which should therefore, be treated with some caution in terms of transferability.

2.15.4 Paper 4: Dickson, Knussen and Flowers (2007)

The findings from this study were presented as two inter-related themes which were; 1. GPs commonly delegitimised CFS/ME and attributed the illness to a psychiatric cause (i.e. depression), causing disappointment, frustration, hatred and an 'state of anomie', defined as having no regard for generally accepted social or moral standards, in the patient and 2; the personal loss of support and trying to negotiate an understanding of CFS/ME with loved ones, was considered as much of a burden with associated stigma, rejection and loss, as the illness itself. In their background review, the authors reported the paucity of literature linked to the experiences of partners, families and friends of people with the illness, which may be useful to note in terms of ideas for future research. Procedural rigour was demonstrated throughout the study and included; mention of ethical considerations; IPA methodology; demographics of the fourteen participants, seven men and seven women, between twenty one and sixty eight years of age, all of whom had a

medically confirmed diagnosis of CFS/ME; details of the in-depth interviews employed for data collection, choice of location and interview durations of 30 – 90 minutes. One criticism of this study may be that one of the participants was interviewed in the researcher's own home. This may have placed the researcher at some risk in terms of personal safety, or if the participant had ongoing support needs, provided an opportunity for the researcher to be contacted perhaps inappropriately, at some time in the future. However, mention of university ethical approval being granted provided some reassurance that researcher safety had been considered although this was not made explicit.

A limitation of this study may be considered to lie in the recruitment process. Seven participants were recruited from a local Reiki clinic after the generation of a list by the organiser. It had to be assumed however, that this was produced with the consent of the participants, as no mention of data protection issues was included. The remainder of the participants were recruited through friends and colleagues of the first author, making explicit the relationship of the researcher to the participants, adding to the study's transparency in terms of methods.

Despite possible limitations, the study is considered to provide transferable findings applicable to my own study, as the experiences of men are reflected in the verbatim quotes included. These provided direct evidence linked to the two inter-related themes mentioned above. Additionally, and uniquely, the authors mention an awareness of the literature reporting that women with CFS/ME feel less listened to than men by the medical community. This they state however, was not found to be the case in their own study, which is the only one in this review to contain almost equal numbers of men and women in their sample, making their claims more credible than studies such as Ware (1992).

2.15.5 Paper 5: Larun and Malterud (2007)

The first of the two meta-syntheses was by Larun and Malterud (2007). The review included twenty qualitative studies, published between 1993 and 2005, all focusing on how patients and also medical doctors in practice, experience CFS/ME. Key authors in the field appeared in this review. Recognised guidelines for meta-syntheses were followed and a clear audit trail for the selection and rejection of papers was given, strengthening the credibility and dependability of the data. A limitation identified by the authors was that it was difficult to guarantee comprehensive inclusion of qualitative studies in meta-

syntheses, as key words used may not necessarily capture all those that could appropriately be included.

The authors of the review claimed to have extended the level of interpretation of the primary studies included and developed constructs linked to; 1. Symptoms experienced and the impact of these on everyday life, 2. Illness beliefs and causal attributions and 3. Doctor – patient interactions. Caution needs to be observed however, when considering how dependable these findings are in terms of men with CFS/ME. When scrutinised, the number of studies which may have included men's accounts was estimated as a possible nine out of the twenty, but this was unclear. Of the total number of people with CFS/ME included across all studies, an estimated 438 women and 103 men are mentioned, but no identifiable quotes from men are included in the findings or other gender specific data.

An identified limitation of this review was that many of the studies included had recruited participants from community-based CFS/ME support groups. This may have meant that people who did not have the illness were included, or people with other delegitimised conditions who attended in the absence of access to more appropriate support were included and therefore, dependability of the data was threatened. It is reasonable to consider however, with accounts of approximately 541 people being included in the review, that experiences of living with CFS/ME were represented to some useful degree.

The authors concluded that the identity of adults with CFS/ME is challenged if their illness is not legitimised by the medical profession and others, which was also reported by Ware (1992), and leads to a sense of burden and loss of previous self, in addition to suffering the symptoms of CFS/ME. They also concluded that people with CFS/ME try hard to deal with its impact and learn more about how to cope, making them knowledgeable about their illness, which sometimes challenges medical authority, in terms of their understanding or acceptance of the condition, consistent with the findings of Cooper (1997).

This meta-synthesis addresses the issue of self-identity for people with CFS/ME and how this is impacted upon by living with the illness. Whilst it is unclear which data are directly attributable to men, I consider credible insights were provided in terms of the impact of CFS/ME on 'doing' or occupations and the implications of how what we do, or not, link to the notion of occupational transition, and impact on the notion of occupational identity.

2.15.6 Paper 6: Arroll and Senior (2008)

Arroll and Senior (2008) focused on the experiences of symptom conceptualisation and obtaining a diagnosis of CFS/ME. Eight women and two men were recruited via two local CFS/ME support groups, identified from a list held by a national charity. Ages of participants ranged from thirty five to sixty seven years and illness duration was also reported and varied from six to fifty three years. An acknowledgement that hard to reach people were not included was made, i.e. those who were severely affected. A comprehensive description of the IPA process was provided demonstrating good analytical rigour. A limitation of this study was considered to be the use of telephone interviews as a data collection method. Despite calls lasting between twenty six and ninety minutes, I do not consider this was the most appropriate collection tool for a phenomenological study, where the importance of contextual factors and field notes, and the building of rapport and non-verbal communication, are all acknowledged as usefully adding to the depth of the data. This decision however, was defended by the authors as they claimed that participants were concerned about exacerbating chemical sensitivities and that the researcher's needed to be flexible, in terms of changing interview times due to levels of unpredictable fatigue being experienced. This self-critical analysis added to the confirmability of the study.

Key findings from this study included the importance of symptomatology and illness course; interference with daily and working life; frequency of symptoms; external information; and diagnosis and treatment. The authors concluded that internal as well as external factors contributed to symptoms perception, that obtaining a diagnosis was not the end of the illness journey and that a straightforward progression into dealing with the illness was problematic. These conclusions resonate with the difficulties associated with the current lack of a proven cure for the illness and reflect the heterogeneity of the symptoms experienced.

The authors suggested that future researchers may wish to conduct longitudinal studies, in order to better understand experiences over time, rather than rely on retrospection.

The experiences of the two men included in the study appear in verbatim quotes, one of which, aged thirty-nine years, mentioned his supportive GP. However, this participant considered that GPs employ gender biases when treating people with CFS/ME and that men were treated more favourably than women. This was perhaps myth, or reflected

experiences of cultural stereotypes and medical encounters for this person, which resonates with the Cooper (1997). The other man represented, reported attributing his symptoms to the natural ageing process as he measured his health in terms of still being able to do things and the occupational impact of having CFS/ME was reported. These findings contributed to the designing of my study, as they indicated that occupational engagement and participation were used as a measure of health and illness severity and indicated the impact of this on the individual.

2.15.7 Paper 7: Dickson, Knussen and Flowers (2008)

Dickson, Knussen and Flowers (2008) was based on their research published in 2007, which I have also included earlier in the review and critiqued their design more fully there. Although the authors analysed the same data, the 2008 paper focused on experiences specifically linked to concepts of identity crisis, loss and adjustment, for people of living with CFS/ME. In their findings three inter-related themes were identified, they were: 1. Identity crisis, agency & embodiment, 2. Scepticism & the self and 3. Acceptance, adjustment & coping. The authors concluded that an ongoing sense of personal loss with reduced agency & control is experienced by people with CFS/ME and that notions of identity, control and agency are regained via adapting activities to ensure a degree of success. The authors also suggested that future research should be conducted to explore adaptation to chronic illness. This study was of particular interest to me as it resonated with and supported my pre-understandings gained through clinical practice, linked to the importance of the notions of occupational identity, occupational disruption, occupational injustice, occupational transition and occupational adaptation. Additionally, the authors emphasised the importance of the psychosocial environment for successfully regaining the factors mentioned in their findings. As was mentioned in my critique of their study from 2007 above, the 2008 paper also included the data from eight women and six men and was therefore considered to provide transferable findings applicable to my own study, to some degree, as the experiences of four of the men were reflected in the verbatim quotes included.

2.15.8 Paper 8: de Carvalho Leite *et al.* (2011)

Study eight was by de Carvalho Leite *et al.* (2011) a multi professional team of researchers, including an occupational therapist. The focus of the study was to report on the need for equity in health and social care services as expressed by adults living with CFS/ME. Thirty-five participants, all of whom had a diagnosis of CFS/ME, were recruited to the study. Eight were men, all over the age of twenty-six years. The authors claimed

that maximum variation sampling was employed to capture a wide range of experiences, as thirty five people were selected from a pool of fifty two potential participants and seven women, who were from ethnic minority populations, were included. All of the men included were however, of white British ethnicity. Recruitment was advertised through support groups and practitioners and also via the then National Observatory of people with CFS/ME in England. This was an organisation funded in the 1990s by various charities to conduct research into CFS/ME to fill the evidence gaps in the literature. The organisation no longer exists in this form.

The overall rigour of this study was demonstrated thoroughly with evidence of the four elements of trustworthiness: i.e. credibility, transferability, dependability and confirmability clearly identifiable (Lincoln and Guba, 1985). For example, rich data were collected over time via multiple methods including focus groups and multiple interviews, triangulation of data and researchers was employed, the recruitment strategy was clearly described, demographics of the participants included and member validation was used. Interestingly, theoretical triangulation was also employed to construct a new conceptual model incorporating previous research of relevance with their emerging concepts.

The main findings from this study were that there is a need for timely and flexible symptom control, illness management and financial support as all are important in alleviating the impact of CFS/ME and enabling personal control. The authors concluded that the attitudes of health and social care practitioners and policy makers, as well as the general public, could be changed by learning more about the experiences of people with CFS/ME. This they suggested, would promote advocacy, shared decision making and co-ordinated action and promote human rights for those with CFS/ME. They also suggested that there was a need for further research focusing on non-white populations as they suggested that people from minority ethnic groups may be under-diagnosed in primary care and disadvantaged by this practice.

In summary, this was a methodologically strong study and despite only one man's experiences being reported on specifically, perhaps indicating caution should be exercised in terms of transferability, the main findings resonate with the findings of the other studies in this review and also strongly with my clinical experience/prejudgement. Of particular interest to me, was mention of the importance of the role of occupational therapy in assisting those with CFS/ME to maintain their employment.

2.15.9 Paper 9: Anderson *et al.* (2012)

The second of the two meta-syntheses included in this review comprised thirty four qualitative papers, seventeen of which were included in the first meta-synthesis by Larun and Malterud (2007) critiqued in my review earlier. The authors had included a flow diagram of the steps suggested in the PRISMA (Moher *et al.*, 2009) systematic review tool, to list the number for articles identified through database searching, screening for eligibility and the number of studies finally included. An identified strength of this review was found in its critical appraisal of the papers they included, as all were considered of appropriate quality through using PRISMA (*ibid*).

When scrutinised, only four new papers of relevance to my study were included. Thirteen papers were also included that focused solely on the experiences of women with either CFS/ME or FMS, experiences of people with cancer related fatigue, or just the accounts of GPs, to gather multiple perspectives of living with a chronic illness. The GP-focused studies were included in my review of the literature linked to exploring the notion of CFS/ME, which appears earlier in this thesis.

I questioned the credibility of this review however as the researchers claimed their review built on the earlier meta-synthesis by Larun and Malterud (2007) and uniquely included experiences of physicians. This was however incorrect, as Larun and Malterud (2007) did report on these experiences.

In their findings the authors claimed that failure of a medical label reinforces psychiatric explanations of CFS/ME and stigma due to stereotyping of people by health professionals, families and friends. Additionally, identity changes and reductions across physical, social and economic domains of life were reported and consequential efforts by the individual to cope and balance activity. They concluded that health professionals required more education to assist them with making a diagnosis in order to legitimise CFS/ME. Although this study uniquely included data collection linked to the experiences of family members, the authors failed to present these findings in their report. These data would have supported the suggestion by Dickson, Knussen and Hlavaty (2007), that family experiences need to be researched further to provide valuable insights into family dynamics and CFS/ME. Future research was suggested linked to community based sampling to explore sociocultural factors and the need for more qualitative research to

better understand experiences of marginalisation was recommended, a concept resonant with that of occupational injustice.

In summary, studies included in this review were synthesised and thematically presented to link experiences of the participants included in all papers, not just those linked to participants with CFS/ME. This resulted in the review being of very limited relevance to my own study, as it was impossible to identify the accounts of men with CFS/ME, with only two men reported as being included in one out of the thirty four studies, a very small percentage therefore, in the overall number of participants, making it difficult to generalise and transfer the findings.

2.15.10 Paper 10: Arroll and Howard (2013)

The findings of this study were presented in four main themes, which were: 1. comparisons of past to present self; 2. effects of social isolation on identity; 3. subsequent insights of others and 4. the positive notion of post traumatic growth (PTG) which was claimed to be more difficult for people with CFS/ME than for those with cancer.

Both authors of this study provided reflexive accounts of their own experiences of living with CFS/ME claiming they were both recovered, perhaps adding to the confirmability of the study in phenomenological terms. They also acknowledged that their experiences undoubtedly influenced the research process and findings making transparent their relationship to their participants and the topic.

The background to their study was based solely on the experiences of women, reinforcing my understanding that men's experiences were difficult to identify. The authors concluded that the gradual process of letting go, building up and rebuilding described as post traumatic growth (PTG) was experienced by some people with CFS/ME but not others. They also suggested that health was experienced as a 'yo-yo' and life as in limbo, with impermanence attached to any life plans. This resonated with the notions of 'anomie' reported in the study by Dickson, Knussen and Flowers (2007). The authors recruited seven women and three men to their study via local support groups in the south east of England, one participant was known personally to the second researcher.

A comprehensive description of the IPA process was included and the double hermeneutic of the participant firstly making sense of their experience, which was then made sense of by the researcher was explained. In terms of transferability, the voices of three men were captured in the rich data quotes included. The authors, both of whom are psychologists, suggested that psychological interventions such as mindfulness may be able to assist patients in their coping. Interestingly, they also suggested that restoration or discovery of meaningful occupation has a vital role to play in influencing subjective well-being and identity.

Limitations of this study may be considered as lack of information linked to participant demographics and the lack of descriptive clarity regarding the location and duration of the interviews, making replicability unlikely. Additionally, only one-off interviews were conducted which may have limited in-depth rich data from being generated or the opportunity to develop and extend understandings of experiences. Generally however, the credibility, dependability and confirmability of this study seemed trustworthy and the authors' suggestions regarding future research were novel. These included the idea that it may be helpful to investigate factors which led to some people with CFS/ME being able to positively re-evaluate their lives whilst others remained unable to do so with longitudinal studies being conducted for this purpose.

2.15.11 Paper 11: Anderson, Jason and Hlavaty (2014)

The final study included in this review focused on the natural historical development of CFS/ME in a community-based population. The authors employed grounded theory to develop their findings which were reported in three inter-related categories, they were: 1. the importance of understanding the context in which the illness is experienced, 2. the physical construction of the illness and 3. coping and illness management strategies. They concluded that medical and social inequity still existed for people with CFS/ME (consistent with de Carvalho Leite *et al.*, 2011), and especially women (consistent with Cooper, 1997), and that future research was needed to ensure patients' voices were heard and should be longitudinal in design (consistent with suggestions made by Arroll and Senior, 2008). They also suggested that it would be useful to capture experiences linked to topics such as suicide, but failed to provide a rationale for this.

Participants recruited to this study had been part of a larger CFS/ME study conducted some ten years earlier. Nineteen participants were included, sixteen women and three

men. Procedural rigour was evident in this study as the researchers were trained in research processes and their flexibility in terms of methods employed was included, for example ensuring participants had a choice between face to face or telephone interviews. For some researchers however, the use of telephone interviews may have been considered a limitation in a qualitative study where rapport, the use of non-verbal communication and the psychosocial context provides valuable data to support data generation, analysis and the production of contextualised findings. Interestingly, the authors claimed to have explored the phenomenology of CFS/ME but chose a grounded theory rather than an interpretive approach to address this. However, it was claimed that rich data were generated and the team of researchers triangulated analysis to ensure credibility and analytical rigour was demonstrated through a clear description of the process of grounded theory and inclusion of thematic summaries and frequency analysis tables.

A limitation of this study is linked to the lack of recognition on the part of the openly acknowledged feminist authors, to consider the possibility of symptoms experienced by women participants, such as weight gain, period pains and hormonal changes, being attributable to normal, age-related, health changes. Additionally, the study, although including data linked to the experiences of three men with CFS/ME, was published in an international women's health journal which does not seem like the most appropriate place to represent their voices given the demographic of the journal's readership.

The notion of occupational identity was mentioned in this study but it was limited to the epistemology of the authors who were psychologists, as they used this to describe identity in lay terms, as related simply to paid employment as opposed to including other occupations, such as socialising, leisure or personal care for example. This is unlike the definition of occupational identity adopted by myself, other occupational therapists and occupational scientists, who define this in a more comprehensive manner linking the notion to all a person does to occupy their time i.e. their 'doing' across all aspects of their daily lives and not simply to work/paid employment. Touching on this aspect of identity was however, meaningful to me in terms of my study, but some caution needs to be observed as with all other studies in this review, as the experiences of men are not reported in any great depth.

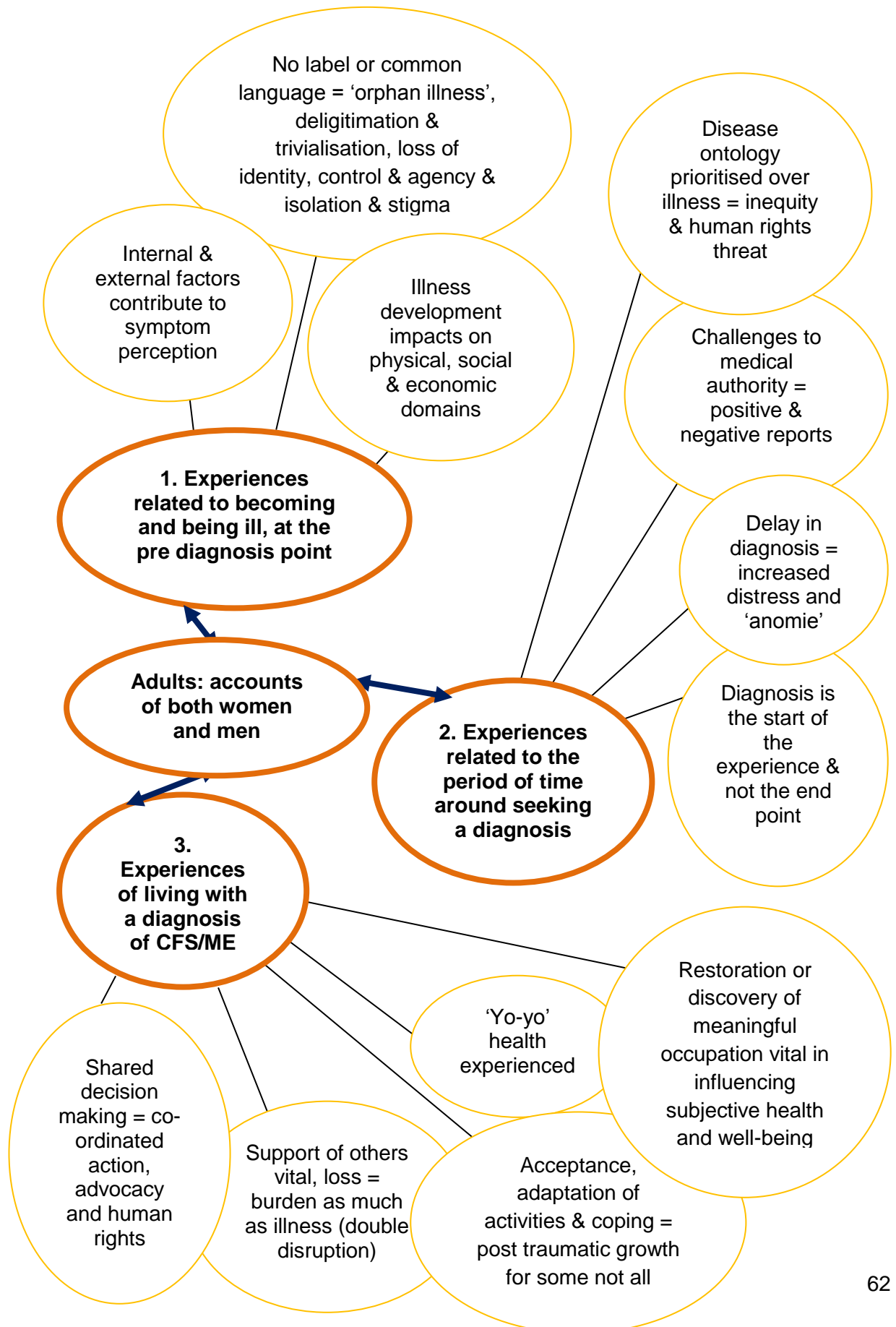
2.16 A Synthesis of the findings in two steps

All of the studies in this review included the accounts of adults with CFS/ME and accounts represented were predominantly those of women. The findings were therefore synthesised in two steps: Step 1 was a synthesis of all papers and Step 2 a synthesis of extrapolated verbatim quotes identifiable to ten male participants across seven papers.

2.16.1 Step 1: adults with CFS/ME

This review of the literature identified a range of inter-related findings, all reporting on the impact of CFS/ME on the day to day lives, activities and occupations of **adults** (both men and women) with the condition, which I have synthesised here into themes. In order to reflect the historical development of the experiences the themes reflect the chronology of illness development. This is consistent with Tuck and Human (1998) and Arroll and Senior (2008) who reported that the temporal nature of experiences is an important feature in how understandings are expressed by those with CFS/ME to others. To make some sense of these themes therefore, they are organised in a temporal way at three points in the illness experience and appear as: Theme 1. Experiences related to becoming and being ill, at the pre- diagnosis point; Theme 2. Experiences related to the period of time around seeking a diagnosis, and; Theme 3. Experiences of living with a diagnosis of CFS/ME. These themes appear on the following page in Figure 1.

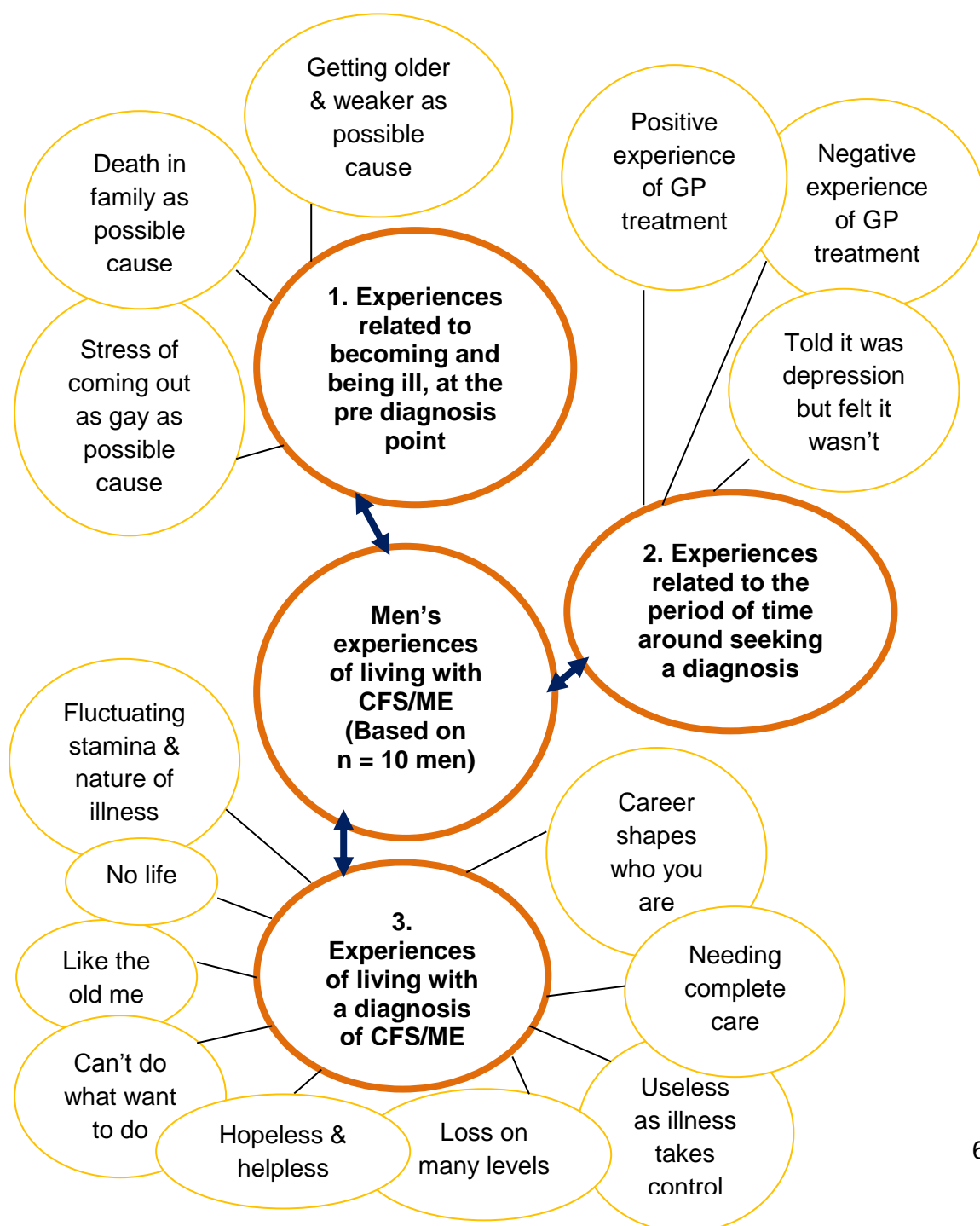
Figure 1: Step 1 A synthesis of the findings (adults/men and women) 3 inter-related themes



2.16.2 Step 2: men with CFS/ME

From the literature included in the review I identified that in seven of the eleven papers that limited data were presented linked to the experiences of ten men with CFS/ME. I therefore, extrapolated these data, which were in the form of ‘one-off’ verbatim quotes, and mapped these into the three inter-related themes identified in the synthesis of the adult data in Step 1. Quotes represent the experiences of ten men across the papers and were as follows:

Figure 2: Step 2 A synthesis of the findings (men) 3 inter-related themes



2.17 Summarising men's experiences of CFS/ME from the existing literature

Based on the themes identified in Steps 1 and 2 of the synthesis, it may be reasonable to suggest that the experiences of men, in terms of possible causes for illness development, seeking a diagnosis, and living with CFS/ME did not seem to differ greatly from those of women. However, before concurring with this suggestion, threats to the credibility, transferability, dependability and confirmability of these data need to be considered. For example, identified threats included those posed by four out of the seven studies containing quotes from men recruited from community based support groups. This may have meant, as previously mentioned, that the men may, or may not, have met diagnostic criteria for CFS/ME, and/or may have been experiencing other health conditions which were undisclosed. Additionally, only two of the seven studies, which included men's data (Dickson, Knussen and Flowers, 2008 and Anderson, Jason and Hlavaty, 2014), made mention of the need for participants to meet some sort of screening criteria for the presence of CFS/ME prior to recruitment. From the background literature available it would seem therefore, that in total, only four quotes were identifiable from men who had some form of clinically confirmed diagnosis of CFS/ME.

Other methodological considerations of importance for judging the quality of the studies were not always reported and therefore, threatened the dependability and confirmability of some of the findings. These included for example, a lack of reporting as to how data were analysed and findings reached. Furthermore, in several studies, only one-off interviews were conducted, making it unlikely that rich, in-depth data were generated to explore the meaning of living with a complex, long-term condition. The importance however of conducting multiple interviews over time to reflect the temporal aspects of living with a chronic illness is commonly advocated in the academic literature (Sandelowski, 1999; Cohen, Kahn and Steeves, 2000; Fleming, Gaidys and Robb, 2003).

Further threats to the credibility of the data included an apparent lack of understanding of the nature of severe CFS/ME by Cooper (1997), who claimed participants included one woman who was severely affected by the illness. The woman's reported functional abilities however, included organising and running community based meetings and talks, which would in my clinical opinion, have been much more than someone who was severely affected could have coped with, and inconsistent with the more contemporary and recognised definition of 'severely affected' as appears in the literature (NICE, 2007).

Bearing the above factors in mind, I decided that some caution needed to be observed before considering men's experiences of living with CFS/ME were well understood in the literature. Whilst arguably the extrapolated men's quotes provided some indication of the meaning of living with the condition, I was unable to interpret these data further in order to adequately address this topic. A deeper understanding of living with the illness and its impact on the men's day to day lives and occupations therefore was not possible. This was effectively because, only parts of the men's accounts, or 'snap-shots' of their experiences were accessible from the quotes. Important contextualised factors contributing to the meaning of their experiences were not reported. From the background literature available therefore, it seemed that men's experiences of living with CFS/ME were not as well understood as they might be. Consequently, I considered that the findings of the review had limited application in terms of informing improvements to occupational therapy practice and any subsequent potential to tailor services to meet men's needs. I concluded therefore, that in order to address this gap in the literature there was a need to generate rich, in-depth contextualised data specifically from men living with CFS/ME.

2.18 The review in summary

The eleven studies included in this review incorporated a variety of qualitative designs and theoretical frameworks linked to authors' epistemologies. Within the eleven studies, a variety of data collection methods were mentioned. The most common was the semi-structured interview (Ware, 1992, Cooper, 1997, Dickson, Knussen and Flowers, 2007, Arroll and Senior, 2008, Dickson, Knussen and Flowers, 2008, de Carvalho Leite *et al.*, 2011 and Arroll and Howard, 2013) although some authors pointed out that, in the spirit of phenomenological enquiry, the schedule was used as a probe and not followed in a rigid way (Dickson, Knussen and Flowers, 2007 and Dickson, Knussen and Flowers, 2008).

When employed, interviews took place in a variety of settings including the participant's own home or work setting, clinic settings and in the case of one study in the researcher's own home (Dickson, Knussen and Flowers, 2008). Additionally, interviews were frequently reported as being one-off (Ware, 1992, Cooper, 1997, Dickson, Knussen and Flowers, 2007, Arroll and Senior, 2008, Dickson, Knussen and Flowers, 2008, Arroll and Howard, 2013). One-off interviews would not have enabled data to be gathered over time as preferred in phenomenology and therefore limited the richness of the stories shared due to the inability to pick up on and develop deeper meanings as they emerged from one

encounter to the next. Other methods of data collection mentioned included the use of a focus group to assist with thematic development to be addressed during individual interviews (de Carvalho Leite *et al.*, 2011) and the use of pre-set questionnaires (Tuck and Human, 1998). The use of questionnaires did not however, enable an open-ended dialogue or text to be shared and a meaning clarified and was therefore, acknowledged as a study limitation.

In terms of reliability/dependability of data, participants' memory was mentioned in some studies and reliance on their memory to provide stories was stated as a possible limitation. This was mentioned as memory is well documented in the literature as commonly being a concern for some people with CFS/ME (NICE, 2007). This concern however, is not necessarily considered to be an issue in terms of phenomenology as meanings of experiences are discussed and co-created during the research encounter, rather than assuming that truth or objectivity will only be gained by accurate memory recall.

In terms of trustworthiness all nine of the primary data collection studies included degrees of evidence of credibility, transferability, dependability and confirmability (Lincoln and Guba, 1985). The strongest studies however, where all four elements of overall rigour were most evident were de Carvalho Leite *et al.* (2011) and Anderson, Jason and Hlavaty (2014).

Of the eleven studies included in this literature review, only seven included clearly identifiable men's data, in the form of verbatim quotes, collected at the primary data collection phases. These studies were; Cooper (1997), Dickson, Knussen and Flowers (2007), Arroll and Senior (2008), Dickson, Knussen and Flowers (2008), de Carvalho Leite *et al.* (2011), Arroll and Howard (2013) and Anderson, Jason and Hlavaty (2014). These studies could be considered as providing relatively weak evidence to refute the need for my study to be conducted, as all contained verbatim accounts of men's experiences. In total ten men were represented in the data via verbatim quotes however, it was unclear whether all of the men had a clinically confirmed diagnosis of CFS/ME. In the remaining four studies, men's experiences were amalgamated into the experiences of the predominant voices of female participants. These studies were; Ware (1992), Tuck and Human (1998), Larun and Malterud (2007) and Anderson *et al.* (2012) and could be

considered as providing the strongest evidence to support the rationale for me to conduct my study.

Because of the dearth of studies available linked specifically to the experiences of men with CFS/ME, studies of both men and women in combination had to be identified in order to provide understandings. Across all the papers included in this review, in excess of five hundred adult participants with CFS/ME were identified. Of this figure however, the number of male participants included was unclear, as this was not always stated by the authors. It was estimated to be approximately one hundred and twelve. However, the voices of only ten men were heard via verbatim quotes identified from scrutinising all studies. Importantly however to me, was that none of the studies available in the published literature and included in this review, reported exclusively on men's experiences of living with CFS/ME. Whilst any shared experience of living with CFS/ME is acknowledged as potentially useful to me and others with an interest in the topic, it is argued that the experiences of men with CFS/ME are currently underrepresented in the literature as compared to the stories of women. It was concluded therefore, that this clearly demonstrated a gap in the academic literature linked to the experiences of men with the condition and was therefore, the rationale for the focus of my study. I therefore, set out to gather rich in-depth accounts of the experiences of men with the condition. This was in order to potentially inform health and social care practice and policies and educate others about what living with this illness is like.

Interestingly, there was no mention of people with CFS/ME, neither men nor women, being involved in any aspect of the studies in terms of the design of the research or dissemination of study findings. This is an issue I felt that needed to be addressed in terms of future research, as it is a requirement of the National Research Ethics Service for researchers to demonstrate user-involvement in research in line with current health policy drivers linked to inclusion (Morrow *et al.*, 2010). The inclusion of people with CFS/ME in this way would help facilitate partnership working and the reduction of power differentials between service users and health professionals. Importantly and more specifically, it would also enable the experiences of men to be captured and a better understanding of CFS/ME to be achieved in order to move research and practice forwards as advocated by Anderson *et al.* (2012).

2.19 Summary of the chapter

In this chapter the background to the study has been explored in detail. The current parameters of research linked to CFS/ME were presented and the ongoing need for further research into the lived experience was highlighted. The specific need for men's experiences to be captured and better understood was addressed to generate new knowledge and understandings for practice purposes. The following chapter presents the ontological and epistemological considerations made in order to contextualise my worldview and explores how this shaped the research enquiry.

Chapter 3:

Ontological and epistemological considerations of the enquiry

3.0 Introduction

In this chapter definitions of the concepts of ontology and epistemology are included and are related to research paradigms or worldviews. The importance of addressing ontological and epistemological considerations when conducting social research is presented and the influence of these concepts on the research process are addressed. My worldview as an occupational therapist is presented along with how this shaped the research enquiry. The rationale for the selected underpinning ontological and epistemological framework, referred to as the philosophical foundation of the study, is also included and provided support for the selected methodology.

3.1 Defining ontology and epistemology

When embarking on any academic enquiry the need for the researcher to consider their individual beliefs, or 'worldview', also referred to as ontology and epistemology, is acknowledged in the literature (Creswell and Plano Clark, 2011). The definitions of these terms have therefore been considered. Ontology may be defined as:

- *"The science that deals with the principles of being."* (Chambers, 2011, p. 1077).

Definitions of ontology are concerned with the nature of reality or truth and what we as human beings believe this to be (Patton, 2002). In addition to acknowledging one's ontology the need to consider one's epistemology is also important. Epistemology may be defined as:

- *"The theory of knowledge."* (Chambers, 2011, p. 521).

Definitions of epistemology are therefore concerned with how we know what we know (Patton, 2002).

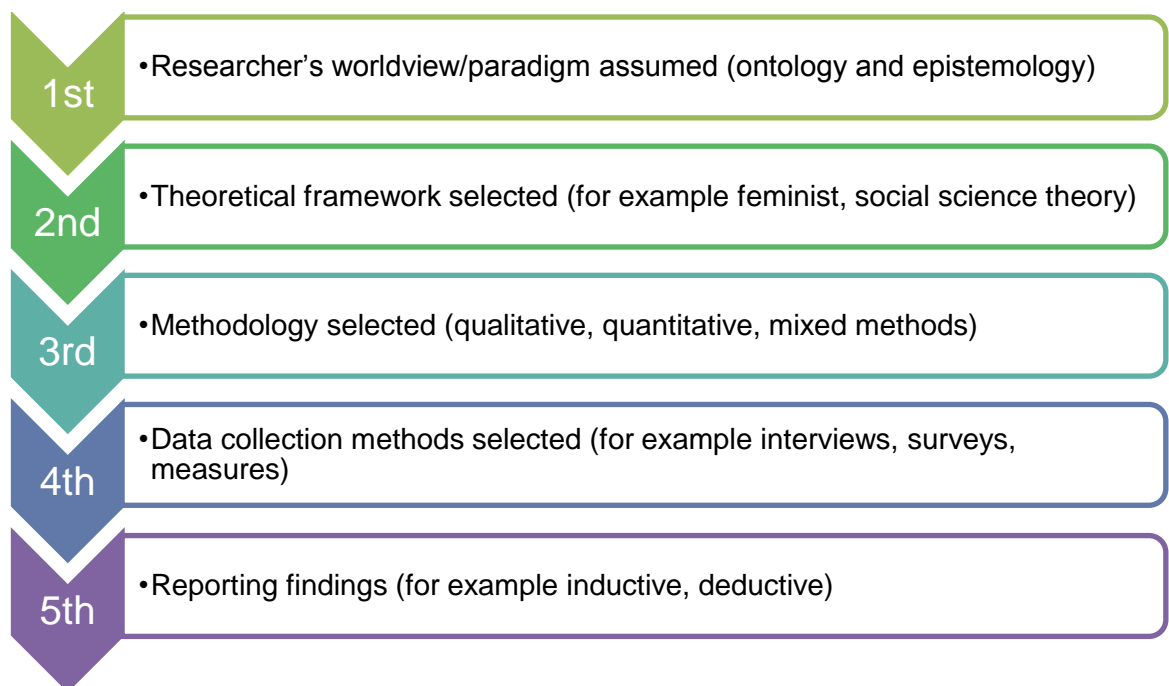
In combination, our ontology (or what we believe is truth) and our epistemology (how we can know about this), provide us with our worldview. Our worldview is formed through

experiences of 'being-in-the-world' both past and present, and our beliefs, values and motivations for future being. These factors lead our decision-making in terms of how we act in the world and therefore, influence the decisions researchers make about their starting point of entry into any research enquiry and subsequent conduct.

3.2 The influence of ontology and epistemology on the research process

In social research the influence of the researcher's worldview underpins the aim of the study, guides the construction of the research question, the selection of the methodology and also the methods employed for data collection (Marks and Yardley, 2004). This influence on the research process is illustrated in Figure 3 below:

Figure 3: Influence of the researcher's worldview (ontological and epistemological assumptions) on the research process



(Adapted from Creswell and Plano Clarke, 2011).

3.3 Defining the concept of truth for researchers from differing worldviews

Defining the concept of truth concerning beliefs about the nature of reality in social research enquiry has been the subject of ongoing ontological debate for some time (Lincoln and Guba, 1985; Wilkinson, 2011). Research designs may broadly/generally be considered as falling into quantitative, qualitative or mixed methods paradigms and each will be underpinned by differing worldviews or ontological and epistemological assumptions (Vasilachis de Gialdino, 2009; Creswell and Plano Clarke, 2011). In broad terms quantitative researchers may be considered as taking the worldview that a single truth or objective reality is “*out there*” (Lincoln and Guba, 1985, p. 28) and can be discovered through using highly structured methodologically inflexible designs such as experimentation (Robson, 2002). Defined as positivists, due to their positive beliefs in the value of science and scientific method (Lincoln and Guba, 1985, Gadamer, 2004), researchers of the positivist persuasion therefore, may adopt the role of detached observer and impose strict controls on the conduct of their research. This they believe enables a variety of identified variables to be managed and therefore, eliminated from their enquiry. These strategies may be employed by positivists in order to reach claimed objective truth and for example, statistical significance or identification of causal predictors (Lincoln and Guba, 1985). The splitting off of variables employed in experimental designs is based on the concept of Cartesian dualism, a concept where mind and body are considered as distinct and not inter-related or inter-dependent on each other or the individual’s thoughts, culture and nature (Harrington, 2005). Dualism has however, received criticism from modern social researchers as it is considered an inadequate conceptual orientation for understanding the complexity and the contextualised nature of human experience (ibid). Unsurprisingly, dualism was the basis on which medicine and the biomedical approach was founded to enable an ‘observer’ to ‘observe’ a ‘subject’ of interest in a detached manner (Mehta, 2011).

Qualitative researchers hold a nondualist belief and acknowledge the interdependency of variables, or contextual factors, and their contribution to human experience (Koch, 2006; Finlay, 2011). Additionally, the notion of a single objective truth or reality existing is also rejected in favour of the notion of the existence of multiple realities (Mason, 2002; Patton, 2002; Marks and Yardley, 2004; Creswell and Plano Clark, 2011). Ontologically and epistemologically therefore, values held by qualitative researchers include a desire to enter into the research encounter to interact in a ‘subject to subject’ partnership with the participant via the inter-subjective space (Lincoln and Guba, 1985). Through a relationship

of this kind, a co-production of rich data may be achieved which they believe, holds the potential to be transformative as both parties have the opportunity to understand experiences differently (Gadamer, 2004).

For those with a worldview based on the utility of mixed methods designs, a combination of both qualitative and quantitative methods hold some value in research in the human sciences (Creswell and Plano Clark, 2011). It is acknowledged in the literature however, that particular challenges are presented in terms of reconciling potentially conflicting ontologies and epistemologies at the point of interface between the differing types of data generated when employed to answer the same question.

Reflexivity and study design: notes taken from my research journal 2012

Originally I had considered using a mixed methods design to explore men's experiences of living with CFS/ME, with a theoretically driven focus linked to the sociological notion of biographical disruption (Bury, 1982). This was in part, because I had access to a data base containing quantitative data linked to items such as sickness impact and various measures of fatigue. Additionally some limited qualitative data were included, which I found interesting, such as what people referred to the service expected to gain from attending. I had thought that by performing a secondary analysis of these data, and supporting these with semi structured interview data that accounts of the lived experience of having CFS/ME would in part be achieved. After trying to extrapolate biographically disruptive accounts through secondary data analysis however, I iteratively came to the conclusion that, whilst I was driving the design of the study in a theoretical manner, the nature of my research question demanded a data driven design. I realised with the help of my supervisor that I was searching for a methodology that I could employ to make sense of what it was I wanted to explore. My supervisor suggested interpretive phenomenology would be more appropriate and interestingly introduced me to the work of Hans Georg Gadamer which I adopted. For this reason I rejected a theoretically driven, mixed methods design, and analysis of the secondary data, in favour of an interpretive phenomenological design. This I believe was the correct decision to enable a 'better fit' between the design of the research, the aim and question.

3.4 Rationale for selecting a qualitative methodology

I conducted this study as I wanted to know more about how CFS/ME was experienced by men living with this condition and the impact of this upon their 'being-in-the-world' and occupations. Mindful of my worldview, I did not set out to establish a single objective reality or truth, causal relationships between variables or offer hypotheses for testing, but rather, to generate through co-production, an understanding of the multiple realities of men's experiences of living with CFS/ME. My ontology drove me to pursue this question and in order to address this epistemologically I adopted a qualitative naturalistic methodology (Lincoln and Guba, 1985). Whilst I was aware that several forms of qualitative design appear in the literature I selected phenomenology as both the ontological and epistemological foundation of the study based on the nature of my research question linked to investigating the meaning of experiences. Making this decision took some time however, as I explored the literature and familiarised myself with Gadamer's work, eventually taking about a year to consolidate some understanding of phenomenology which excitingly resonated with my worldview. I became aware that various forms of phenomenology existed (Cohen, Kahn and Steeves, 2000). These included the earliest form, a positivist or quantitative version, descriptive phenomenology, originally called descriptive psychology based on the works of Edmund Husserl (Husserl, 1931). Consequently, Husserl is considered as the founding father of phenomenology. Additionally I learned that following on from descriptive phenomenology, experiential phenomenology was developed known as hermeneutic or interpretive phenomenology based on the works of Hans-Georg Gadamer (Gadamer, 2004) who extended the work of his teacher Martin Heidegger (Heidegger, 1962).

3.5 Rejecting descriptive phenomenology

The work of Husserl, a German mathematician, and later philosopher (1859-1938), was concerned with establishing mathematical truths linked to logical investigations (Husserl, 1931). Additionally, Husserl's descriptive phenomenology focused on the essence of awareness or consciousness and he argued that it was possible to describe a phenomenon without reference to presupposition, interpretations and explanations (Greetham, 2006). To describe consciousness therefore, he believed that engagement with day to day life, practical concerns and cultural assumptions could all be bracketed out of one's awareness, a notion he referred to as the 'phenomenological epoche', reduction or bracketing of the natural attitude (Husserl, 1931). However, Martin Heidegger, a student of Husserl's, recognised the importance of moving from pure description to

interpretation to better understand the meaning of situated human consciousness or 'being-in-the-world' (Heidegger, 1962). Heidegger therefore, acknowledged the importance of presuppositions and prejudgements of both 'self' and 'other' as contributing to our consciousness and established what later became known as hermeneutic phenomenology (Alvesson and Skoldberg, 2009). This is also referred to in the literature as interpretive phenomenology (Cohen, Kahn and Steeves, 2000) where importantly it is also acknowledged that elements of description are firstly necessary in order to then reach interpretation. According to Finlay (2011), descriptive and interpretive phenomenology are polarised and therefore, sit on a theoretical continuum.

Unlike Husserl, I consider that the natural attitude, that is, what people do in their everyday lives, their practical concerns and cultural assumptions, all play a part in the meaning of experiences. In terms of my research, this means the natural attitude of the participants involved. In addition to this, researchers such as myself who employ hermeneutic phenomenology uniquely reflect their own natural attitude and valuable prejudgements in the research process (Smythe, 2007; Tufford and Newman, 2010). This differs significantly therefore, from those employing 'pure description' and bracketing in Husserlian terms. Overtly acknowledging my prejudgements prior to and during the research process through documenting these in my research journal, enabled a more authentic encounter during the research interviews and contributed to my interpretations of the data due to my closeness to the subject matter. This is consistent with Gadamer's view of the usefulness of prejudgements in enabling a starting perspective from which new understandings may be realised (Gadamer, 2004). For these reasons Husserl's positivist, descriptive and decontextualized form of phenomenology was rejected for the purposes of addressing the research question in favour of hermeneutic/interpretive phenomenology.

3.6 Exploring hermeneutic phenomenology

The definition of the term hermeneutic stems from the Greek word 'hermeneia' which means to interpret or translate (Lawn and Keane, 2011) and Porter and Robinson (2011) provide a useful definition of hermeneutics for the purposes of academic enquiry:

"In its most basic sense hermeneutics refers to the many ways in which we may theorize about the nature of human interpretation, whether that means understanding books, works of art, architecture, verbal communication, or even non-verbal bodily gestures." (Porter and Robinson 2011 p. 1).

Historically, hermeneutics was applied to theological texts to assist with interpreting biblical meaning (Lawn, 2006). The popularity of using a hermeneutic approach and specifically hermeneutic phenomenology has however, increased in contemporary health based research. This is linked to researchers' interests in exploring the meaning and impact of living with illness and is a topic which has gained recognition in the associated literature (Cohen, Kahn and Steeves, 2000; Hammell, 2004; Finlay, 2011). For this reason I considered that hermeneutic phenomenology held particular resonance with the aim of my study and I began to learn more about this methodology.

3.7 Acknowledging the various forms of hermeneutic phenomenology

Within the philosophy of hermeneutic phenomenology various forms are driven by epistemological considerations, such as; Paul Ricoeur's (1913-2005) hermeneutics of psychoanalysis; and Jurgen Habermas' (1929-) critical hermeneutics of society, addressing his interests in social emancipation for all (Porter and Robinson, 2011). Through these various forms however, including Gadamer's, which will be discussed further, runs a common thread linked to the importance of the interpretation of human experience.

3.8 The nature of dialogue within hermeneutic phenomenology

Within hermeneutics the role of interpreting dialogue in the form of texts (written word) and communication (spoken word) to aid understanding is recognised (Alvesson and Skoldberg, 2009). Of interest to me as an occupational therapist however, was Gadamer's broader definition of dialogue which pays attention to three predominant forms all of which I consider as actual or potential therapeutic modalities for practice. They are: 1. Art works; 2. Texts; including unique poetry and 3. Language; both spoken dialogue and unspoken body language (Gadamer, 2004). For Gadamer these forms of dialogue are all means of allowing us to make sense of a person's 'being-in-the-world' and without which, no understanding would be possible (ibid). Gadamer emphasises that these are not theories or methods, but rather, ways of encountering fundamental truths about being and are therefore, ontological in nature. Importantly, this existentialist view of reality and how this is known is the essence of his work referred to as philosophical hermeneutics (Gadamer, 1976; Porter and Robinson, 2011) and is a view which resonated to my selves as clinician, researcher and educationalist.

3.9 Gadamer's philosophical hermeneutics as the foundation of the enquiry

Adopting Gadamer's philosophical hermeneutics enabled me to focus on the meaning of experiences whilst being mindful of broader, inter-dependent cultural and social factors, both past and present and represented in the dialogue shared to explain the reality of the lifeworld (Cohen, Kahn and Steeves, 2000). This means that via a variety of dialogue I was able to gain an understanding of how individuals interpret their day to day lives, activities and occupations in context. Braun and Clarke (2006) suggested that this position aligns the researcher to a contextualist approach, in that subjective experience is identified somewhere on a continuum between realism at one pole and constructionism at the other. A contextualist approach may also be considered as an interpretivist-constructionist approach, as priority is given to the meaning of experiences with secondary attention paid to contextual factors during data collection and analysis (ibid).

Gadamer's seminal work 'Truth and Method' (2004) was first published in German in 1960 and translated into English some years later. The focus of this work was philosophical hermeneutics which Davey defines as:

"An interpretation of interpretation, a prolonged meditation upon what "happens" to us within "hermeneutic experience" when we are challenged by texts and artworks, ancient and modern... It reflects on the historical and cultural preconditions of individual hermeneutic experience and seeks to discern it in something of the predicament, character, and mode of being of those who "undergo" such experience." (Davey, 2006 p. 1).

In Truth and Method Gadamer (2004) emphasises that our existence itself, termed as 'dasein' by Heidegger (1962) and also referred to as our 'being-in-the-world', is historically and culturally situated in tradition known as that which is handed down. Additionally, he claims that experience is what we understand via dialogue and without some understanding no further understanding is possible. He suggested that when we engage in dialogue it challenges us to ask ourselves what dialogue asks of us in its various forms (Gadamer, 2004). By adopting what he referred to as an open phenomenological attitude (Finlay, 2011) new or different interpretations may be realised. These are not however, realised via an inflexible scientific method. In common with qualitative researchers he also rejected claims that scientific method has a monopoly on the acquisition of multiple truths in terms of human experience. He suggests that use of such a rigid technique ignores and fails to capture understanding linked to the infinitude of human experience (Gadamer, 2004). In preference, he argues, as mentioned above, that philosophical hermeneutics

may be used as both an underpinning philosophical orientation to, and an epistemological framework for, conducting research linked to human experience (ibid). This orientation Gadamer claims, facilitates a flexible sharing of the reality of 'being', referred to by Gadamer as the perspectives or horizons of others, via the metaphorical concept of the hermeneutic circle, a term coined first by Heidegger (Heidegger, 1962). Sharing horizons in this way makes a fusion of horizons possible. This fusion takes place in the inter-subjective space between 'self' and 'other' where new or different understanding of realities is possible (Gadamer, 2004). The concepts of the hermeneutic circle and fusion of horizons are synchronically linked and will now be explored further as they form a central part of this thesis.

3.10 Exploring the metaphorical concept of the hermeneutic circle

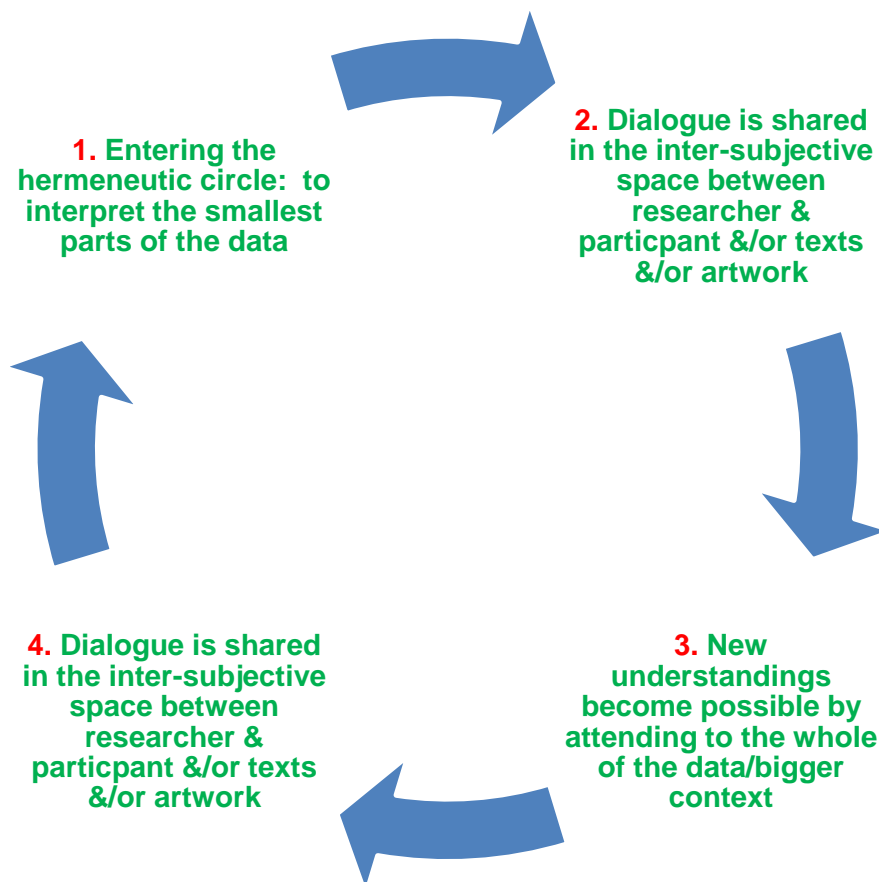
"At the very root of hermeneutics lies circularity."
(Alvesson and Skoldberg, 2009, p. 138)

Gadamer emphasised that in order to understand human experience we need to move back and forth between the component parts of a person's experiences and their broader contextualised experience of 'being-in-the-world' (Gadamer, 2004). This he suggested enables us to understand how the parts of experience contribute to the whole and vice versa and therefore, how the meaning of being for the individual is conceptualised. An illustrative example of how the hermeneutic circle may be helpful in aiding our understanding of human experience appears in the literature by Cohen, Kahn and Steeves (2000) when they suggested:

"...the metaphor that fits is that of a person stepping back from a painting to better view it as a whole."
(Cohen, Kahn and Steeves, 2000, p. 58).

When we step back therefore, we are arguably able to see so much more than simply the corner or part we were viewing when we were up close. Additionally, and interestingly we are then able to see and interpret the components simultaneously and establish a different meaning of what we are seeing and experiencing. My interpretation of this is represented in Figure 4 below:

Figure 4: Moving round the hermeneutic circle to illustrate how new understandings of experience may be realised: My interpretation



Gadamer likens this process of sharing dialogue in the inter-subjective space between two people, in a dynamic and continuous movement, to and fro in a cyclical fashion, from part to whole and back again, as akin to the naturally occurring nature of play (Gadamer, 2004).

Employing the hermeneutic circle in research sits well within an interpretive phenomenological methodology as understanding parts of the data and how these contribute to the whole data set is possible. Findings co-produced in a naturally occurring conversational manner can be read in full to provide an overview, or the big picture, and then re-read to identify specific episodes and events of meaning in the person's life. Understanding how one has impacted on the other can then provide new understanding and insights which can help practitioners improve clinical practice.

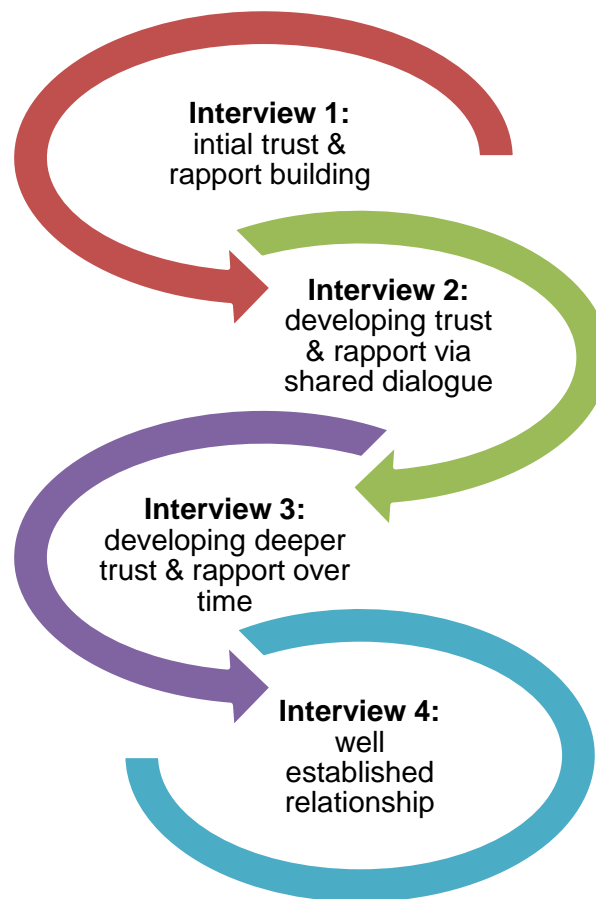
3.10.1 Reconceptualising the hermeneutic circle as a spiral process

The hermeneutic circle is reconceptualised in the literature as the hermeneutic spiral by Debesay, Naden and Slettebo (2008). The concept of a spiral rather than a circle is suggested to reflect Gadamer's claims that all experience of "being-in-the-world" is continuously reinterpreted over time, unlike perhaps the concept of a closed circle might imply. Reconceptualising the circle as a spiral therefore, enables the interpreter "to avoid deterministic assumptions" (Debesay, Naden and Slettebo 2008, p. 58) of experiences being somehow inflexibly fixed.

3.10.2 The utility of the hermeneutic circle/spiral across multiple interviews

An essential feature of hermeneutic phenomenology is the importance of conducting multiple research interviews over time to reflect the temporality of experiences and develop trust and rapport (Cohen, Khan and Steeves, 2000). I consider therefore, that reconceptualising the hermeneutic circle to a spiral is useful. By following the hermeneutic process in a spiral fashion trust and rapport may be strengthened and deepened from one interview to the next. This can contribute to establishing authentic and genuine encounters between researchers and participants as the spiral is revisited over time to make sense of the flow of experience (Csikszentmihalyi, 1997 and 2002; Hasselkus, 2011) via a temporal horizon (Whitehead, 2004). Following the hermeneutic circle in a spiral fashion for trust and rapport building purposes is illustrated in Figure 5 below:

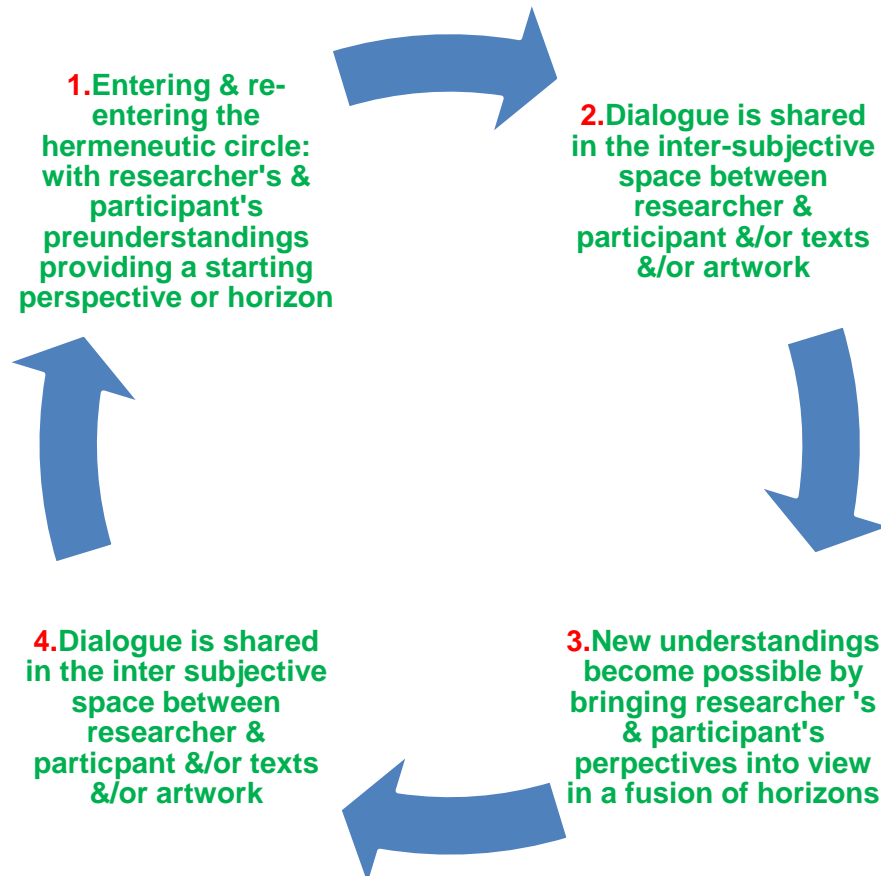
Figure 5: Rapport and trust building between participant and researcher reflecting temporality using the hermeneutic circle in a spiral fashion across multiple interviews



3.11 Exploring the metaphorical concept of fusion of horizons

Complementary to, and operating alongside the hermeneutic circle, is a second circle which introduces and situates the researcher's prejudices or preunderstandings of the phenomenon of concern (Alvesson and Skoldberg, 2009). These preunderstandings, defined by Gadamer (2004) as prejudgements, are considered as the individual's starting perspective or horizon of experience by Gadamer (ibid). According to Gadamer, a perspective or horizon is formed through a negotiation of past and present experiences between two people. Through bringing together the starting perspectives of two people a fusion of horizons may enable an opportunity for new and shared understandings and interpretations to be made. My interpretation of the metaphorical concept of fusion of horizons is illustrated in Figure 6 below:

Figure 6: My interpretation of the concept of Gadamer's fusion of horizons enabling new understandings to be realised by researcher and participant:



3.12 The philosophical orientation: a summary of collective underpinning assumptions

In addition to the centrality of the concepts of the hermeneutic circle and fusion of horizons in Gadamer's work (2004), other unique assumptions are important to acknowledge. Therefore, a summary of the collective assumptions underpinning his work are stated in Box 3:

Box 3: A summary of the collective assumptions underpinning Gadamer's work

- All understanding of our 'being-in-the-world' is gained via experience and expressed through dialogue, including verbal (linguistic in a basic sense) and non-verbal communication, texts, including poetry and artwork.
- Understanding human experience cannot be achieved using a positivist method employed in the natural sciences; instead philosophical hermeneutics may be adopted for this purpose.
- Without some prejudice/preunderstanding or prejudgement of the phenomenon of concern, no understanding is possible.
- Understanding is gained through attending to the parts of experience and additionally to the broader context of experience, via the hermeneutic circle in an ongoing cyclical fashion, more accurately conceptualised as an ongoing spiral continuously being followed over the life course.
- Understanding is possible through 'effective historical consciousness', in that all understanding is formed over time through the temporally situated nature of experience and as such, is continuously being reinterpreted within the context of past events, present situations and possible future being. Understanding therefore, can only ever be partial and is transient/temporary, as it is continually being re-framed as more experience is gained on a day to day basis.
- Dualism and the fragmented self that is mind and matter does not exist separately, we are whole beings situated in a cultural context (tradition).
- For Gadamer, culture means tradition and that which is passed down or on from one generation to another over time.
- Expressed horizons of experience, include both inner horizons (linked to characteristics that shape our future expectations and perceptions of our self) and outer horizons (linked to characteristics of the environment that shape expectations of our interactions with our surroundings).
- Shared expression of horizons enables new and different understandings of experience to be generated via a fusion of horizons between self and other.
- Genuine dialogue can only be achieved if the self is phenomenologically open to the horizon of the other in a subject to subject relationship.

Adapted from Gadamer (2004).

Whilst most of the assumptions listed above have already been addressed the significance of the valuable role of the researcher's prejudgements and the importance of attention to genuine dialogue are worthy of further exploration.

3.13 The role of prejudice in understanding human experience

Gadamer postulated that 'being-in-the-world' and everyday life is complex and is always situated in historical, social and cultural contexts (Gadamer, 2004). This he referred to as the "*embedded self*" (Lawn and Keane, 2011, p. 153). As such, he overtly acknowledged and valued the concept of prejudice, something positivists would view negatively as biases and capable of jeopardizing the rigour of their scientific project. Instead, Gadamer considered prejudices as prejudgements, important influences in shaping the reality of an individual's life experiences and a necessary component in enabling understanding (Gadamer, 2004). This was illustrated by Gadamer when he stated that: "*it is necessary to fundamentally rehabilitate the concept of prejudice and acknowledge the fact that there are legitimate prejudices.*" (Gadamer, 2004 p. 278).

Prejudice for Gadamer, was rehabilitated into prejudgement - something that is handed down historically over time via us being 'thrown' into our being within a cultural and social context (Gadamer, 2004). Additionally, and influencing this thrownness, are our current experiences which are impacted upon by past and new experiences, via Gadamer's notion of 'effective historical consciousness'. This concept makes the nature of reality an ever shifting concept (ibid) and consequently, the notion of multiple realities was acknowledged by Gadamer (ibid) again in line with the worldview of experiential researchers (Noble and Smith, 2015).

Furthermore, for interpretive phenomenologists, meaning is believed as being understood at a given moment in time and as being susceptible to change over time (Lawn, 2012). Researchers of this persuasion also believe that reality will be interpreted in a potentially different way by different individuals as their prejudgements will play a part (Finlay, 2011). This worldview or ontological orientation is consistent with mine. The orientation therefore underpinned my efforts to better understand the contextualised nature of living with CFS/ME for men and how this impacted upon the reality of their day to day lives and occupations considered as their 'being' in addition to their 'doing, belonging and becoming'.

In light of Gadamer's beliefs linked to the value of prejudgements researchers using his philosophical orientation are encouraged to openly consider their prejudgements about the phenomenon of concern. The purpose of this is to ensure prejudgments are acknowledged but do not dominate the interpretive encounter (Lawn, 2006). This, it is suggested, can be achieved through recording prejudgements in a research diary or similar which can be revisited throughout the enquiry to compare changes in understandings over time (Finlay, 2011).

3.14 Gadamer's attention to genuine dialogue to aid understanding

"It is in dialogue that language becomes most itself." (Freeman, 2011 p. 547).

Gadamer paid particular attention to the importance of achieving genuine dialogue between 'self' and 'other'. This is an issue I consider of particular importance for health professionals and qualitative researchers alike. The importance of paying attention to dialogue in the research encounter was stated by Fleming, Gaidys and Robb (2003):

"Understanding may only be possible through dialogue, with researchers being open to the opinion of the other. In this sense, the notion of dialogue does not only mean a conversation between two people, it is also possible to have a dialogue between reader and texts. In both instances language is considered the constitutive moment and it is through language that understanding becomes possible." (Fleming, Gaidys and Robb, 2003 p. 117).

In order to achieve a 'genuine dialogue' with the other, Gadamer suggested we need to enter into dialogue in an open and honest phenomenological manner to achieve shared understandings and a fusion of horizons as already presented (Gadamer, 2004). This notion and its potential usefulness in research enquiry has been explored by Binding and Tapp (2008) who explained that according to Gadamer, three possible perspectives or levels of communication, which are detailed overleaf in Table 4, are open to us when interacting with the other. Researchers adopting Gadamerian Levels one and two are considered as engaging in a disingenuous dialogic encounter, as they do not acknowledge the value of the 'other' as a human being, but instead, view the 'other' as an object of research. This level of dialogue is commonly included in the natural sciences in positivist designs. However, researchers striving to understand human experience from a humanist stance would aim to achieve level three communications between self and other enabling a genuine dialogic encounter to be achieved. For Gadamer, it is only if level three communications are shared between self and other that achieving different understanding of 'being-in-the world' is possible (Gadamer, 2004). At level three, respect

and regard is equal and positive between self and other. An awareness of these levels therefore, can provide researchers and clinicians with a useful analytical framework for identifying whether a genuine encounter has taken place. Consequently, this awareness may provide an opportunity for a fusion of horizons and subsequent transformation of understanding and improvements in clinical practice to be made as claimed by Vandermause and Fleming (2011):

“Meaning can be generated as participants share their experiences, articulate new understandings, and respond to researcher interrogatives that generate interpretation and add to extant knowledge. As novel explications and understanding of experiences unfold, clinical health care practice is advanced.” (Vandermause and Fleming, 2011 p. 375).

3.15 Achieving level three communications between self and the ‘other’

The three levels of communication Gadamer suggested as a framework for assessing the genuine nature of dialogue are summarised in Table 4 overleaf:

Table 4: Gadamer's 3 Levels of Communication (adapted from Binding and Tapp, 2008).

Level	Summary of Gadamer's 3 Levels of communication in Binding and Tapp (2008).	Role of the other.	Genuine encounter achieved?
1	Aim: A means to an end. For example: seeing a patient as a case or using a research participant as an informant to see how they behave.	<ul style="list-style-type: none"> • The 'other' (person) is seen as an object instrumental in a certain way in certain conditions. • Employed in research designs of a quantitative nature. 	No.
2	Aim: A one to one relationship but in a calculated way. For example: the relationship is one in which each strives to outdo the other.	<ul style="list-style-type: none"> • The 'other' is expected to respond in a competitive way in order to formulate a better argument in response. May be rivalry, or agree to disagree or complete dominance of one over the other. 	No.
3	Aim: Concern with the subject matter and with its possible truth. For example: neither participant presupposes to know the truth, rather each is open to the possibilities inherent in the other's views.	<ul style="list-style-type: none"> • Object is not the focus, the subject matter is the focus, the 'other' is equal and: <ol style="list-style-type: none"> 1. Open to the other's position. 2. Considers the essence of questions as a response to one who seeks to break open the being of the other. 3. Opens up possibilities that were not there before the question was asked. • Employed in research designs of a qualitative nature and in empathic clinical practice. 	Yes.

3.16 Establishing truth without method: a weakness or a strength of Gadamerian philosophical hermeneutics

In philosophical hermeneutics no inflexible pre-prescribed method is advocated to understand the meaning of reality in terms of human 'being'. There is therefore no right way of making an interpretation. Instead, by interpreting dialogue, the said and/or the unsaid, framed as what the dialogue asks of the interpreter, is believed to be the means for achieving shared understandings via a fusion of horizons (Gadamer, 2004). In terms of the research encounter therefore, it may be assumed by more traditional, positivist researchers that the possibility of generating ever-changing interpretations and understandings of human experience without a strictly prescribed method may be considered a weakness of hermeneutic phenomenology and philosophical hermeneutics (Fleming, Gaidys and Robb, 2003; Alvesson and Skoldberg, 2009). It may be additionally assumed that valuing prejudgements or 'biases' as part of the enquiry might obscure the discovery of objective truth (Robson, 2002). Mindful of the ontological basis of qualitative research however, these elements may also be considered as their greatest strength. Importantly rich insights into human 'being-in-the-world' can be gained in a flexible way and valued by paying attention to the everyday which is often overlooked and taken for granted. Lawn (2006) discussed one of Gadamer's central claims concerning how experience may be misappropriated through method and stated:

"Method occludes truth or rather that a basic and fundamental encounter with truth is lost once we resort to a dependence on method." (Lawn, 2006 p. 60).

A similar criticism of rigid method is described in the occupational science literature as stated by Christiansen and Townsend (2011):

"...qualitative researchers may feel that empirical science is much too rigid, simplistic and hopelessly lost when trying to appreciate and understand (the complexities of) social and cultural phenomena." (Christiansen and Townsend, 2011 p. 42).

Bearing these criticisms in mind, my intent to research the lived experience of men with CFS/ME was therefore, addressed using the epistemology of Gadamer's hermeneutic phenomenology and philosophical hermeneutics, which appealed to my ontological stance which is now further addressed in the next section where my prejudgements are explored.

3.17 My ontology and epistemology: situating my prejudgements in this enquiry

"We are always part of what we seek to understand." (Lawn, 2006, p. 39).

3.17.1 Prejudgements linked to methodology

Before commencing this study I was aware that historically the co-production of rich experiential data with patients began to engage the attention of occupational therapists during the 1980s and 1990s (Turpin and Iwama, 2011). The importance of hearing patients' stories, sometimes referred to as occupational narratives reflecting their multiple realities of daily life, has gained momentum in occupational therapy research for practice purposes (McColl *et al.*, 2003; Finlay, 2011; Hasselkus, 2011). In order therefore, to understand and know more about the multiple realities of the men involved in the study I considered that a qualitative naturalistic methodology (Lincoln and Guba, 1985) was the most appropriate to adopt and specifically that of interpretive phenomenology.

In line with the philosophical orientation and selected methodology it was important for me to acknowledge my prejudgements and perspective, referred to metaphorically by Gadamer as mentioned, as our horizon of experience (*ibid*) linked to the study. This I did in an openly phenomenological manner, by recording in a research journal my experiences of working with men with CFS/ME. Recognising my existing prejudgements in this overt way, enabled me to be aware of my starting point or perspective from which I could build new and different understandings of the meaning of living with CFS/ME for the men concerned. The negotiation of past and present experiences between self and the other occurs frequently for me in clinical practice and historical understanding of both patient and clinician played an important part in this encounter, what Gadamer refers to as 'effective historical consciousness' (Gadamer, 2004).

Being introduced to the work of Gadamer by a member of my PhD supervisory team was exciting for me, as the potential for capturing truths via dialogue and texts including artwork, resonated strongly with me as an occupational therapist. Additionally, my epistemological stance based on professional knowledge and skills steeped historically in humanistic roots, guided me when attempting to capture everyday human experiences during the clinical encounter. Such clinical encounters brought me into contact with men with CFS/ME, where I tried to interpret their illness experiences through dialogue and

data/texts, in the form of clinical questionnaires and other health-related records. Furthermore, my personal values and beliefs, or ontology, were motivational in my quest to understand the perspective or horizon of the person with CFS/ME, in a caring and empathic way. This in part was driven by a desire to ensure occupational justice (Townsend and Wilcock, 2000) for all, where access and resources are available to support meaningful participation in society. Many of the people who were referred to me have experienced occupational injustice. Although not termed as such by the patients concerned, many anecdotally reported to have been misunderstood by others in terms of their illness leading to reduced opportunities for occupational participation. This was sometimes by health professionals and more frequently it seemed, by their families and friends, whilst struggling to cope with the impact of illness in their day to day lives.

As a therapist, I enter into the clinical encounter with past experiences of not only working in the clinical field of CFS/ME but additionally, perspectives based on my own 'being-in-the-world' and associated life experiences. These, at times, I use reflectively to establish rapport and normalise and validate experiences of some of the patients I see. This is what may be referred to in the literature as 'therapeutic use of self' defined as: "*planned use of his or her personality, insights, perceptions, and judgments as part of the therapeutic process*" (Punwar and Peloquin 2000, p. 285). Similarly, the people who use the service in which I work will also bring their experiences of 'being' and prejudgements to the encounter and these will be embedded, as are mine, in historical tradition summarised here as a combination of culture, language and customs situated in a person's everyday world (Lawn and Keane, 2011). Prejudgements come into play in the clinical encounter for me in a positive rather than a negative way and assist the patient and me in knowing ourselves better through sharing our beliefs, values and opinions, which in turn, enable us to understand others through reflective self-application (Gadamer, 2004). I found this overt acknowledgement and positive reframing of prejudgments in the work of Gadamer refreshing. This, I think, is because I have sometimes struggled with the adequacy of researcher claims to objectivity when using standardised or validated measures for considering the complexity of human experience and the disruptive nature of living with CFS/ME for the individuals referred to my clinical service.

Like Gadamer I agree ontologically and epistemologically that we each need some perspective/horizon from which to begin to try and understand the perspective of the other. With this worldview in mind, I therefore considered my clinical prejudices or prejudgements equipped me well for entering into a genuine encounter to explore the

illness experiences of men with CFS/ME, about whom little published literature was available. Without my prejudgements I considered men's experiences may not have been paid any further attention in the literature and a lack of understanding about these may still remain. I therefore, made a pragmatic decision to research men's experiences of living with and beyond CFS/ME as I was aware that most academic literature was related to the experiences of women with the illness. I wanted to better understand the meaning of living with CFS/ME for men and considered that it might be different in some way from the meaning of it for women.

I was prepared therefore, to enter into the research encounter in an open manner to encourage accounts to be shared in a respectful and non-hierarchical partnership. I have learned that these elements are what Gadamer (2004) would consider to be fundamental to achieving a genuine level 3 dialogic encounter which has the potential to be transformative for all involved. This is part of what motivated me to adopt a Gadamerian orientation to this study. I have summarised these elements in the flow diagram below which formed part of the process of acknowledging my prejudgements before data collection commenced:

Figure 7: The process of acknowledging my prejudgements

Researcher's (my) prejudgements recorded in research journal (aids understanding: e.g. will men's experiences of CFS/ME differ to women's?)



Data collection phase of study = brings together contextual perspectives/horizons



Dialogic encounter genuine?  No = misunderstanding



Yes = Fusion of horizons



Understanding transformed

Reflexivity and the study focus: notes taken from my research journal 2015

Before commencing the study, I had expected that masculinity would be spoken about by the men recruited much more than it actually was. Additionally, as a female researcher I considered that I might have fewer prejudgements on 'maleness' whatever that might be, perhaps than a male researcher, and therefore, provide a unique view of experiences in this respect.

Trying to 'genuinely' understand the phenomenological nature of occupation is important to occupational therapists. Fundamentally, we understand "that the same occupation can be experienced differently by different people" (Molineux, 2004 p. 211). Building an open and honest relationship with those who use my service through genuine dialogue is essential to effective occupational therapy clinical practice and an issue about which I care a great deal. My own practice is most rewarding when I feel I have genuinely connected in a conversational partnership with the other person. This is achieved by us both jointly listening, discussing, questioning and responding to each other to explore both

the patient's experiences of living with CFS/ME and my experiences of working for many years in this clinical field. This includes the opportunity to discuss the patient's expectations of the service, concerns and needs and we conclude our initial meeting by agreeing on a shared and jointly negotiated plan of action/treatment. The aim of this is to put the patient in control of their own health and well-being and reduce power differentials between myself as the health professional and the person as a recipient of health care services. This is a personal quality marker of my professional knowledge and skills and I consider that any clinical encounter would be unsatisfactory and give me cause for concern, if this point of agreement was not achieved at the end of our initial meeting. As a clinician I would refer to this process as rapport building in order to establish a therapeutic relationship **with**, rather than **doing unto** the service user (Turpin and Iwama, 2011).

3.18 Fusing the philosophical hermeneutics of Gadamer with occupation and occupational therapy

Drawing on an existentialist perspective of 'being-in-the-world' based on the philosophical hermeneutics of Gadamer (2004) and the occupational therapy literature, in particular the work of Wilcock (1998), Rebeiro *et al.* (2000) and Hammell (2004), I decided to fuse philosophical and theoretical frameworks to better understand the meaning of living with CFS/ME for the participants involved in the study. This enabled me to explore their illness experiences in terms of its impact on their 'being-in-the-world'; their occupations, considered as 'doing'; and notions of 'belonging', or connectedness to others; and 'becoming', linked to who they wanted to be. The combination of 'being, doing, belonging and becoming' was organised to emphasise being as a pre-condition to 'doing, belonging and becoming' in line with the philosophical orientation of the study. In the occupational therapy literature however, 'doing', considered inter-changeably as 'occupation', is usually stated as the pre-condition to 'being, belonging and becoming' (Wilcock and Hocking, 2015). Hammell (2004) acknowledged however, that being has perhaps historically been paid less attention by occupational therapists than doing and suggested that in order to better understand the meaning of occupation for the individual that the concepts in combination (along with belonging and becoming) require attention in future research to improve client-centred practice (Hammell, 2004). Hasselkus (2011) supported this view when she stated that:

"I propose that we are missing a lot by our tendency to focus so predominantly and sometimes almost exclusively on the doing aspects of our daily occupations – in our personal lives and our work." (Hasselkus, 2011, p. 187).

Attention to a combination of these concepts was therefore the focus of my enquiry and occupation was seen as a dimension of being as Hammell (2004) and Hasselkus (2011) suggested.

3.19 Identifying congruency between philosophical orientation and methodology

Congruency between philosophical orientation and methodological design is recognised as important in the literature, as incongruence may threaten the trustworthiness of a research study (Morse and Singleton, 2001; Converse, 2012). Gadamer's ontological stance linked to understanding human experience fits well with an interpretivist-constructionist approach (Lincoln and Guba, 1985). It was considered therefore, that this orientation was congruent with my selected methodology as both enabled an interpretation of the meaning of the individual's 'being-in-the-world', whilst acknowledging some influence from contributory social and cultural factors.

As mentioned earlier in this chapter, interpretation and understanding of human experience can only ever be partial (Vessey, 2009; Freeman, 2011). It can never be total as the possibilities of interpretation are forever changing and impacted upon by historically situated experiences over time (Gadamer, 2004). This means that my interpretations of the data were made during the data collection, analysis and writing up phases of the study. Potentially therefore, if I revisit the interpretations after completing the study I may reinterpret the findings in the light of ongoing experience of 'being-in-the-world' linked to the topic and via effective historical consciousness. The findings as presented therefore represent my interpretations made in 2015/16 and for which I accept responsibility. Whilst declaring this I might be criticised by some researchers with a positivist worldview as a weakness of the findings, acknowledging the possibility of an ever-changing interpretation is seen as a strength in aiding understanding in hermeneutic phenomenology (Gadamer, 2004). Rather than threatening the findings it is recommended as a necessary step in the production of trustworthy Gadamerian hermeneutic research (Fleming, Gaidys and Robb, 2003) and therefore integral to the selected methodology.

For the purposes of this study I considered that using philosophical and occupational therapy frameworks in combination enabled a broad and holistic exploration and synthesis of the meaning of having CFS/ME for the participants involved, in addition to paying

attention to the detail of the impact of the condition on their occupations, which as an occupational therapist was of particular importance to me for purposes of clinical practice. Linking philosophical and occupational frameworks in this way therefore, enabled what Whiteford and Hocking (2012) considered to be “*new ways of knowing*” [about occupation] (Whiteford and Hocking, 2012 p. 165) in line with the drive by occupational scientists to learn more about the nature and meaning of occupation and its influence, both negative and positive, on survival and subjective meanings of health and well-being (Wilcock and Hocking, 2015).

3.20 Summary of the chapter

Adopting an interpretive phenomenological stance based on the philosophical orientation of Gadamer, I consider, has utility in both research and clinical practice as it enables patient voices to be authentically and compassionately heard. I entered into this enquiry therefore, with the expectations of doing just that: co-producing rich accounts of what it means to live with CFS/ME for the men involved. I was open to entering into the enquiry in a phenomenological manner acknowledging my prejudgements but welcoming the opportunity to understanding differently perhaps, by generating co-created accounts during the research interviews. I wasn't sure whether men's experiences of living with the illness would be different to that of women's or whether we would spend most of the interview time discussing masculinity or maleness, I was, in Gadamerian terms, open to the possibilities. In the next chapter the methodology of the study is presented.

Chapter 4:

Methodology

4.0 Introduction

In this chapter I link the selected methodology to the underpinning philosophical framework detailed in Chapter 3. I describe in detail the stages followed in the research process from the start of the study through to completion of the final report. I justify the method and locations used for data collection purposes and the practical management of the interviews. Sources of data, both expected and unexpected are identified. The importance of attaining a genuine dialogue between self and other during interviews is also discussed. The analysis of the data is explained in detail and an audit trail for this phase of the study is included.

Issues relating to the trustworthiness of qualitative research are addressed generally and also specifically in relation to this study. I provide evidence to support and justify decisions made throughout the research process in reflective notes which appear periodically and in italics providing context to my decision-making processes.

4.1 The selected qualitative methodology

For the purposes of addressing the research question I selected a qualitative methodology and specifically that of hermeneutic phenomenology based on the work of Hans Georg Gadamer (2004). Understanding how CFS/ME is experienced by men living with this condition was the focus of the study and I therefore decided this methodology was the most appropriate to employ. Qualitative designs enable exploration of selected phenomena and may broadly be considered as interpretivist-constructionist in nature (Lincoln and Guba, 1985), as interpretations are co-created between the researcher and participant and there is acknowledgment of the context in which they are experienced and constructed. In terms of context, interpretive phenomenologists consider that interdependent cultural and social factors, represented in the language people use to describe their reality of their experiences, are acknowledged in data collection, analysis and interpretation (Cohen, Kahn and Steeves, 2000). Braun and Clarke (2006) suggested that this position aligns the researcher to a contextualist approach, in that subjective

experience is identified somewhere on a continuum between realism at one pole and constructionism at the other. I decided therefore, that an interpretive phenomenological approach afforded me the opportunity to gain an understanding of how the men experienced their day to day lives, activities and occupations in context. Acknowledging the context in which participants lived their lives both past and present, and in terms of future possibilities, is consistent with Gadamer's notion of effective historical consciousness (Gadamer, 2004). Importantly however, whilst cultural and social contexts are acknowledged by Gadamer and other interpretive phenomenologists, they do not take precedence over the meaning of experience for the individual (Cohen, Kahn and Steeves, 2000).

The importance of ensuring the congruency between the philosophical orientation and methodology is recognised in the literature and incongruence is considered as a threat to trustworthiness (Morse and Singleton, 2001; Converse, 2012). Being mindful of this, I adopted Gadamer's ontological and epistemological stance, postulating that all understanding of human experience is gained via sharing a dialogue in the language people use, both verbal and non-verbal body language and communication in the form of written texts and/or artworks. This orientation fits well with a contextualist (Braun and Clarke, 2006) or interpretivist-constructionist approach as described by Lincoln and Guba (1985) and provides therefore, congruency and a degree of trustworthiness.

4.2 Sampling Strategy

Compatible with the interpretive phenomenological tradition, a purposive sample of men with CFS/ME was identified to address the research question (Finlay, 2011). Purposive sampling is referred to by some authors as criterion sampling (Creswell, 1998) or strategic sampling (Mason, 2002) which enables researchers to access a range of unique experiences within a given phenomenon (in this case CFS/ME) and identification of cross-contextual similarities. Additionally, I employed a maximum variation approach as I set out to recruit men from across the adult life span to facilitate collecting a range of experiences (Patton, 2002). Potential participants were identified from an existing clinical and research database established in 2007, held at a specialist NHS centre for people with CFS/ME. All men had a clinically confirmed diagnosis of CFS/ME and all had either previously accessed the service or were doing so at the time. As a member of the clinical and research team for the centre, I had approved access to this database for both clinical and research purposes. At the time recruitment commenced, the data of 120 potential

participants were included in the database. The youngest men whose data were included were in their late teens whilst the eldest was eighty years old.

Sample sizes in qualitative research are not set with the intention of being representative of a wider population of participants, unlike sizes in quantitative research designs (Patton, 2002). Additionally, and in interpretive phenomenology in particular, rich, in-depth accounts are generated for purposes of data analysis and therefore, commonly generate large sets of data (Mason, 2002). In order to cope with handling the data generated, a sample size of up to ten participants is usually selected (Starks and Trinidad, 2007; Finlay, 2011). For this reason I set out to recruit between eight and ten men and to possibly include those in their late teens, twenties, thirties, forties, fifties, sixties, seventies and eighties. I deliberately avoided recruiting a convenience sample from community based voluntary support groups, as based on my clinical experience and supporting literature review, I was aware that not all attendees would necessarily have a clinically confirmed diagnosis of CFS/ME. Table 5 summarises the inclusion and exclusion criteria for the study:

Table 5: Inclusion and exclusion criteria for the study

Inclusion Criteria	Exclusion Criteria
Men referred to the service of any age but preferably a spread from late teens to men in their eighties if possible.	Men who lacked capacity to consent because of the seriousness of their condition.
Men who were referred to the Service either with a firm diagnosis of CFS/ME/PVFS or had a diagnosis confirmed by the clinical team following assessment.	Men who were experiencing a significant relapse in their condition at the time of the planned research interview and would find it difficult to be interviewed due to the severity of their fatigue-related symptoms.
English speaking men.	Men who were actively being clinically treated by the researcher.
Men who could provide informed consent to take part.	

Originally, I intended that the experiences of men between 18 and 25 years of age would be the focus of the study. This decision was based on my experiences and pre-

judgements linked to particular occupational issues identified for young men with CFS/ME accrued in clinical practice. These had included for example, difficulties in accessing social situations in the evenings due to the severity of their illness and fears over personal safety when out in public places due to fatigue and physical weakness. These issues taken in context, I considered, may have been interesting to have researched further. However, some difficulty was experienced in recruiting men within this age bracket. Reasons for this included men moving away from the area to attend university (as I learned from one of the potential participants who contacted me to inform me of this fact). Therefore, after successfully recruiting only two young men after a period of approximately six months and after sending out ten letters of invitation, I decided to revisit my sampling strategy. With consideration of the time constraints for completing this study and the lack of literature linked to men's experiences of CFS/ME of any age, the inclusion criteria were therefore broadened. This enabled me to recruit men of any age from the fatigue database and consequently an improved recruitment rate was achieved.

4.2.1 The potential impact of the researcher on the participants

In order to prevent participants or myself from feeling uncomfortable or compromised in any way, I decided not to invite any men I was actively clinically treating into the study. This was in order to try and avoid the men from seeing me as a health professional and as belonging to a socially privileged group of knowledgeable experts (Wharton, 2005). This also prevented any blurring of participants understanding or expectations between treatment and research (Morse, 2007a), which I considered was important to ensure that the men could be supported adequately, ethically and appropriately during any treatment phases within the centre.

The importance of managing potential participant misconceptions of the role of the clinician-researcher was explored in the literature by Hiller and Vears (2016). These authors discussed how the clinician-researcher holds a dual-perspective in the qualitative research process, which presents both opportunities and challenges. Opportunities include the suggestion that the clinician's perspective assists with ease of access to participants in the research recruitment process and a willingness of their patients to participate, which was experienced by me during the recruitment phase of my study. Conversely however, an increased willingness to be involved, may present the challenge of participants expecting some form of treatment intervention from the research, such as those perhaps gained in clinical trials. Additionally, feelings of obligation to help out the clinician may be a burden for some patient-participants. However, Hiller and Vears (*ibid*)

suggested that by the clinician-researcher employing reflexivity to identify the impact of their role on the process from the start, and by making explicit the purpose of any qualitative research, challenges of this nature may be managed in a timely way, adding to the overall rigour of the study.

I considered therefore, that I needed to be a reflexive researcher (Finlay and Gough, 2003) in order to explore the impact I might have on the study participants and be mindful of not being tempted (based on my humanistic prejudgements), to adopt the role of the clinician during the research interviews. Following this reflexive process prevented the interviews from becoming therapeutic encounters and clinician/researcher-participant/patient boundaries from becoming unclear. Adopting such a stance may be considered as a form of reflexive bracketing (Gearing, 2004).

As part of this reflexivity, the importance of being sensitive to any perceived power differentials between patient-participants and the clinician-researcher was acknowledged, not simply before the study commenced, but also as recommended, throughout the research process (Karnieli-Miller, Strier and Passach, 2009). This acknowledgement is consistent with Gadamer's concept of a Level three encounter where there is equal partnership between self and other in a non-hierarchical way (Gadamer, 2004). This can be achieved by the clinician-researcher entering into the research process as a facilitator in a collaborative, informal and egalitarian manner, in order to redistribute power ownership (Karnieli-Miller, Strier and Passach, 2009). Of particular importance in fostering this approach in interpretive phenomenology, is the choice of a naturalistic setting for the data generation phase of a study to put participants at their ease (Cohen, Khan and Steeves, 2000; Mason, 2000). The overall aim in reducing power differentials between researcher and participants in qualitative research therefore, is one of democratising the research process from start to finish (Karnieli-Miller, Strier and Passach, 2009). This is an aim consistent with my ontology and the epistemology of occupational therapy, and therefore, a factor that greatly influenced how I conducted the study.

Reflections on power differentials and gender in the research process:

Entering into a genuine partnership was something that was very important to me throughout the study. My desire not to be seen as the 'all-powerful' therapist and therefore, 'gate-keeper' to health service provision (Sharkey et al., 2009) was important to me to avoid. Instead, I strove to establish the role of the engaged researcher by making

explicit the nature of my role, the enquiry and the selected methodology. Additionally, and from an ethical perspective, I also ensured that if clinical advice or interventions were identified by me, or requested by the participants, that the Participant Information Sheet (see Appendix B) included contact details of a senior clinician at the Bath Centre for Fatigue Services. This strategy, not only supported the participants where necessary, but also myself, as I ran the risk of becoming upset or frustrated if I was unable to meet any clinical needs identified. Adopting this strategy therefore, provided not only a 'safety net' for the men, but also for me, and was suggested as ethically appropriate research practice in the literature (Smythe and Williamson, 2004). My aim was to approach the enquiry with dignity and respect for the men in order to foster genuine partnership working. One advantage of entering into the research process as an experienced clinician I considered meant that I had developed useful skills in communication and rapport building which assisted me in making partnership working more easily achievable.

I also reflected on the importance of socially constructed notions of gender (Wharton, 2005) and issues linked to traditional male socialisation (Sweet, 2012) and how these might impact upon the research process. I considered that with my own culturally embedded socialisation and prejudgements of 'being female' as opposed to 'being male', I may have been entering into what Warren (1988) described as a potentially strange or unfamiliar space. Arguably however, this space was more familiar to me than perhaps the space entered into by female researchers who had little or no experience of working with men with CFS/ME. Regardless of these reflections however, the importance of hearing the voices of men with CFS/ME remained my research concern. I therefore endeavoured to explore this in an open and reflexive manner, entering this space, in some depth and over time, to co-create understandings and interpretations of the men's experiences. This I felt was particularly important for myself and other female clinicians, coming from a largely female dominated profession.

4.3 Participant recruitment

I identified potential participants from the fatigue research database. Before any contact was made however, the electronic NHS Data Tracking Service was used to check whether the person was recorded as 'live' or 'deceased' to prevent any potential offence to the family of a deceased patient and possible consequential financial penalty to the Trust for associated damages. However, none of the men selected from the database were recorded as 'deceased'. The Centre's administrator then sent out a letter of invitation, a consent form and a participant information sheet to those identified (See Appendix B for copies of the Letter of Invitation, Consent Form and Participant Information

Sheet). The information sheet stated that any participation in the study was entirely voluntary. A detachable contact details slip was included in the communication, plus a pre-paid envelope for return to me as the named researcher, if they wanted me to contact them to discuss their interest further. Those invited to take part had up to four weeks to respond to this invitation. If after four weeks no response was received, this was recorded to prevent them from the burden of being invited twice and it was assumed they were not interested. Invitations were then sent out to other men identified from the database in batches of four, to stagger potential recruitment, on three separate occasions. From this process eight men were recruited aged 21-68 years.

When completed contact slips were returned, I telephoned potential participants to thank them for their interest and provide them with the opportunity to discuss the study further, addressing any outstanding questions they had. Following this, and if they wished to participate, arrangements were made for their first interview to take place at a time and place of their choice. All of the men I spoke with agreed to participate. This process continued until eight men with a range of ages were recruited to the study. A spreadsheet of interviews arranged and completed was stored in line with all ethical requirements, to assist with organisation and monitoring of the recruitment process.

Consideration was given to handling a recruitment response which exceeded sample size requirements. To address this, a 'Thank You Letter' (see Appendix C) was sent to invitees if necessary, which included an explanation as to why no further participants were needed. I did not however, need to use this letter as pacing the rate of invitations posted out enabled me to control participant recruitment and stop when the sample size of eight was achieved. The decision to recruit eight instead of ten participants was due to the extensive amounts of data that were generated as interviews were completed. Twenty three interviews in total were conducted and to have continued recruitment to ten participants I considered, would have made data handling potentially overwhelming and unachievable in the time available for the completion of the study. Additionally, it is also questionable whether a smaller sample of six or a larger sample of ten would have altered the findings.

4.4 Ethical considerations

Full ethical approval for this study was gained from the National Research Ethics Service (reference number: 13/SW/0105) and the research and ethics committees for the

University of the West of England, Bristol (reference number: HAS/13/11/146) and the RNHRD NHS Foundation Trust Bath (reference number: 90222). Widening of the inclusion criteria to include men of any age was possible as a substantial amendment was made to the approvals already in place and agreed by the relevant research ethics committees.

A second substantial amendment was also made when it became evident that I did not have enough time within the study timescales to personally transcribe data generated from all twenty three interviews as I had intended. Therefore, after transcribing five transcripts (all data for participants 1 and 2) and taking some advice from a more experienced researcher, a further substantial amendment was made and approved for a member of the post graduate research administrative team at UWE to assist with this task. As the participants had been recruited on the understanding that I would be the transcriber of their data, a letter was sent to participants 3 – 8 requesting permission for a research administrator to complete this task. All participants gave permission for this to be performed which was recorded in the recruitment spreadsheet (see Appendix D).

Reflexivity and transcribing the data: notes taken from my research journal 2014

The decision to allow someone else to transcribe the data was not taken lightly. I experienced some disappointment as I felt I should have been able to manage this myself. Additionally, I was concerned that allowing someone else to do this would in some way distance me from the data. However, using interpretive phenomenology meant that I continuously read and re-read and listened to the data recordings. This ensured that I maintained closeness to the data and reduced my concerns about fragmentation and becoming detached or unfamiliar with the men's accounts.

4.5 Written informed consent

Written, informed consent was taken once, immediately prior to the first interview being conducted and only after I had explained the study on two separate occasions with potential participants. This was firstly via a telephone call, if the man returned the completed contact details slip as mentioned and secondly, at the face to face meeting before the first research interview commenced. At this point a copy of the consent form was signed by the participant for inclusion in their medical records held at the Centre. Additionally, a photocopy of this was made by the researcher for the participant to keep. If

their interviews were conducted at home, the document was copied back at the Centre and was sent to the participant in the post within a few days of their interview taking place. If interviews were conducted in the Centre, a copy of the consent form was made and provided immediately prior to their first interview.

Reflexivity and the consent process: notes taken from my research journal 2013

In my ethics application I had assumed that consent needed to be taken before each interview and therefore, up to four times with each participant. This however, was felt not to be the case by the ethics committee who reviewed and approved my application. I was surprised at this as potentially a series of interviews may have been conducted over a period of up to a year and I felt therefore, that in fairness to the participants, this would have been the correct thing to do in case they wanted to change their minds about involvement in the interim, or perhaps become unwell and therefore, unable to engage in subsequent interviews. This made me consider that maybe I was over-rigorous in my assumption/decision-making re consent and the research process. However, whilst written consent was not taken for subsequent interviews verbal consent was sought in order to arrange these interviews and before the interviews commenced.

4.6 Participant safety and risks to the data

The safe protection of data and the maintenance of anonymity of study participants are key considerations in any research encounter (Vijayanathan and Nawawi, 2008). Particular care needs to be taken when data are linked to a small-scale qualitative study of NHS patients (Morse, 2015a). When the study sample is relatively small, the degree of risk of revealing participant-identifiable information is increased. Men recruited to the study were therefore, allocated a recruitment number in the first instance; the first participant recruited was P1, the second P2 and so on, for my research records, field diary and organisational purposes. During the data collection phase and after our first interview had taken place, I invited all of the men to select a pseudonym of their choice to protect their identity and ensure confidentiality in all study outputs. Additionally, other identifiable information such as the location of their homes and places of work were removed from the transcriptions, the quotations used in data analysis, and production of findings. Types of employment were also made less specific, again to protect anonymity. The participants' pseudonyms of choice were as follows:

- Participant 1: George
- Participant 2: Edmond
- Participant 3: Luke
- Participant 4: Sparky
- Participant 5: Billy
- Participant 6: Andy
- Participant 7: Christopher
- Participant 8: Arnold

Reasons for choice of pseudonym were not provided by all of the men. Some however, such as Billy, had admired the 1950s pop star Billy Fury so selected that name. Interestingly, Sparky had wanted to be like the main character in Roald Dahl's book 'Danny Champion of the World' who is described as lively and 'sparky'. Sadly however, he felt this was not possible in his real life due to his illness. Vandermause and Fleming (2011) acknowledged the importance of participants selecting their own pseudonyms in hermeneutic studies and described how this process may add to deeper understandings for the researcher:

"Participant pseudonyms can reflect meaningful real-life identities that enliven the research project and represent lived experience. Although the origins of the self-chosen pseudonyms cannot be overtly described in the study findings (to protect identities) they can anchor the participants' investment and enhance the thinking that leads to deeper levels of interpretation". (Vandermause and Fleming, 2011 p. 371).

I considered that the use of pseudonyms in this study enlivened the work and added to my understanding of the men's experiences through contextualising factors that had held some importance to them in their lives.

Additional risks to the data included the generation of data in the participant's own home, often referred to in the literature as a naturalistic setting (Mason, 2002; Bowling, 2002; Finlay, 2011, Rubin and Rubin, 2012). Research conducted in naturalistic settings may add to the degree of risk posed to data protection, as opposed to that conducted for example, in a more controlled NHS clinical setting. Additionally, the transit of data between the point of collection and its return to the pre-agreed safe place of storage, as

per the agreed ethics approval, was a responsibility I took seriously in order to ensure participant safety at all times. Data were also protected throughout transcription and analysis and headphones were worn to protect the identification of participants whilst listening to the interviews during transcription and analysis. All data were stored as per relevant regulatory frameworks which included those from the Department of Health (2005) the UK Data Protection Act (UK HMSO, 1998), the Centre's research governance principles and UWE Research Governance (2013). Only I, as the principal investigator/researcher was aware of the identity of the eight participants. The rest of the PhD supervisory team only had access to participant pseudonyms, anonymised data and outputs.

All participants were made aware that their GPs would be informed by letter of their involvement in the study (see Appendix E). This was considered a safety measure just in case a participant needed GP support due to their involvement in the study and also reduced the burden of a participant needing to explain the study to the GP.

Additionally, the PIS included contact details of a senior clinician who was a member of the fatigue centre as a point of contact if the participants had felt distressed or wanted to discuss clinical issues that might have arisen during the research encounter. Contact details for the Samaritans charity for emotional support after the interview if required, were also included.

Provision was also made for participants who may have become unduly distressed during an interview. If these circumstances arose, I had planned that the participant would be given the option to have the recorder turned off in order to recover and a pause in the interview would have been suggested. An option for the participant to recommence the interview after a short break, or to terminate the interview if preferred, was also provided. If this situation had occurred, the participant would have been reassured that they had a free choice to do this without any negative consequences and the interview would have been concluded. I did not however, need to employ this strategy as none of the participants became unduly distressed during interviews.

4.7 Researcher safety

As a key element of good clinical practice, lone working arrangements were put in place to reduce safety risks to myself as a female researcher when conducting 'off-site' fieldwork research (UWE, 2012). I conducted a risk assessment and this was ratified by my manager at UWE and then stored on the organisation's risk register (see Appendix F). Risk assessment measures were followed during fieldwork and included recording off-site visits in a research diary kept in a locked cabinet in my office at the Bath Centre for Fatigue Services. A senior member of the CFS/ME clinical team was informed of the whereabouts of the list on the understanding that this was only to be accessed if it was considered that my safety was at risk. Before off-site visits were conducted, I informed the named team member of the date and time of the planned visits and the anonymised participant number of the person I was visiting. For example, P1 meant I was visiting Participant number 1, P2 number two and so on. In the unlikely event of cause for concern, my colleague was given access to the key to my research cabinet which would have enabled discovery of the identity of the participant visited, contact details and geographical location. Additionally, as part of the risk assessment, I ensured I had a working mobile telephone with me at all times and I rang my colleague to inform her when I had left an off-site venue, to reassure her of my safety following the completion of each interview. A code word to alert her to significant risk of personal harm was adopted and known by myself and my colleague if I considered that police intervention/immediate help was needed. However, I did not experience any significant risks to my safety during off-site fieldwork.

Consideration was also given to the possible need for me to debrief after each interview and this was arranged with a senior clinical colleague who was named in the ethics approval and documentation. This strategy ensured that I had an outlet for what Morse (2000, p. 540) refers to as "*the emotional toll of qualitative research*", which she stated is often inadequately addressed in the literature. I found debriefing particularly helpful on one occasion, after one of the participants had discussed the traumatic nature of his childhood experiences of being beaten by his father.

4.8 Transcriber Safety

Something that I had not anticipated was the need for the transcriber to also debrief following her exposure to the contents of the interview data. Debriefing was therefore

provided by me in a confidential space during the handover of the encrypted data stick containing the transcriptions.

4.9 Methods of data collection

4.9.1 Interviews

As my aim was to explore the ways in which men made sense of their experiences and articulated these, the main data collection method selected for the study was that of face to face, in-depth, 1:1, unstructured interviews, conducted in a place and at a time of the participant's choice. I conducted twenty three interviews in total. The value of employing in-depth interviews to generate rich data, and therefore, explore the meaning of how a certain phenomenon is experienced, is widely reported in the literature (Kvale, 1996; Cohen, Kahn and Steeves, 2000; Mason, 2002; Patton, 2002; Groenewald, 2004; Whitehead, 2004; Finlay, 2011; Vandermause and Fleming, 2011; Rubin and Rubin, 2012; Beck, 2013; Lucas, 2014). Additionally, the importance of interviewing those with direct experience of a given phenomenon, as opposed to second hand experience, is fundamental when employing interpretive phenomenology (Patton, 2002). Furthermore, Robson (2002) in addition to Gadamer (2004) suggested that prior understanding of the phenomenon of interest or a degree of familiarity with this is useful when using interpretive phenomenology. This suggestion I considered fitted well with my pre-judgements and experience linked to the topic.

The use of unstructured interviews when employing interpretive phenomenology is recognised as enabling the topic to be shared in a conversational manner (Cohen, Kahn and Steeves, 2000; Vandermause and Fleming, 2011). These differ from structured or semi-structured interviews, as no interview schedule is used to guide the encounter. The unstructured nature of the interview enables experiences to be shared in an unrestricted manner and interpreted, rather than reduced, due to using pre-selected questioning. This conversational approach is congruent with Gadamer's notion of free-flowing dialogue generated in a play-like fashion via the Hermeneutic Circle (Gadamer, 2004). The only structure to the interviews I conducted was a reminder of the rationale for the study and I opened the initial interviews with the following invitation or similar:

“So thanks again for meeting with me. There's no predetermined agenda. You know the purpose of my study, so wherever you want to start is great and we will just take it from there.”

Data were therefore, gathered in this way over a series of up to four individual interviews with each participant to provide us with the opportunity to share in-depth, rich accounts of their experiences of living with CFS/ME. A decision regarding the number of interviews conducted was based upon co-created agreement between each participant and me during the process. For example, Edmond managed two relatively long interviews, sharing all he needed to about his experiences in this time as he considered he was cured of CFS/ME. Conversely, others such as Luke needed to pace his interviews over four meetings due to becoming fatigued during the interview process.

I considered that participant involvement should not exceed four interviews, as in my pre-judgement, any greater number may have been too onerous to commit to for a man with enduring fatigue and this information was included in the participant information sheet. Additionally, I had anticipated that each individual interview might last between approximately one to two hours and therefore, the possible presence of fatigue-related symptoms on the day of the interview and any risk or fear of post exertional fatigue, needed to be taken into account. However, in order to encourage the men to be involved in more than one interview, a time span of approximately twelve months was offered for them to pace their interview participation if required. Contrary to my pre-judgements however, all of the men preferred to complete their interviews within four to nine weeks.

The importance of conducting multiple interviews over time is considered as an essential feature of hermeneutic phenomenology (Cohen, Kahn and Steeves, 2000; Fleming, Gaidys and Robb, 2003), enabling rapport and trust-building and therefore, facilitation of a genuine dialogical encounter between the researcher and the participant. The importance of this temporal aspect of data collection was also emphasized by Sandelowski (1999).

4.9.2 Other sources of data

In addition to the interview data which may be considered as only a partial representation of any interview encounter (Mason, 2002), my field notes and a critical reflective research journal were considered as sources of data. These sources were used to record the non-verbal dialogue of the participants, such as George fidgeting and obviously looking uncomfortable and nervous at the start of our first interview, making it important for me to put him at his ease and establish rapport as best I could. I did this by using a soft tone of voice when reminding him of the purpose of the study and created a comfortable physical distance between us for interviewing purposes to ensure he did not feel his personal

space had been invaded. Additionally, contextual information linked to time of the interviews and locations and immediate reflections post interviews were made in long-hand and revisited as part of the data analysis. These sources of data are identified as useful in hermeneutic phenomenological research in providing background and context to the study and also enabling pre-judgements to be recorded on an ongoing basis (Barr, 2006). Furthermore, they may be considered as sources enabling data triangulation and thereby, adding to the robustness of the data generated (Denzin and Lincoln, 1994; Blaikie, 2000; Mason, 2002; Gubrium and Holstein, 2003). Unexpected sources of data were also presented during the data collection phase of the study by George and Andy and this supported and augmented their interview data. George provided two pages of typed notes, which summarised some of his illness experiences which were particularly important for him, and Andy provided two poems and several paintings which he said he had produced as an outlet for some of his illness-related frustrations. Cohen, Kahn and Steeves (2000) mentioned the usefulness and serendipitous nature of data that might be produced during interviews that may not have been anticipated. The rationale for this, they suggested, is associated with the participants' desire to share their horizons of experience and support the researcher's attempts to understand their experiences in a different way. For me, this unexpected data added to the richness of the accounts generated through the interview process. Mason (2002) discussed how qualitative researchers may be criticised for focusing on only transcribed dialogue from interviews and as such limit interpretations of experiences. Like Gadamer, Mason acknowledges that visual representations have the potential to convey meaningful experiences and if presented can usefully add to the richness of the data generated and the overall story.

4.9.3 Entering the 'hermeneutic circle'

In order to co-create rich and contextualised data linked to the person, place and temporal aspects of experiences, hermeneutic phenomenology incorporates both descriptive and interpretive elements (Cohen, Kahn and Steeves, 2000) captured by moving metaphorically through the 'hermeneutic circle' during the interviews as described in Chapter 3. Each participant's broad account over time and also of equal importance, its component parts, were explored in line with the Gadamerian orientation I employed. I first entered into the hermeneutic circle with an awareness of how this might facilitate data collection, with each participant, unaware of how the process might operate at the start of interview one. Through sharing dialogue in the inter-subjective space between me and the participant, a fusion of horizons was possible and a different understanding of the meaning of living with CFS/ME achieved.

4.9.4 Following the hermeneutic circle over a course of interviews

The process of following the hermeneutic circle was revisited at subsequent interviews, and up to four times in total, with each participant. This enabled me to build on previously co-created data and initial interpretations and importantly, facilitated generation of new and richer data in the process through a fusion of perspectives or horizons. As mentioned in Chapter 3, I considered that it was helpful to envisage the use of the hermeneutic circle in the data collection phase of a study as a spiral process which enabled understanding to be conceptualised as open and ongoing rather than a restricted closed circle might imply (Debesay, Naden and Slettebo, 2008). Moving in a spiral fashion over the course of the interviews one spiral builds upon the next, layering the meaning of the data. Rather than conceptualising 'being-in-the-world' as a series of discreet stand-alone (hermeneutic) circles not linked to past events or future possibilities of being, this layered, ongoing process enables the context of experiences and the importance of Gadamer's notion of effective historical consciousness to be considered. As subsequent interviews were conducted, new horizons of the meaning of living with CFS/ME were shared and rich data co-created as the participants and I were willing to be open to the contribution of the other, enabling preunderstandings to be challenged and potentially reframed into new and different understandings.

Reflexivity: and the interview process

To satisfy the requirements of the National Research Ethics Service I had to produce a semi-structured interview schedule as part of my ethics application. Through becoming more familiar with interpretive phenomenology however, I became aware that the use of such a schedule would probably stifle the research conversation and unduly lead the research encounter and possibly privilege the agenda of the researcher as opposed to enabling an evolving and dynamic dialogue. Nervously therefore, I set out to work without the schedule but admit to taking it along to the first interview as an aide memoire and as a safety blanket just in case the conversation dried up. Surprisingly, the schedule was not needed and was never used by me in any of the 23 interviews conducted. Evolving dialogue was much more interesting than my pre-set questions however semi-structured they were. Reflecting on this, I was able to see how my confidence as a developing interpretive phenomenologist had increased in a relatively short period of time about which I was pleased. More importantly for me however, was how 'right' it felt in terms of fostering a genuine dialogue with participants. For qualitative research it is I believe, the only way to capture a shared understanding of a given phenomenon and has resonance with the notion of shared care and truly client-centred practice which I greatly value.

4.9.5 Location of the interviews

A choice of location was offered to all participants when each interview was arranged. The rationale for this was based on several factors. Firstly, the importance of using a familiar and naturalistic setting referred to as research “*in-the-field*” by Bailey (2007 p. 2) is acknowledged as helpful when attempting to generate data linked to daily experiences and can facilitate the co-production of contextualised and meaningful understandings. Secondly, using a non-clinical setting for health related research can assist in reducing, and at best removing, any potential power differentials between the participants and health professional researchers like me (Gubrium and Holstein, 2003). The importance of being mindful of power issues and social positioning in the research context was addressed by Poindexter (2003) and Etherington (2004):

“When we enter into relationships with our research participants it is inevitable that issues of power come into focus and require us constantly to scrutinise and interrogate our own positions, views and behaviours.” (Etherington, 2004, p. 226).

Participants varied in their choices of interview locations; some preferred all of their interviews to be conducted in their own homes (George, Sparky, Billy, Christopher and Andy). Others, such as Luke and Arnold, chose the NHS hospital trust where my research office was located. Importantly this office has soft furnishings and provided a quiet and comfortable space within which I could guarantee no interruptions during their interviews (Finlay, 2011). I also considered that using my office was more appropriate than a clinic room and would reduce the possibility of the interview feeling like a treatment session. Refreshments were also provided for comfort purposes.

Edmond selected a mixture of locations, with his first interview being conducted in my office and the second at his parents’ home nearby. Most found being interviewed at home to be convenient. For Luke however, it was easier to be interviewed in my office, as his interviews took place after he had finished work which was located closer to my office than his home. Arnold made a conscious decision to keep the research interviews separate to his home life mentioning this would probably be more acceptable to his partner. Times of interviews were negotiated with the participants and accommodated their family, social and work commitments.

4.9.6 Contrasts between location of interviews

My preferred choice for interviewing participants was in a naturalistic setting. Interviews conducted in the participants’ own homes or those of their parents were, I considered,

more interesting for me as a qualitative researcher. In these naturalistic settings I was able to notice and experience factors of contextual importance to participants and incorporate these into interpretations of shared experiences. For example, both Edmond and Christopher voluntarily showed me where they had spent most of their days at the times when their illness was at its worst. Both were confined to an armchair in a given room and place which enabled my understanding of their experiences to be greater perhaps than relying on them describing this in some other unrelated place such as the hospital. Additionally, I was able to meet some of the men's family members, all of whom were welcoming and supportive of the study.

As mentioned, some participants for reasons of convenience chose to be interviewed at the Bath Centre for Fatigue Services where they had accessed fatigue treatments. Although I ensured a quiet and undisturbed comfortable office was available for the purpose, I much preferred interviewing in-the-field; visiting participants at home enabled me to detach myself from my clinical role and become a visiting researcher and equal partner in the research encounter as opposed to a clinician conducting hospital-based research on familiar work-based territory.

4.9.7 Management of data collection

Interviews for all participants except Andy, took place with only myself present in the interview room. Andy however, requested that his wife be present for all four of his interviews to act as an aide memoire should his memory let him down during the interview process. I was not expecting this and was concerned about the ethical approvals I had in place to interview only the recruited participants as opposed to family members. I did not discuss my concerns with Andy however, as I did not want to exert any perceived authority over the interview process and create this dynamic before we had even commenced our first encounter. Instead, I supportively agreed that if Andy thought it would be helpful for his wife to be present that she would be very welcome to sit in on the interviews. Fortunately the issue of ethics was addressed without me needing to discuss this with Andy and his wife, as the dialogue generally was between the two of us, with Andy occasionally asking his wife for clarification in terms of chronological events. During the interviews she chose to sit quietly some distance away from where we were recording, ready to help Andy with details if he asked. For ethical reasons therefore, comments provided by Andy's wife were not included in the data analysis but arguably were however, reflected in Andy's dialogue to some degree. These decisions I consider were an illustration of good ethical practice a view supported by Mason (2002) who

acknowledges the need at times to make on the spot moral decisions during qualitative data collection involving face to face methods.

Research interviews were all conducted by me as recommended in interpretive phenomenological studies to foster rapport building through the process (Munhall, 2013), and were digitally recorded to ensure verbatim accounts were captured (Kvale, 1996). Moving back and forth in a dialogic encounter between two people during research interviews can facilitate an open and genuine encounter where different understandings of the phenomenon of focus may be generated (Binding and Tapp, 2008). The naturally occurring nature of a genuine conversation can be achieved by adopting an open questioning stance, synonymous with what Gadamer considers a level three encounter (ibid), rather than employing a semi-structured interview schedule in studies using a hermeneutic approach to research. From the twenty-three interviews conducted rich, in-depth accounts of experiences of what it means to live with CFS/ME were co-created in a naturalistic manner. This involved an exchange of free flowing dialogue during the interviews where horizons were shared to reach different understandings of the phenomenon of interest.

4.9.8 Facilitating Level 3 Gadamerian dialogue between myself and the participants

I anticipated that barriers potentially affecting a level three encounter with participants with CFS/ME might have included difficulties with concentration, memory and/or word finding difficulties (NICE, 2007) and this is where I think my pre-judgments as an experienced clinician were very useful. In this situation as a researcher, I used my knowledge of CFS/ME and my communication skills to guess some of the words that participants struggled to find and presented a potential solution to the barrier in the encounter. Examples of this appear in my data where the participant is struggling to find the right word and after a pause and with care and sensitivity, I suggest a suitable word and the participant confirms that is what they wanted to say. This happened during the data collection phase of my study on several occasions and the participants demonstrated how grateful they were by thanking me for understanding what they were trying to say without them being able to articulate what they meant at the time. I consider that a less clinically experienced researcher may not have been able to notice a participant struggling with these symptoms of CFS/ME and as a consequence, a genuine research encounter may not have been possible.

Additionally, as a skilled clinician I was aware of the need to monitor whether a participant was becoming too fatigued to continue an interview and addressed this potential barrier with them if I felt this was the case. I was able to identify the signs of someone becoming fatigued and suggested a follow-up interview instead of carrying on regardless in a quest to obtain data. This was helpful in that it pre-empted an over-expenditure of energy during the interviews in a jointly negotiated way and enabled further interviews to be arranged as necessary, rather than adding to the burden of living with the impact of enduring fatigue exacerbated by the research interviews.

Approaching data collection in the spirit of partnership facilitated the first interview with some participants who clearly saw me as a health professional and anticipated I would set the agenda in terms of how long the interview would last and the sort of questions they would be asked. This is a clear demonstration of how most participants afforded me professional authority at the start of our encounters. However, attempting to achieve a fusion of horizons was important to me and an attempt to reduce possible power differentials in terms of perceived 'subject-object' dualism (Foucault, 2003; Lawn and Keane, 2011). I was therefore, prompt in emphasising that there was no schedule of pre-set questions to be answered or minimum or maximum time limits imposed on the interview by me. I reassured participants that the aim of our meeting was for us to explore their experiences of living with CFS/ME and encouraged each of them to start their accounts wherever they wished and in whatever way made sense to them. This enabled what Gadamer (2004) would consider to be open, honest and genuine level three research encounters. Qualitative data were co-created from 23 interviews of variable length, with participants being interviewed up to four times each.

4.9.9 Rejecting the use of formal member checking of transcriptions

Although frequently adopted by researchers employing qualitative designs, member checking of the interview transcriptions, sometimes referred to as respondent validation (Creswell, 1998; Robson, 2002), was not used in this study which is consistent with interpretive phenomenology (Fleming, Gaidys and Robb, 2003; Mason, 2002; Harper and Thompson, 2012). Formal member checking commonly involves the sending of transcriptions to participants following interview completions for comments and corrections and subsequent researcher amendment. In interpretive phenomenology however, the reality of experiences for the individual are considered to be continuously changing and shifting based on the influence of new experiences, both gained over time and those embedded in historically-situated events. Therefore, data co-created during the interviews,

were considered to be reflective of understandings of living with CFS/ME at that point in time. However, a more naturalistic and conversational checking of shared horizons and understanding did occur through participant interpretation and reflection of perspectives shared during data collection (Morse, 2015a) both during the interviews (Munhall, 2013) and at the start of subsequent interviews. Fleming, Gaidys and Robb (2003) mentioned the importance of seeing each interview as part of the hermeneutic circle and rather than member checking, advocated for a discussion of the main points of each encounter before subsequent interviews commence. All participants, when offered, were keen for me to summarise previously agreed understandings at the beginning of subsequent interviews, which provided the opportunity for us to build deeper and richer understanding on these shared foundations. I know this process was valued by participants as they reported it as helpful in facilitating their re-engagement in subsequent research interviews, which I consider, contributed to maintaining rapport and trust between us. Additionally, these summaries enabled us to pick up where we had left off previously and as the interviews were also conducted over a relatively short period of time, between 4 – 9 weeks, this may have meant that understandings of their illness experiences perhaps did not change significantly during this time, relative to the time they had been living with the illness overall. However, in the spirit of interpretive phenomenology changes in experience over time are acknowledged and this would not therefore, have been an issue of concern.

4.10 Data Analysis

To analyse the data a method of thematic analysis (TA) was used based on the work of Braun and Clarke (2006) and extended throughout the process to incorporate interpretive development of the data within Gadamerian and occupational science frameworks. These authors suggest a six phase step by step guide for TA that can be used as a stand-alone method or employed within a variety of qualitative study designs, as a tool to assist analysis to identify themes or patterns in the data. In my study TA was used in conjunction with the Hermeneutic Circle to ensure a robust and systematic approach to data analysis. TA can be used in this complementary and flexible way as its use is not dependent on any particular epistemology or theory, a quality described by the authors as “*theoretical freedom*” (Braun and Clarke, 2006 p. 5). This is the major difference between Interpretive Phenomenological Analysis (IPA) and interpretive phenomenology. Whilst only one form of IPA is considered as currently existing, it is intrinsically linked to underpinning psychological assumptions and was designed by and for psychologists and therefore tends to emphasise psychological interpretations, adhering to a pre-defined and inflexible process in terms of data analysis (ibid). A further criticism of IPA is that the links between

experience and the role of socio-cultural factors is difficult to identify (ibid). Although IPA is acknowledged as phenomenological in nature, I rejected it as I considered a Gadamerian orientation enabled a less deterministic way of interpreting the experiences of participants. Additionally, whilst a Gadamerian orientation acknowledges contributory psychological, social and cultural factors these are not prioritised over the importance of dialogue. Instead these factors are considered collectively to provide contextualised meaning of 'being-in-the-world', which contribute to the dialogical focus of hermeneutic phenomenology (Cohen, Khan and Steeves, 2000).

I considered that the theoretical flexibility of Braun and Clarke's TA (2006) mapped coherently onto the concept of the Hermeneutic Circle and therefore, was complementary to the philosophical orientation of my study. In common with research employing hermeneutic principles, TA pays attention to the smallest parts of the data as well as the larger parts to contextualise experiences in order to facilitate in-depth analysis and generation of rich data. Additionally, Braun and Clarke (2006) pointed out that data analysis "*rarely happens in an epistemological vacuum*" (Braun and Clarke, 2006 p.12). This viewpoint I consider resonates with the importance of making overt pre-judgements and assumptions as postulated in Gadamerian research endeavours (Gadamer, 2004). Used in combination then, I considered that employing TA and the Hermeneutic Circle enabled me to comprehensively explain the 'how' of analysis and interpretation, factors which may frequently be neglected in qualitative studies according to Braun and Clarke (2006). The six Phases of TA as suggested by Braun and Clarke (2006) and how these complement the Hermeneutic Circle are illustrated in Table 6:

Table 6: How the six phases of thematic analysis, adapted from Braun and Clarke (2006), complement the Hermeneutic Circle (HC).

Phase	Description of phase	HC characteristics	How the 6 phases complement the HC
1	Familiarising self with the data: Reading full data corpus, verbatim transcription, checking against recordings.	Attention paid to the whole of the data co-created and the smallest parts of the data and the larger parts by moving round the HC to form a holistic picture of the data/experiences.	Entering the hermeneutic circle/spiral and beginning to get a first grasp of the data post data collection, includes descriptions and initial interpretations of transcribed interview texts, poems and artworks.
2	Generating initial codes: For me, data-driven versus theoretically-driven, manually paying equal attention to each data item, using highlighters and notes in the margins for interpretations and potential themes, collating codes from the data set for each participant for each interview and naming these; Broken into 2 sub-phases by myself to aid analysis: Phase 2.1: listing codes with identifiable participant number, interview number and code number to use for adding to themes and audit purposes; and Phase 2.2: populating list of codes with verbatim data extracted from transcriptions.	Identifying the parts of the experience and naming these.	Developing an understanding of the data via shared horizons co-created during data collection.
3	Searching for themes: Making hard copies of the extracted data from Phase 2.2 and manually making cards for each coded item, beginning to sort these into piles of potential themes, labelled <i>using researcher's words</i> , reading and re-reading the extracts to identify relationships between them, creating initial thematic maps for each participant.	Moving round the Hermeneutic Circle to acknowledge how parts relate to the whole in terms of experience.	A global inspection of the data, checking how the parts of the data relate to the broader whole in terms of experience in a cultural context, <i>using participants' own words</i> (different to Braun and Clarke, 2006) to do so to remain close to the text.

Phase	Description of phase	HC characteristics	How the 6 phases complement the HC
4	Reviewing themes: Creating a set of candidate themes and related sub-themes, reading all collated data to check coherent patterns, possibly recoding some of the data as understanding is deepened (an ongoing and organic process), checking whether themes 'work', in terms of the whole data set for the participant, if not return to recoding and refining until satisfied 'contours of the data' are represented and a story to address the research question is generated.	Moving between the parts and the whole of the data in cyclical way on more than one occasion.	Reading and re-reading the data to deepen understanding and interpretation, notes and descriptions added to collated data.
5	Defining and naming themes: Describing the distinct scope and context of each theme concisely, providing a consistent account of how the sub-themes contribute to the named theme, identifying what is interesting about them and why, ensuring there is not too much overlap between themes, if so return and refine coding in Phases 2 – 4.	Development of interpretations using an open phenomenological stance.	Producing a supporting narrative for interpretations within themes and identifying how themes are distinct from and relate to each other.
6	Producing the report: Telling the story the data represents and go beyond description	Presenting interpreted experiences based on the sum of the parts of the HC.	Interpretations of dialogic encounters (including artworks and poetry presented) to address the research question and illustrate experiences of the phenomenon of focus.

4.10.1 Addressing criticisms of TA

Whilst the use of TA has been criticised in the past for its lack of rigour (Boyatzis, 1998), it is suggested that it is gaining credibility with researchers through the adoption of a consistent approach with identifiable and auditable stages enabling robust analyses of qualitative data to be conducted (Braun and Clarke, 2006). These authors also proposed a common vocabulary for qualitative researchers to use to make TA better understood. This includes the terms of data corpus to describe the whole data (i.e. from all participants) and data set to describe the data from individual participants. The term data item is used to identify each individual piece of data collected of interest, or the smallest parts, and the term data extract, to signify a categorised or coded chunk of data from a data set, useful when identifying verbatim quotes. I have therefore adopted these terms in this study to improve understanding of the analysis process. The application of these terms is summarised in Table 7 below and illustrated with examples from my own data:

Table 7: Thematic Analysis Vocabulary Adapted from Braun and Clarke (2006)

TA Term	Definition	Example
Data corpus	All data collected in a study.	All data from the eight participants in this study i.e. 23 transcribed interviews in total.
Data set	A sub section of the data corpus.	Data from each participant i.e. eight data sets in total, varying from the transcriptions of 2 – 4 interviews for each man.
Data item	An individual piece of data collected of interest.	Identifying the item “ <i>beast</i> ” used to describe CFS/ME.
Data extract	A categorised/coded extract of data from a transcription.	Participant 2, Pseudonym: George: “ <i>I’ve had chronic fatigue syndrome since April 2008</i> ” 1/1/1 (Interview 1, line 1, code 1) Coded for: Length of time with CFS.

A further criticism of TA appears in the literature by Buetow (2010). This author considers that whilst in TA recurrent or repeated codes can assist in pattern identification within and across data, codes which appear less frequently may be ignored or considered of less importance and therefore, paid less attention to in project reporting. To manage this, Buetow suggested the concept of saliency analysis to extend and make more

comprehensive the process of TA. Saliency analysis enables highly important non-recurrent codes of relevance to the aims of the study to be identified. This is a strategy I employed to identify and code the uniqueness of experiences for each participant. This ensured that non-recurrent codes were not ignored, but reported upon comprehensively alongside commonalities in experiences, considered as recurrent codes, in the findings chapter of this study.

An audit trail adapted from Braun and Clarke (2006) for the stages of data analysis is detailed in Box 4 overleaf as a summary of their six Phases of TA:

Box 4: Audit Trail for Data Analysis adapted from Braun and Clarke (2006)**Phase 1****Familiarising self with the data:**

- Transcription of interview data and use of field documents, noting initial ideas.
- Some additional reflective notes, poetry and artwork provided unexpectedly by participants during data collection.

Phase 2**Generating initial codes from significant statements:**

- Codes generated from individual interviews of each participant.
- Phase 2.1 per participant, codes from multiple interviews gathered together.
- Phase 2.2 identified codes then supported with data extracts.

Phase 3**Searching for themes:**

- Searching for themes and sub themes.

Phase 4**Reviewing themes:**

- Checking themes are coherent and creating a thematic map.

Phase 5**Defining themes and interpreting the data:**

- Defining and naming themes and researcher interpretations using Gadamerian and Occupational Science frameworks for purposes of interpretation.

Phase 6**Production of the report by forming a coherent picture of the whole:**

- Transformation of data for each participant and across participants to provide a coherent narrative text to address the phenomenon of interest.

Braun and Clarke's (2006) six Phases of TA will now be discussed in more detail and in relation to this study.

4.10.2 Phase 1: Familiarising self with the data

In Phase 1 all data were transcribed verbatim before analysis commenced. They were then checked against recordings for accuracy and punctuation and amended if necessary. The use of the symbols ‘...’ in the transcripts was to signify breaks and pauses in the dialogue between responses. Square brackets [] were employed to signify where I had added my own clarifying comments to the text. During transcription each line of interview data was given a line number from the first word-processed line through to the last. Additionally, lines of data were either labelled as ‘P’ attributing the data to the participant or ‘R’ attributing the data to myself as the researcher. When the transcription of each interview was completed a hard copy was made and read and re-read to ensure familiarity with the data was achieved. This ensured the Hermeneutic Circle was entered into as each participant’s whole data set was read and re-read paying attention also to the component parts during the process. The interviews were read with the research question in mind. This involved reading the data in a manner which attended to three aspects; firstly, reading in a literal manner, to identify items such as significant dates in illness experiences; secondly, reading in an interpretive manner, to identify what the participant meant and; thirdly, reading in a reflexive manner to explore and identify my role in the research process (Mason, 2002). Manual coding of the data then commenced.

4.10.3 Phase 2: Generating initial codes from significant statements

In Phase 2 a system of coding was employed to capture rich and salient data linked to participants’ experiences rather than “cherry picking” (Morse, 2010, p.3) from thin or inadequate data. This is considered to be a process of ‘complete coding’ as opposed to ‘selective coding’ where only specific instances in the data of theoretical interest are identified (Braun and Clarke, 2013). This meant that all data were coded as opposed to purely highlighting the recurrence of pre-determined phenomena. This enabled an in-depth analysis to be conducted both into and across each participant’s data and the data to speak for themselves (Braun and Clarke, 2013). Codes were, therefore, derived from the data rather than pre-determined by me as the researcher. Small parts of the data referred to by Braun and Clarke (2006) as ‘data items’ and at other times larger chunks of data, referred to as ‘data extracts’ were coded, that addressed the research question. Redundant or irrelevant data (Braun and Clarke, 2013), such as that perhaps related to opinions about non-related phenomena, for example, were not coded and thus excluded from the analysis. Commonly in thematic analysis codes for clustered parts of data are labelled using the researcher’s own terms. However, I avoided this preferring to use the participant’s own words to remain loyal to the data co-created. This systematic

engagement with the data felt more authentically reflective of the individual's experiences and using their own words more faithful in terms of reporting (Starks and Trinidad, 2007).

Data items and extracts were uniquely coded in numerical order and I created phases 2.1 and 2.2 in order to support the codes and identified data in tabular form with data extracts from the interviews. The use of unique participant numbers named 'P' numbers from P1 – P8, enabled interview data to be attributed to individual participants and for an auditable trail to be followed through the process of data coding. In every item and extract of data the participant's unique 'P' number was coded first, the interview number second, and the salient point coded third. For example, in P1's/George's first interview the first coded salient point appears as: 1/1/1 and salient point 2 appears as: 1/1/2 and so on, through to the end of the transcript for interview one. For George's second interview, again his unique P number was coded first, the interview number second and the first salient point third and therefore appears in coded form as follows: 1/2/1. This system of coding was used as the first step in data management throughout the twenty three interviews. (See Appendix H for an example of this coding system). This system of coding enabled a data-driven approach to analysis (Braun and Clarke, 2006) as opposed to a theoretically-driven approach which may be considered as less interpretive and therefore miss the point of the meaning of experiences for the participants, in favour of coding the researcher's pre-judged opinions, theories and ideas.

My PhD supervisory team were involved in the coding process as both my Director of Studies at the time and I coded George's first interview independently to explore whether we were capturing a wide range of data items and extracts which were reflective of his experiences rather than me adopting a theoretically-driven or pre-judged approach. Following this exercise we were able to identify that we concurred in identifying data items for George linked to his illness experience. This was not to seek validation of my analysis but rather to establish whether I had adopted an open phenomenological stance to the process considered important in hermeneutic phenomenology (Starks and Trinidad, 2007). Adopting what is referred to in the literature as a phenomenological attitude (Finlay, 2011) as opposed to only selecting items of interest to me, avoided privileging my own pre-understandings rather than those I had co-created with George. All data, including interview transcriptions, poems and Andy's artworks, were analysed following the Phases of TA as suggested by Braun and Clarke (2006). During this process an open phenomenological stance was adopted by me where I was mindful of my pre-judgements, particularly in respect of epistemological assumptions linked to the notions of occupational

science. This may be considered as a form of reflexive bracketing as described by Gearing (2004) and helped to ensure that I was not tempted to jump straight to and focus on, pre-determined theories of potential relevance of which I was aware. This would not have been in keeping with the nature of interpretive phenomenology, which is data-led rather than theory-led, via the co-creation of data to expand shared understandings of the phenomenon of interest (Cohen, Khan and Steeves, 2000; Fleming, Gaidys and Robb, 2003). Methodological assumptions made when employing hermeneutic phenomenology included an acknowledgement that both descriptive and interpretive elements are incorporated to capture data (Cohen, Khan and Steeves, 2000) which were reflected in Phases 3-5 of Braun and Clarke's TA (2006).

Details of the age of each participant at time of diagnosis, and at their interviews, number of interviews conducted, location, duration, and time span of interviews and initial codes generated in Phase 2 (Braun and Clarke, 2006) are summarised and appear at the beginning of the Findings Chapter in Table 9.

4.10.4 Phase 3: Searching for themes and Phase 4: Reviewing themes

In Phases 3 and 4 the challenge of data reduction was addressed. Considerable amounts of data were generated in this study, which, whilst relevant and interesting, required transformation (Blaikie, 2000) in order to produce a manageable report within the parameters of the thesis guidelines. This task took a considerable amount of time but was possible due to robust familiarisation with the whole story of the data corpus and its component parts (data sets, data extracts and data items) achieved in Phase 1. This enabled me to summarise the participants' accounts ensuring that the contours of the data were represented in the themes and sub-themes identified (Braun and Clarke, 2006). This I consider is an illustration of how the hermeneutic circle assisted me in data transformation and complemented TA by identifying themes and sub-themes as parts of the hermeneutic circle, meaning contextualised experiences of the participants were identifiable.

The refinement of the number of codes during TA was possible as the number of codes naturally reduces as smaller and larger codes are perhaps combined to make a more meaningful/contextualised code. Hence for example, initial codes generated for P6/Andy were 151 but reduced to 138 as data items were reviewed and added together to form more meaningful codes included in data extracts of experience (see Appendix I for an

example of how initial codes were generated over the course of a set of interviews for P2/Edmond).

During Phase 3, and once potential main themes and sub-themes had been manually organised through a cut and paste sorting exercise, an initial thematic map was devised for each participant and read through to assist in understanding, describing and recording interpretations of the data (see Appendix J for an example of an initial thematic map). A justification for the use of diagrams such as these to present qualitative data was provided by Mason (2002) which she considered was four-fold and is summarised here: diagrams can 1. assist in the analytic process; 2. make complex data easier for the reader to comprehend; 3. assist in illustrating cross-data comparisons and; 4. add to the aesthetics of presentation. Reflecting on this rationale I considered therefore, that all of these factors were relevant to the presentation of my data in the findings chapter and enhanced the presentation of the data as Mason suggested.

Initial thematic maps of the data were iteratively refined in Phase 4 of TA when a dependability audit was made through checking whether themes and sub-themes made sense and had coherency. A measure of coherency related to whether the themes and associated sub-themes provided a convincing account of the experiences of participants. Themes were not organised in a hierarchical fashion as all related to each other to some degree. They were however, clearly worth being a theme in their own right and were defined with a short description of their scope and content. In terms of time-scales, the TA was conducted chronologically i.e. P1 first and P8 last.

Reflection on manual cut and paste data sorting

Although I had attended training a few years ago for using NVIVO, a recognised software package for qualitative data analysis, I had found the software application fairly complicated to use and reliant on a degree of technology, which I did not feel I had the time to revisit for analysis purposes. Additionally, I considered that the manner in which the data may become fragmented when using the application was potentially unhelpful when interpreting the contextualised nature of experience. I also acknowledged that I much preferred having instant visual access to piles of potential themes and sub-themes on cards which I could leave out in an accessible place in order to sort, re-sort, dwell with and consider how and if my thinking made sense of participants' experiences. Whilst I acknowledge that computer packages for data analysis are valued by some qualitative

researchers, the need for me to see all of the data in 3D form was important. This enabled me to see the parts of the data and the bigger picture for all of the participants. Additionally, I considered that dialogic engagement with the data extended beyond the interviews and included field notes and my reflections which were read in combination. For these reasons therefore, I rejected the use of NVIVO for this study.

4.10.5 Phase 5: Defining themes and interpreting the data

During Phase 5 all themes were named using the participants' own words, a deviation from Braun and Clarke's TA practice (2006), and given an individual and concise definition to demonstrate their uniqueness. A narrative was then written to describe and interpret each of the overarching themes and sub-themes and these were additionally supported with verbatim data extracts to illustrate the richness of the data (see Appendix K for an example of Phase 5 of the TA process).

4.10.6 Knowing when to stop analysing the data in interpretive phenomenology

In Gadamerian terms it is acknowledged that any interpretation of experience can never be finite and will potentially be different between interpreters and is always open to new interpretation as time passes and more experience is gained to alter horizons of understanding (Gadamer, 2004). Despite this, the value of interpretation is also acknowledged and seen as holding the potential to generate in-depth insights into patients' experiences of health and healing, and therefore impacts positively upon health care practice and policy (Vandermause and Fleming, 2011; Converse, 2012). Whilst mindful of not providing a once-over light-touch interpretation of the data, Braun and Clarke (2013) also addressed the importance on knowing when enough is enough in terms of data analysis and interpretation. They advise researchers of the importance of letting go of the analytic process in a pragmatic manner. In order to address this issue in Gadamerian terms, it is suggested that as hermeneutic researchers, we need to consider how and when we close the hermeneutic circle of interpretation which is summed up by Debesay, Naden and Slettebo (2008):

“Our grounds for adequate understanding must therefore be based on the fact that all interpretation cannot be equally plausible, and that the researcher can achieve a great deal by listening to their informants and showing good judgement. At the same time one should bear in mind the hermeneutic insight that the understanding cannot be final. But this closes the circle of understanding, if only for now.” (Debesay, Naden and Slettebo, 2008, p. 65).

The decision to close the hermeneutic circle is usually a pragmatic one based on the need to produce the research report in a timely fashion. Additionally at this point, the researcher it is suggested should declare that all interpretations are their own and accept responsibility for this action as I do for this study (Fleming, Gaidys and Robb, 2003).

Reflexivity and data analysis: Taken from research journal April 2014

At first in this process I allowed my pre-judgements to take precedence over participants' dialogue and unduly privileged the position of the researcher's horizon. I realised I was trying to shoe-horn their data into my pre-judged conceptions/labelled themes, making analysis overwhelmingly difficult to handle. Once a member of my supervisory team, who is an experienced interpretive phenomenologist, had reminded me to use the participants' own words (as compared with Braun and Clarke (2006) who use their own labels), the process of data analysis became instantly more manageable and importantly, more meaningful.

Reflections and the analytic process: Taken from research journal December 2015

Using the TA process of Braun and Clarke (2006) is flexible but can be fragmenting and result in generating an overwhelming amount of data items which results in significant amounts of time required to construct a meaningful whole in terms of qualitative experiences in interpretive phenomenology. Dwelling with the process of TA provided me with the skills to produce a robust trail to replicate for subsequent analysis and the ability to construct an audit trail. During analysis I was reminded to ensure analysis is faithful to the data from a dialogic point of view and that the use of participant's own terms for labelling themes and sub themes rather than imposing my own terminology was a form of bracketing in action. I discovered that there are no epiphanic or light bulb moments in IP. It is a matter of engaging with the co-created data and making an analysis which is mine, for which I take responsibility, acknowledged as finite but open to the interpretation of any other subsequent reader at any subsequent time.

4.10.7 Phase 6: Production of the report by forming a coherent picture of the whole

In Phase six of TA Braun and Clarke (2013) considered the production of the final research report and usefully provided guidelines on what to include in an academic report for publication purposes. At this point in a research study Mason (2002) suggested that the researcher needs to revisit the intellectual puzzle originally posed and the research question/s and link these to the type of argument that the data will present. This is where

the congruency of study design, theoretical and philosophical frameworks, methods of data collection and data analysis should be synergistic in order to form a robust and trustworthy report (Mason, 2002). In order to achieve synergy it is acknowledged in the literature that the knowledge and skills of the researcher are identified as intrinsic to the quality of the report produced for academic purposes (Sandelowski, 2011).

Also in Phase six Braun and Clarke (2013) addressed the importance of the quality criteria the report needs to address if it is to be considered as trustworthy. This factor was given in-depth attention by Lincoln and Guba (1985) when they discussed the credibility of research in terms of convincing the reader, the researcher and also the participants involved of the quality of the report. The issue of ensuring quality in qualitative research will now be considered.

4.11 Addressing trustworthiness in qualitative research

Fundamental to qualitative or naturalistic inquiry (Lincoln and Guba, 1985) is the underpinning ontological concept of the existence of multiple rather than one objective reality of human experience of 'being-in-the-world' (Mason, 2002; Sandelowski, 2006). Qualitative research therefore, may be subjected to criticism from quantitative or positivist researchers who frequently employ measurement to generally seek to establish a definitive end point in their research investigations and a single objective truth in their findings (Sandelowski, 1997; Morse, 2007b). Additionally, positivists may consider that qualitative data appear as a simplistic representation of the everyday (Morse, 2008b; Morse, 2008c). Morse however, highlights the "*deceptive simplicity*" (Morse, 2008b, p. 1311) of qualitative studies and mentions how associated theoretical and methodological decisions may be underestimated by positivists. Whilst Gadamer acknowledges the utility of a positivist research paradigm for exploring the natural sciences as previously mentioned, he rejects its application when investigating contextualised human experience for the fundamental reason given above (Gadamer, 2004). Similarly, researchers employing hermeneutic phenomenology and other qualitative designs also reject the criteria used to judge the quality of research in the natural sciences in their endeavours to understand human experience. Instead, alternative criteria for this purpose were suggested by Lincoln and Guba (1985) and are commonly adopted by researchers of a qualitative persuasion (Guba and Lincoln, 1989; Mason, 2002; Ballinger, 2004; Finlay and Ballinger, 2006; Finlay, 2011; Morse, 2015b). These alternative criteria, whilst

acknowledged by some as still being the subject of active academic debate (Rolfe, 2006; Polit and Tatano Beck, 2010), will now be identified and explored further.

4.11.1 Suggested criteria for judging the quality of qualitative research

Demonstrating the overall trustworthiness or rigour of research studies from either paradigm is a subject that is given significant attention in the academic literature (Koch, 1993; Mason, 2002; Whitehead, 2004; Curtin and Fossey, 2007; Freeman, 2011; Sandelowski, 2011). However, given the variance in the underpinning ontological assumptions of each paradigm, the parameters of quality are defined and evaluated differently for quantitative as compared to qualitative research (Lincoln and Guba, 1985). Table 8 below summarises terms/criteria used to assess quality in the two main research paradigms commonly used to produce and support convincing findings and academic arguments:

Table 8: Criteria for judging the trustworthiness of qualitative research

Paradigm: Qualitative	Paradigm: Quantitative
Credibility	Validity internal
Transferability	Validity external/generalisability
Dependability	Reliability
Confirmability	Objectivity

Adapted from Lincoln and Guba (1985), Koch (1993) and Mason (2002).

These comparable terms will now be explored in more detail.

4.11.2 Credibility as compared to internal validity

Internal validity is a term employed by positivist researchers using a rigid method to prove objectivity (single truth), causal relationships and to achieve replicable results (Mays and Pope, 2000). This ontological position is at odds with naturalistic or qualitative inquiry which supports the concept of multiple truths constructed by human beings of their experiences of 'being-in-the world' (Robson, 2002; Mason, 2002). Lincoln and Guba (1985) therefore suggested that the criterion of credibility is more appropriately used and that a qualitative study is considered credible if the following criteria can be demonstrated: prolonged engagement and broad scope of experiences reported; depth and richness of data; data generated from a variety of sources; peer debriefing and; discussing interpretations with participants. These criteria then need to be supported by evidence of documentation and accounts to convince the reader, the researchers themselves and also the participants that a study has credibility. In terms of this study, all of the above criteria were addressed adding to its credibility. This I consider is demonstrated as; multiple interviews were conducted over a period of time with eight participants, which led to in-depth rich data generation from a variety of sources, and involved peer debriefing and discussions during all, and at the start of, subsequent interviews.

4.11.3 Transferability as compared to external validity/generalisability

“Arguably the most important factor contributing to the failure of taking qualitative findings seriously is the frequently cited but false charge that they are not generalizable.” (Sandelowski, 1997, p. 127).

External validity is a criterion linked to the confidences quantitative researchers have in their results in terms of claiming whether the findings are generalisable to similar populations (Lincoln and Guba, 1985). As qualitative researchers do not set out to make such generalisations it is therefore a criterion rejected in favour of the notion of 'fittingness' (Lincoln and Guba, 1985; Koch, 1993; Sandelowski, 2006). This term is used when considering whether there are any similarities between the contexts of the data, established by generating rich, thick descriptions and subsequent interpretations, in order to demonstrate similarities in contexts. Findings illustrative of similarities in experiences identified as meaningful may therefore also be considered as having application to others (Morse and Singleton, 2001) in similar situations. Such qualitative findings are therefore, considered as being transferable (Sandelowski, 1997).

4.11.4 Dependability as compared to reliability

An obvious example of how reliability is demonstrated in positivist designs is the use of laboratory experiments where a rigid protocol is followed and researchers do not stray from the pre-agreed task (Gadamer, 2004). In qualitative designs however, whilst the design of the task and intellectual puzzle are considered and stated before research commences (Mason, 2002), the nature of real world research is acknowledged as iterative and as developing organically and flexibly throughout the course of the study (Robson, 2002; Braun and Clarke, 2013). This does not mean that qualitative researchers adopt an 'anything goes' attitude to their work but rather, that a dependable audit trail of their evolving decision-making is available for scrutiny, supported by an audit trail represented in a step-wise manner (Whitehead, 2004). The production of this trail can then be judged by the reader as to whether fair and reasonable representations of the findings have been made (Lincoln and Guba, 1985). If confirmed then the study may be considered as dependable.

4.11.5 Confirmability as compared to objectivity

Key to establishing confirmability is the responsibility of qualitative researchers to document how the findings of their study have been reached (Lincoln and Guba, 1985; Koch, 1993). Objectivity is removed from the characteristics of the investigator and shifted to focus on the data, to check whether these represent the multiple realities of the participants involved (Lincoln and Guba, 1985). This process should make it possible therefore to establish if multiple realities are confirmable through the reading of the report.

4.11.6 Evidencing the qualitative criteria

As my study utilized a qualitative design attention was paid to the criteria of credibility, transferability, dependability and confirmability and the ontological assumptions underpinning these were acknowledged. Table 9 below provides examples of how I have evidenced these criteria in my study:

Table 9: Evidencing the qualitative criteria

Criterion	Evidence	Source
Credibility	<p>Congruency between design, methods and philosophical orientation.</p> <p>Multiple interviews conducted; triangulation of data collection using reflexive journal and field notes and hand written notes from one participant and artwork and poetry for one participant; checking of understandings with participants during interviews; rich data co-created.</p> <p>Convincing academic audience/peers.</p>	<p>Ontology and Epistemology Chapter and</p> <p>Appendix L: Published out-puts from the data accepted at peer reviewed European Occupational Science Conference 2015 and UWE Post Graduate Research Conference 2016.</p>
Transferability	<p>Similarities in context of the data identified in shared themes.</p>	Findings Chapter
Dependability	<p>Steps of the research process documented systematically; audit trail for data analysis designed.</p>	Methodology Chapter
Confirmability	<p>How the findings were reached is explained and supporting documentation appears.</p>	Methodology Chapter and Appendices G-J.

In summary, these qualitative criteria should be demonstrated if research findings are to be seen as providing evidence of a quality that is considered as trustworthy and rigorous in the academic literature (Nelson, 2008). Sandelowski (2004) addressed the importance of translating rigorous qualitative research findings into something useful and usable to inform evidenced-based practice. Grace and Powers (2009) also discussed the importance of useable findings to clinicians regardless of the qualitative design adopted, in order to understand the meaning of patients' experiences and their responses to health situations:

“For research from qualitative traditions, strength of evidence for practice is more closely aligned with whether the nature of the findings allows the clinician to determine their utility than with specific study design.” (Grace and Powers, 2009 p. 31).

The findings from this qualitative study are therefore, discussed in terms of the meaning of participants' experiences of living with CFS/ME and their responses to health situations, to determine the utility of my findings for practice. Morse (2008d) usefully summarised the importance of the role that qualitative researchers play in exploring the findings of their studies for participants' benefit:

“We are the authorities on “what it is like to live with a disease”, and the onus is on us to make our research findings useful and accessible to those most directly affected.” (Morse, 2008d pp. 1459-1460).

The study findings are now presented in the following chapter.

Chapter 5:

Findings

5.0 Introduction

In this chapter participant demographics are reported and the relationship of the participants to the researcher is also described. A table summarising the number of interviews, locations, duration and time period over which interviews were conducted and the number of initial codes derived from each interview is included. Study findings generated from the data corpus are then reported in three sections as follows:

1. In section one, I present a table summarising the themes identified from each participant's individual data set and the uniqueness or saliency of each participant's experience is summarised.
2. I include a thematic map for each participant in section two and the uniqueness of their experiences is further reported and illustrated with verbatim quotes extracted from their data.
3. In section three, I include a thematic map of similarities in experiences, referred to as shared experiences, which are supported with quotes from the data analysis.

5.1 Participant demographics

The need to report demographics of importance to contextualise the findings is highlighted in the literature and is presented here (Morse, 2008a). The eight participants included in this study were all white, British males with a clinically confirmed diagnosis of CFS/ME. Selected criteria employed for diagnostic purposes were however, unknown. Their ages at time of interview ranged from 21 – 68 years and at time of diagnosis from 16 – 61 years. Illness duration experienced post diagnosis ranged from approximately 3 – 8 years. Potential triggers for illness development were variable and suggestions for these (if identifiable) appear in the reported findings. Duration of fatigue-like illnesses experienced before diagnosis was indeterminate. One participant, Arnold, had experience of being clinically diagnosed twice over a period of approximately 36 years, with either remission or recovery reported in-between, to a lesser or greater degree.

The three youngest participants George, Edmond and Luke were single and not in a relationship at the time their interviews took place. The other five men were all married and had been for several years. Andy and Sparky had school age children and Christopher and Billy's children were adults. George, Edmond, Luke and Arnold did not have any children.

George and Luke both lived at home with their parents and siblings; Edmond lived in rented accommodation with a friend some two hours distance away by car from his parent's home; Christopher lived in rented accommodation with his wife and adult son; Billy and Arnold lived with their wives in privately owned accommodation and Andy and Sparky lived with their wives and school age children also in privately owned accommodation.

In terms of employment, Billy (68) was a retired manual worker; Edmond (24) was employed full time in an administrative post; Christopher (56) was employed part time and self-employed part time as an adult education tutor; three men, Luke (28), George (21) and Andy (48) were employed part time, all in office-based jobs; and Arnold (61), who was a freelance artist and Sparky (42) who was a management consultant were both self-employed part time.

5.2 Relationship of the participants with the researcher

Three of the eight participants were known to me prior to their recruitment to this study, they were Sparky, Billy and Arnold. I had never met the other participants as they had all been treated by one or more of my colleagues at the specialist fatigue centre where I work. Sparky and Arnold I had met previously, as they had both been involved in providing some information as patient educators for the service. Billy was the only participant that I had been involved with clinically, as he had attended a group treatment programme in which I had participated some years prior to being recruited to this study. Billy was happy to participate mentioning he had been grateful for the help he had received from the Centre previously. Interestingly, I found Billy's interviews to be more superficial in terms of rich data shared. Perhaps on reflection Billy saw me as a clinician who already knew about his experiences as after two relatively short interviews he told me he thought we had covered everything. Interesting due to the seemingly superficial nature of the encounters relative to the other participants' interviews, discussions with Billy seemed less satisfying in some way. This I consider is where my pre-judgement as a therapist played a

part as my professional reasoning told me that in Billy's interviews sharing of horizons and the co-creation of rich data seemed more difficult than with the other participants.

At the time of recruitment, all but one of the participants, Luke, had been discharged from the Centre and therefore, the majority were no longer in receipt of active treatments.

Reflexivity: and the interview process.

The participants I had best rapport with I found were willing to speak with me in an open manner. The two I felt I had least genuine rapport with were Billy who I think saw me as his therapist having known me in this role to some degree because of our previous clinical involvement, and George who seemed vulnerable and young and also saw me perhaps as a health researcher holding some sort of organisational authority. Although I enjoyed all 23 interviews I had to work harder in interviews with Billy and George and they also seemed in some way less rewarding. I recognised my desire to achieve a partnership with the men in order to reduce any discomfort they, in particular, but also I might have, about interviewing them. Additionally, in terms of reducing any power differential during the interviews I was conscious of the dress code adopted by myself. I didn't want to wear what might be considered as 'power clothes' i.e. a formal suit or similar but didn't want to appear too casual or disrespectful either. In the end I opted for smart casual clothes perhaps to put myself at ease as much as the participants. I was also aware that as a female researcher interviewing men at home maybe alone, I needed to be sensitive to their partners' needs and wishes. I confess to feeling more at ease when I conducted interviews in their own homes and was able to meet their partners before interviews took place. This I consider demonstrated approval of their husband's involvement in the study and support for my work which felt important to me. Meeting partners also provided interesting context in terms of how significant others had contributed to their experiences and supported the men.

Table 10 appears below and summarises the number, locations and duration of interviews for each participant. The number of initial codes generated from each interview is reported which were subsequently reduced as the data sets were interpreted and similar codes combined and subsequently grouped into themes and sub-themes which appear later in the chapter.

Table 10: Details of participants, their interviews and number of codes derived

Participant's (P) number and pseudonym, age at time of research interviews and age at diagnosis.	Number of interviews conducted and participant's choice of location. Interviews continued until joint agreement that experiences had been adequately shared.	Time period over which interviews were conducted and duration of each interview. (Fatigue experienced during and as a potential consequence of duration was considered).	Number of initial data codes derived from each interview in Phase 2 (Braun and Clarke, 2006).
<p>P1 George 21 years.</p> <p>Age at diagnosis: 16 years</p>	<p>3 interviews: All conducted at his parental home.</p>	<p>Paced over a 6 week period. 1st = 28 minutes 2nd = 36 minutes 3rd = 48 minutes</p>	<p>143 in total. 1st = 52 2nd = 62 3rd = 29 Final number: 135 (once similar codes were combined)</p>
<p>P2 Edmond 24 years.</p> <p>Age at diagnosis: 18 years</p>	<p>2 interviews: 1st conducted in the researcher's office in a NHS trust 2nd conducted at his parental home.</p>	<p>Paced over a 6 week period. 1st = 93 minutes 2nd = 56 minutes</p>	<p>141 in total. 1st = 110 2nd = 31 Final number: 147 (once similar codes were combined)</p>

Participant's (P) number and pseudonym, age at time of research interviews and age at diagnosis.	Number of interviews conducted and participant's choice of location. Interviews continued until joint agreement that experiences had been adequately shared.	Time period over which interviews were conducted and duration of each interview. (Fatigue experienced during and as a potential consequence of duration was considered).	Number of initial data codes derived from each interview in Phase 2 (Braun and Clarke, 2006).
<p>P3 Luke 28 years.</p> <p>Age at diagnosis: 24 years</p>	<p>4 interviews: All conducted in the researcher's office in a NHS trust.</p>	<p>Paced over a 7 week period.</p> <p>1st = 53 minutes 2nd = 51 minutes 3rd = 58 minutes 4th = 62 minutes</p>	<p>149 in total.</p> <p>1st = 40 2nd = 44 3rd = 22 4th = 43</p> <p>Final number: 108 (once similar codes were combined)</p>
<p>P4 Sparky 42 years</p> <p>Age at diagnosis: 38 years</p>	<p>3 interviews: All conducted in the participant's own home.</p>	<p>Paced over a 5 week period</p> <p>1st = 46 minutes 2nd = 60 minutes 3rd = 63 minutes</p>	<p>151 in total.</p> <p>1st = 51 2nd = 54 3rd = 46</p> <p>Final number: 152 (once similar codes were combined)</p>

Participant's (P) pseudonym, age at time of research interviews and age at diagnosis.	Number of interviews conducted and participant's choice of location. Interviews continued until joint agreement that experiences had been adequately shared.	Time period over which interviews were conducted and duration of each interview.	Number of initial data codes derived from each interview in Phase 2 (Braun and Clarke, 2006).
<p>P5 Billy 68 years.</p> <p>Age at diagnosis: 61 years</p>	<p>2 interviews: Both conducted in the participant's own home.</p>	<p>Paced over a 4 week period. 1st = 48 minutes 2nd = 39 minutes</p>	<p>93 in total. 1st = 59 2nd = 34 Final number: 103 (once similar codes were combined)</p>
<p>P6 Andy 53 years.</p> <p>Age at diagnosis: 48 years</p>	<p>3 interviews: All conducted in the participant's own home.</p>	<p>Paced over a 6 week period. 1st = 59 minutes 2nd = 46 minutes 3rd = 76 minutes</p>	<p>151 in total. 1st = 62 2nd = 29 3rd = 60 Final number: 138 (once similar codes were combined)</p>

Participant's (P) pseudonym, age at time of research interviews and age at diagnosis.	Number of interviews conducted and participant's choice of location. Interviews continued until joint agreement that experiences had been adequately shared.	Time period over which interviews were conducted and duration of each interview.	Number of initial data codes derived from each interview in Phase 2 (Braun and Clarke, 2006).
<p>P7 Christopher 56 years.</p> <p>Age at diagnosis: 49 years</p>	<p>4 interviews: All conducted in the participant's own home.</p>	<p>Paced over a 9 week period.</p> <p>1st = 34 minutes 2nd = 60 minutes 3rd = 52 minutes 4th = 60 minutes</p>	<p>115 in total.</p> <p>1st = 30 2nd = 34 3rd = 24 4th = 27</p> <p>Final number: 98 (once similar codes were combined)</p>
<p>P8 Arnold 64 years.</p> <p>Age at diagnosis: 28 years and then again at 56 years</p>	<p>2 interviews: Both conducted in the researcher's office in a NHS trust.</p>	<p>Paced over an 8 week period.</p> <p>1st = 81 minutes 2nd = 89 minutes</p>	<p>84 in total.</p> <p>1st = 45 2nd = 39</p> <p>Final number: 79 (once similar codes were combined)</p>

5.3 Section 1: Summary of identified themes

A table summarising the themes identified from each participant's individual data set and the uniqueness or saliency of each participant's experience is now presented in Table 11.

Table 11: A summary of themes identified from each participant's individual data set and the uniqueness of each participant's experience.

Pseudonym of participant	Individual themes	Uniqueness of experience
<p>George</p> <p>21 years.</p> <p>Age at diagnosis: 16 years.</p>	<p>Theme 1: I just wanted any explanation.</p> <p>Theme 2: The day when my health changed.</p> <p>Theme 3: Other people.</p>	<ul style="list-style-type: none"> a) He became ill around time of his GCSE exams and was diagnosed in adolescence. b) At 15 he was told a brain tumour may be the cause of his fatigue. c) His illness was trivialised by his teachers. d) Unusually, his memory was not affected by CFS/ME.

Pseudonym of participant	Individual themes	Uniqueness of experience
<p>Edmond</p> <p>24 years.</p> <p>Age at diagnosis: 18 years.</p>	<p>Theme 1: Best that I start from how I got the illness.</p> <p>Theme 2: Nothing more important than understanding what it is.</p> <p>Theme 3: You do have to cure yourself.</p> <p>Theme 4: Care needs to be centred around practical targets.</p>	<ul style="list-style-type: none"> a) Described self as cured of CFS/ME. b) He saw CFS/ME as a 'university illness'. c) Because of his illness he ended his relationship with an attractive woman as it made him feel emasculated. d) Feelings of 'otherness' described when in social situations. e) Felt social isolation impacted positively on recovery. f) Saw the time he was ill as a gap year and therefore missed being ill.

Pseudonym of participant	Individual themes	Uniqueness of experience
<p>Luke</p> <p>28 years.</p> <p>Age at diagnosis: 24 years.</p>	<p>Theme 1: I don't know for certain how long I have had ME.</p> <p>Theme 2: I would be mindful of societal expectations.</p> <p>Theme 3: I don't like using the word career.</p> <p>Theme 4: There are still things I struggle with.</p> <p>Theme 5: I do want to look for ways in which I can help induce a recovery.</p>	<ul style="list-style-type: none"> a) Had no choice but to geographically relocate with family due to lack of financial independence. b) Blames the delay in being diagnosed on him for not doing something earlier rather than on health professionals. c) Felt that culturally he would be negatively judged by women in any new relationships as he had no money and few prospects in terms of financial independence. d) He had applied for jobs and perceived he had been treated unlawfully because of his illness. e) He found it difficult that his father didn't accept his illness for some time.

Pseudonym of participant	Individual themes	Uniqueness of experience
<p>Sparky</p> <p>42 years.</p> <p>Age at diagnosis: 38 years.</p>	<p>Theme 1: I had a virus that attacked my liver.</p> <p>Theme 2: The way you can live your life for the better is to manage the condition.</p> <p>Theme 3: A big part of any person's identity is their physical and mental well-being.</p> <p>Theme 4: It must be difficult living with someone with the condition.</p> <p>Theme 5: I just need to chat with somebody who understands this.</p> <p>Theme 6: As a framework...at the centre is the ME.</p>	<p>a) He trivialised his illness experience despite being hospitalised in an intensive care unit (ICU) in an acute hospital.</p> <p>b) No explanation ever provided for illness in ICU and therefore, faced death without known cause.</p> <p>c) Sparky was made to reapply for his own job whilst off sick.</p>

Pseudonym of participant	Individual themes	Uniqueness of experience
<p>Billy</p> <p>68 years.</p> <p>Age at diagnosis: 61 years.</p>	<p>Theme 1: My wife said it was ME long before the doctors.</p> <p>Theme 2: I worked in a builders' merchants.</p> <p>Theme 3: The first three years are the worst.</p> <p>Theme 4: It did help seeing a lot of other people with the same problems.</p> <p>Theme 5: I still don't think it will go away.</p>	<ul style="list-style-type: none"> a) Wife knew it was CFS/ME before the medics. b) Became ill just before planned retirement so retiring early was less of an issue for him than it might have been. c) Only Billy had found some benefit from attending a community based CFS/ME support group. d) Illness prevented Billy and his wife from following their retirement plans.

Pseudonym of participant	Individual themes	Uniqueness of experience
<p>Andy</p> <p>53 years.</p> <p>Age at diagnosis: 48 years.</p>	<p>Theme 1: Something odd happened.</p> <p>Theme 2: There are a quarter of a million people like me.</p> <p>Theme 3: My tendency is not to speak about things.</p> <p>Theme 4: The impact on the family has been enormous.</p> <p>Theme 5: I am constantly aware of my status of being ill.</p> <p>Theme 6: My big plus has been the attitude of my employer.</p>	<p>a) He became the second person in his family to be diagnosed with CFS/ME; his school age daughter was first.</p> <p>b) As well as via dialogue, Andy uniquely expressed and shared some of his experiences of illness through artwork and poetry which he found cathartic.</p>

Pseudonym of participant	Individual themes	Uniqueness of experience
<p>Christopher</p> <p>56 years.</p> <p>Age at diagnosis: 49 years.</p>	<p>Theme 1: The seriousness of the illness became evident in 2007.</p> <p>Theme 2: I think ME is many, many things.</p> <p>Theme 3: I joined when I was 17.</p> <p>Theme 4: I am much better able to cope so I know I am getting better.</p>	<p>a) Suspected he may have triggered CFS/ME during his time in the services, having joined when he was 17.</p> <p>b) His GP unfairly accused him of drinking heavily after taking a tot of whisky to try and help him sleep.</p>

Pseudonym of participant	Individual themes	Uniqueness of experience
<p>Arnold</p> <p>64 years.</p> <p>Age at diagnosis: 28 years and then again at 56 years.</p>	<p>Theme 1: Maybe I should start from where I got my diagnosis.</p> <p>Theme 2: It's a misunderstood condition.</p> <p>Theme 3: That was the point I died and there was a new me.</p> <p>Theme 4: I would consider myself in some sort of remission.</p>	<p>a) Had experienced fatigue-like illness for longer than the other participants.</p> <p>b) Death of old me and birth of new me described as a consequence of having CFS/ME.</p>

5.3.1 Section 2: Thematic maps

In this section, thematic maps for each participant are presented and the uniqueness of their experience is supported with verbatim quotes extracted from their data.

5.3.2 George

George's Thematic Map

George's experiences of living with CFS/ME were analysed and placed into three inter-related themes. George's own words were used to label the themes. They were:

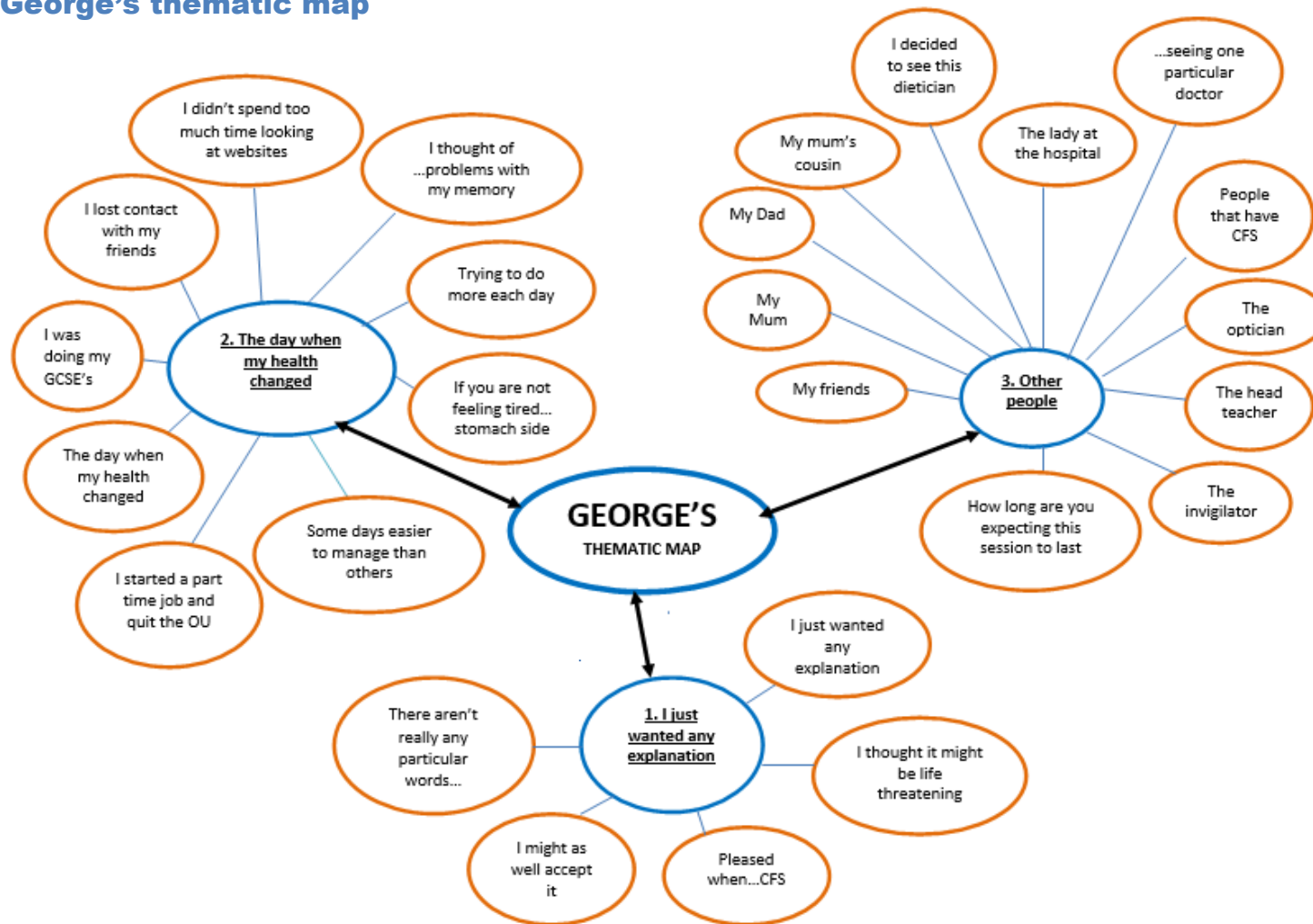
Theme 1: I just wanted any explanation.

Theme 2: The day when my health changed.

Theme 3: Other people.

Themes and contributory sub-themes appear on the thematic map below to provide context.

Figure 8: George's thematic map



Uniqueness of George's experiences

- a) He became ill around time of his GCSE exams and was diagnosed in adolescence.
- b) He faced possibility of brain tumour at 15.
- c) His illness was trivialised by his teachers.
- d) Unusually, his memory was not affected by CFS/ME.

a) He became ill around time of his GCSE exams and was diagnosed in adolescence and b) He faced possibility of brain tumour at 15

George was the youngest participant in this study. He became ill at 15 and was diagnosed with CFS/ME when he was 16, unlike the other participants who were diagnosed later on in life. George provided a unique perspective on the experiences of an adolescent with CFS/ME and how this impacted upon aspects of his school life. Prior to diagnosis and in the absence of an official explanation, George tried to understand how he felt by comparing this with previous illness experiences. This was however, not possible as the significant impact his illness was having on his day to day life and occupations, was new and unfathomable. Additionally, he was faced with the possibility of dying in adolescence and considered this a real threat, due to his horizon of experience linked to his uncle dying prematurely from a brain tumour.

"I was very worried about it as I thought it might be life threatening or something...because I felt so unwell for so long... I think the doctor just thought it [a brain tumour] might be a possibility, then hearing my dad's brother had one as well, I think she thought that was something else to go on really." 1/1/44 - 45, 1/1/98.

George was experiencing significant disruption to his life which went on for several months and led to occupational deprivation as he was unable to engage in his usual activities. After many blood tests, several GPs were still not sure what was wrong which must have been worrying for George. He then had a brain scan which caused more worry initially, but there was some relief for him when results were received and a brain tumour was ruled out.

"I'd seen a few doctors... I can't remember any particular theories that they had... I think a couple said it could be sinusitis...but then others said that sort of [my] health was too serious for it just to be something like that...in around the middle of June I had a CT scan ...well one doctor thought I might have a brain tumour or such ...but the results for that were fine." 1/1/38, 1/1/19 – 21, 1/1/95 – 96.

c) His illness was trivialised by his teachers

Several people appear in George's horizon of experiences of living with CFS/ME contributing either helpfully or unhelpfully to George's experiences. Unhelpful others included his head teacher, an authority figure, who trivialised his symptoms, leading to difficulties in occupational engagement and performance and consequentially, exam failure. George's experiences of trivialisation appear below.

"I think it took quite a while to get her [head teacher] to come round to my side but eventually she did realise that I wasn't just trying to get out of doing them [GCSEs]...to begin with I did feel that she wasn't taking it seriously...I think she was just quite casual really... and she, she'd say things like "oh as long as you write down something during the exams, that's better than nothing"... and she didn't seem too concerned about my health...I didn't think it was very fair really." 1/1/29 – 34.

The trivialisation of his illness by his teachers was traumatic for George and he still felt upset thinking about it during our interviews. Despite this however, he went on to achieve three GCSEs, after he was allowed to sit the exams at home with a school invigilator present. George's voice does not seem to have been heard and there was a lack of a genuine dialogue between George and his head teacher, where power differentials played a part in the situation. Culturally, she expected him to adhere to usual exam procedures like everyone else. George felt let down as the support he had been offered did not materialise. His opinion was not taken into account on that day and the head teacher it is suggested, could be held partly responsible for him failing his exam.

"I try not to really remember that time because that was when chronic fatigue syndrome was at its worst really ... I was doing my GCSEs at the time... I went into school to complete one... I felt terrible during that... I failed the exam ... which didn't really surprise me because of how I felt during it...I did three I think, three exams I think, at home... so I got three C's ... I think that was mostly because I'd done quite well with the course work...it did make me feel a bit better in some ways." 1/1/60, 1/1/24 - 26, 1/1/49, 1/1/53, 1/1/63 - 65.

d) Unusually, his memory was not affected by CFS/ME

Unlike the other participants in this study, George did not experience any problems with his memory due to his illness. This came as a surprise to George, as he had anticipated, through what he had read and heard that this was a common problem for people with CFS/ME.

"By going on various websites... quite a few people just seemed to be mentioning um like their memory wasn't as good as it used to be and then I was sort of concerned that I, that would affect me as well... a lot of people have just told me

that I've got quite a good memory and that's something that hasn't really been affected by chronic fatigue syndrome." 1/2/2 - 1/2/4, 1/1/3.

Reflection from field notes:

At first interview, George seemed to think I might have a pre-set agenda re questions, a reasonable assumption. I wondered however, how many times he had been interviewed by a health professional where he was required to follow their line of questioning without challenging their authority. It felt as though he saw me initially at least, as a person representing power/authority and to develop rapport I had to reassure him about the nature of the study. Our meeting was probably quite different from the usual medical encounters he had experienced during in childhood/adolescence.

5.3.4 Edmond

Edmond's Thematic Map

Edmond's experiences of living with CFS/ME were analysed and placed into four inter-related themes. Edmond's own words were used to label the themes. They were:

Theme 1: Best that I start from how I got the illness.

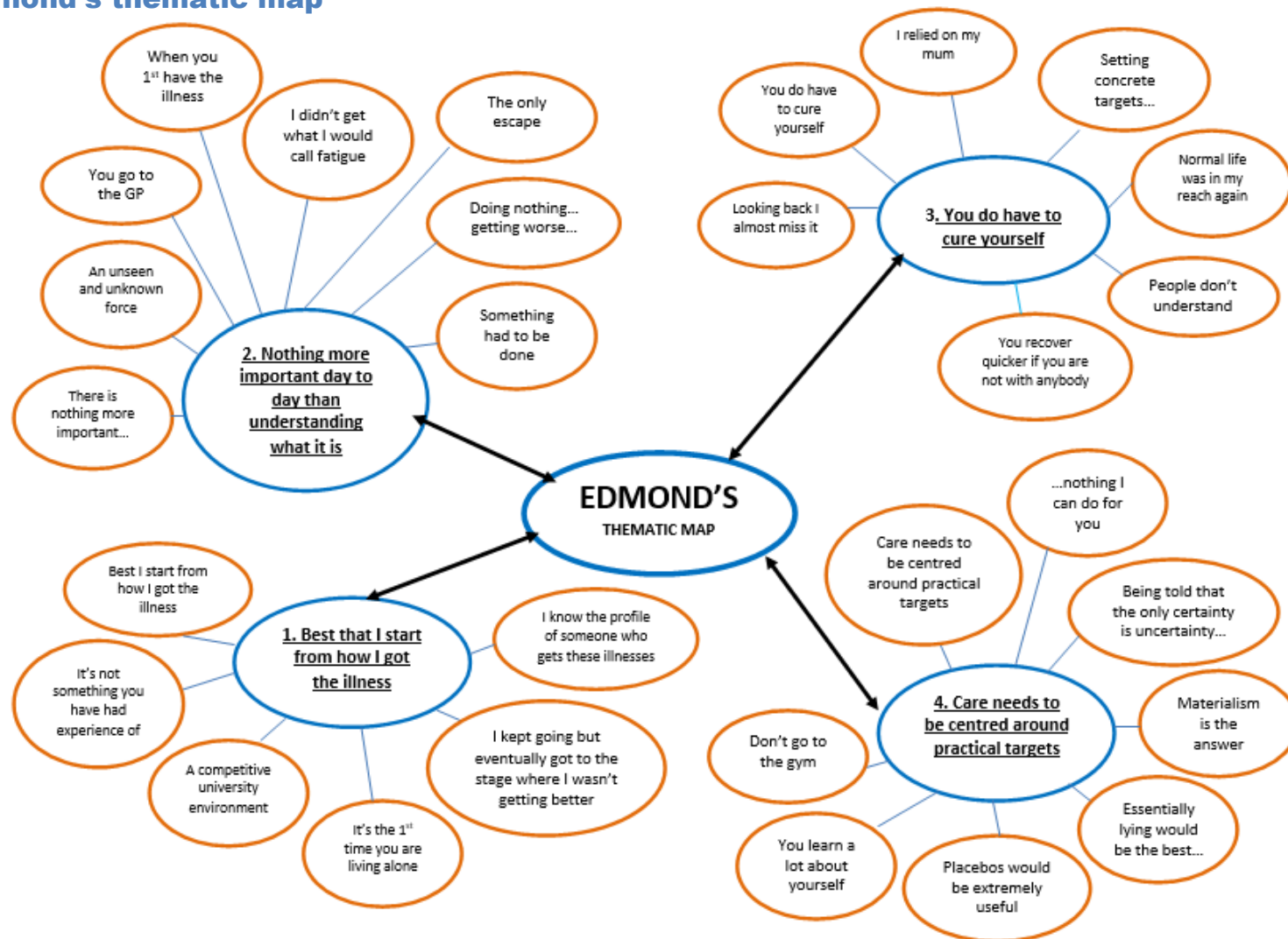
Theme 2: Nothing more important than understanding what it is.

Theme 3: You do have to cure yourself.

Theme 4: Care needs to be centred around practical targets.

Themes and contributory sub-themes appear on the thematic map below to provide context.

Figure 9: Edmond's thematic map



Uniqueness of Edmond's experiences:

- a) Described self as cured of CFS/ME.
- b) He saw CFS/ME as a 'university illness'.
- c) Ended his relationship with an attractive woman as it made him feel emasculated.
- d) Feelings of 'otherness' described when in social situations.
- e) Felt social isolation impacted positively on recovery.
- f) Saw the time he was ill as a gap year and therefore missed being ill.

a) Described self as cured of CFS/ME

When Edmond's research interviews were conducted he considered himself cured of his CFS/ME. This was unique to Edmond, as all other participants in this study were living with the illness when interviewed. His first interview was the longest in the study and lasted for approximately 93 minutes. More importantly however, at the end of the interview he did not appear to be fatigued, something which, based on my pre-judgement, is uncommon for people with CFS/ME, even in its mildest form as defined by Cox and Findley (1998). For Edmond, levels of doing were a measure of him being cured which meant returning to pre-illness being and doing in the world, impacting positively therefore, on his belonging and becoming again who he wanted to be.

"It's only really been in the last couple of months that I have been confident in saying I am a 100% better and even now I think yeah, oh God can I say that 'cos it's always in the back of your mind I think ... but it's only really now that I feel like I used to in terms of my physical ability... it's not having to worry about it, I think, I just never think about it anymore... I mean... I don't suffer the symptoms and I don't worry about suffering the symptoms... so it's those two things I think... I no longer react and I no longer have the reaction to exercise that I used to have and I no longer worry about having that reaction." 2/1/281 - 282, 284, 2/2/50 - 51.

On the subject of how he gained a cure Edmond explained:

*"... I remember ... it was one sentence that I got from [name of specialist occupational therapist] which cured me, on my first meeting it was one sentence it was ... "we generally recommend starting off with very, very low amounts of activity and increasing it by 20% every 2 weeks" and I thought, I heard that and I thought **great** I can do that, that's something you know, that can be **measured** that I can do... that I can measure and I can take back a little bit of **control**, and I know what I'm doing and I've got a plan and that's what did it... and it worked." 2/1/200 - 202, 2/2/76.*

Edmond's pre-illness love of routines and targets enabled him to take on board the idea of pacing activities and occupations leading to his being cured.

b) He saw CFS/ME as a 'university illness'

Edmond attributed the start of his illness to the transition from school to university and found this a difficult time to deal with.

*"...this was a university problem... going from school it's an **unbelievable** work load...and it's an **unbelievable** expectation and it's incredibly difficult because suddenly you go from a school environment where everything is more or less spoon fed to you and suddenly you have to stand on your own two feet academically..." 2/1/77.1 – 2/1/79*

Apart from the need to prove himself academically at university, he was also part of the competitive sports culture. He was therefore, surrounded by external and internal expectations linked to winning and the need to continually push his performance further to achieve the best he could. His need to belong to and to fit in with an unfamiliar and challenging environment was a strong motivator for Edmond. However, he acknowledged that his attempts to become who he wanted to be and belong to this culture, unfortunately contributed to him becoming ill.

"...when you partake in what I would call... elite sport at university... that is every day, doing professionally-supervised exercise, in a very competitive environment... you can always push yourself further, than you think you can and that is always what you have to do if you're going to win..." 2/2/9 – 10.

c) Ended his relationship with an attractive woman as it made him feel emasculated

His girlfriend's physical beauty reminded him of his own physical limitations and led to feelings of emasculation. At a time when he had growing health-related needs, she made emotional demands of him and he therefore ended their relationship. This was clearly a stressor for him as almost immediately on finishing with her, he felt better in himself. He was then better able to cope with his changed sense of identity as a young male and also to use his limited energy to deal with his own needs, in terms of living with CFS/ME and its impact on a day to day basis.

"Her being around in a way , it made me feel even more emasculated... she was quite needy... emotionally needy and the problem was that, obviously when I was ill, I was the one that needed, I was the needy one and so when I ended it, I actually felt a lot better." 2/2/25, 2/1/223, 2/1/228.

d) Feelings of ‘otherness’ described when in social situations

Edmond shared his horizon of concern linked to factors which could have prevented his recovery. These included the attitude of some of his friends, who didn’t quite understand how much the illness impacted on his abilities, due to its invisible nature. These attitudes caused him feelings of what he described as ‘otherness’ while in their company, as he felt he was treated differently by them then because of his illness which impacted negatively on his “being-in-the-world”.

“The feeling of... ‘otherness’ that you get when interacting with normal people , it’s a nasty feeling inside, well I imagine it’s what people who are disabled... people feel and have to deal with on an everyday basis... it’s the feeling that people are reacting to you in a way that is always not to do with you, but is to do with the state of the way you are and that serves to do a number of things; it reminds you of what you have to deal with constantly, even when people are being nice you can’t blame people for this and it’s constantly reminding you of that... and it’s constantly making you feel inadequate...” 2/1/175 – 176.

e) Felt social isolation impacted positively on recovery

Edmond felt trapped and alone with his illness when it was at its worst. He did however discover he was able to escape through isolating himself and taking up model painting again, an occupation over which he felt he might have some control and had enjoyed as a boy. Regaining some occupational competence through ‘doing’ at this point was important as he was unable to control most other aspects of his daily life including his usual habits and routines. Through meaningful occupation he was able to distract himself from the illness, achieving a degree of occupational flow despite the presence of CFS/ME.

“The only escape really was to do something that would take you into a different world but again in quite a solitary way really ...that’s a very strong feeling because nobody else can relate to it.” 2/1/53 – 53.1.

The positive impact of self-imposed social isolation which enabled occupational engagement was uniquely identified by Edmond as contributory to his recovery from the illness.

f) Saw the time he was ill as a gap year and therefore missed being ill

Although the experience of having CFS/ME was largely a negative one for Edmond, he reflected that he missed being ill. For him, illness was associated with emotional and financial support from his family and he grieved for the quiet times at home in the country where his family home was situated. Interestingly, through dependence, Edmond

achieved freedom. On reflection, he saw being ill as the gap year he didn't have and considered he would benefit from a proper gap year, to reflect on his illness experiences and think about his future career. He also recognised a need to deal with the next transition in his life, as he considered he fumbled the last one, between school and university. He was however, pleased that he was feeling back in control of his body and health and was no longer worrying about whether CFS/ME would return, which he felt was is a positive place to be.

“The funny thing is that looking back with hindsight, I almost miss it... I miss having all that time to just to devote to myself and to... having a project that I was achieving in, I'd walk with my mum quite a lot and so we had a great time, going for these walks together and just not having anything, I had nothing to worry about at that point, because... I knew I was getting better ... looking back I do see those good bits as my gap year really and I miss it... I feel I need one. I feel I need, like I need, the space to actually process what I've gone through over the last 5 years.”
2/1/324 – 330.

5.3.5 Luke

Luke's Thematic Map

Luke's experiences of living with CFS/ME were analysed and placed into five inter-related themes. Luke's own words were used to label the themes. They were:

Theme 1: I don't know for certain how long I have had ME.

Theme 2: I would be mindful of societal expectations.

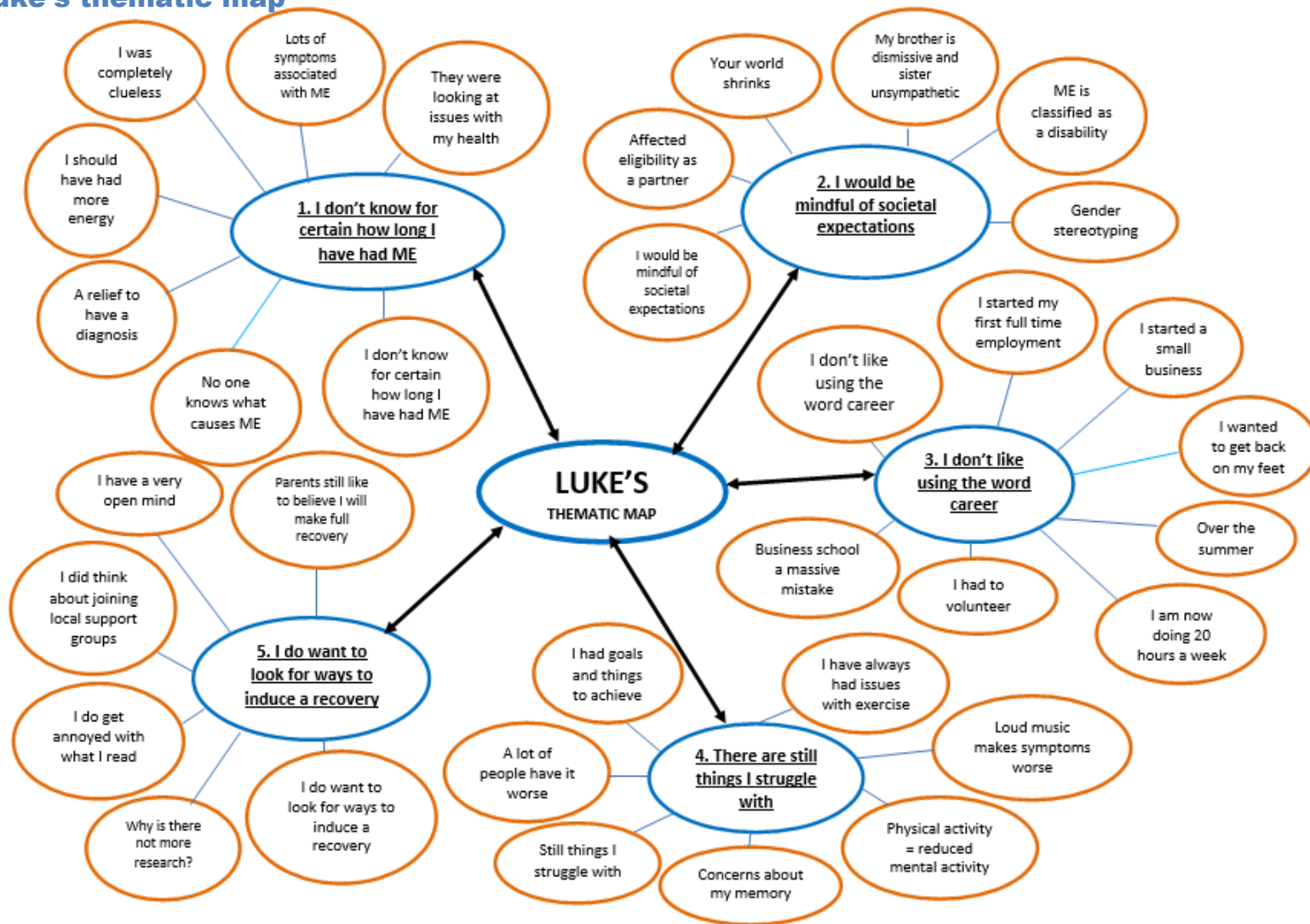
Theme 3: I don't like using the word career.

Theme 4: There are still things I struggle with.

Theme 5: I do want to look for ways in which I can help induce a recovery.

Themes and contributory sub-themes appear on the thematic map below to provide context.

Figure 10: Luke's thematic map



Uniqueness of Luke's experiences:

- a) Had no choice but to geographically relocate with family due to lack of financial independence.
- b) Blames the delay in being diagnosed on him for not doing something earlier rather than on health professionals.
- c) Felt that culturally he would be negatively judged by women in any new relationships as he had no money and few prospects in terms of financial independence.
- d) He had applied for jobs and been treated unlawfully because of his illness.
- e) He found it difficult that his father didn't accept his illness for some time.

a) Had no choice but to geographically relocate with family due to lack of financial independence

Luke acknowledges the traditional cultural expectations he had been exposed to in terms of becoming a young adult and moving out of the family home once he had finished university. The trajectory he followed however was at odds with these expectations as he was not able to meet his anticipated milestones of young adulthood and independence due to his illness.

"...when they moved here, and this was post diagnosis, so I didn't really have much choice but to move with them, because I didn't have anywhere to live in [place they were moving from]... given a choice, I would have my own place... without a doubt." 3/1/22, 3/4/35.

The lack of choice he experienced over how to live his life was further added to as his illness prevented access to social activities in the evenings and contact with some friends was lost due to having to relocate with his parents. These factors fed into a sense of his world shrinking, especially when compared to his time travelling the world, when he was able to do so. Unlike Edmond, Luke craved independence but found it difficult to think about this possibility and what might eventually become of him.

"Can't go out in the evenings and... didn't have any money coming in... Your world shrinks. I also moved down here because my family moved down here, so I moved down with them, so that significantly shrank my social circle." 3/1/38.1, 3/1/39.

b) He had applied for jobs and perceived he had been treated unlawfully because of his illness

Although CFS/ME is acknowledged in current UK equality legislation, Luke felt employers were making negative judgements of him when he applied for easy work. In his eyes it seemed that the law has not protected him which felt unjust and demeaning. He also mentioned that when applying for work, he used dialogue he thought employers would understand when referring to his illness as it appears in the legislation. It seemed to Luke however, that some employers did not necessarily want to understand CFS/ME, as they judged his applications negatively despite the legal requirements linked to inclusivity. Luke's experience provides an example of occupational injustice.

"I have made applications over the last few years to like employers that state their credentials of you know hiring people with disabilities... equal opportunity employers stuff like that and really receiving unbelievable responses from them... some of them they have a double tick they call it a double tick system whereas if you tick a box and say you have got a disability they guarantee you an interview... there was a couple where I you know I ticked the box to say you know I have got a legally defined disability and then they still refused to interview me... I was almost a perfect candidate for these positions... So... it's a catch 22, either you don't tick the box and then they look at your CV and 'oh that's a mess something is going on here' or you tick the box and they are like 'he has got a disability let's look at someone else'." 3/3/18.

"ME is technically legally, classified as a disability... under the Equality Act, but there is almost no way that you can actually enforce that... I was very angry about... the way I was treated when I applied for jobs, because of the condition and because of the employment history that I had... the way I was treated by potential employers..." 3/3/15, 3/3/16

Luke's frustration and worries about potential future financial independence were not helped by the perceived unlawful treatment he received at the hands of some of the employers he encountered.

c) Blames the delay in being diagnosed on him for not doing something earlier rather than on health professionals

Unlike other participants in this study, Luke does not blame his GP for the delay in diagnosing his CFS/ME rather; he takes some personal responsibility for this acknowledging that he should have been better at contacting his GP for help.

"Because I hadn't gone [to see the GP] at the end of the previous year... I couldn't blame anyone but myself for that and so circumstance and you know, bad luck, lead to it being a bit prolonged." 3/2/35.

d) Felt that culturally he would be negatively judged by women in any new relationships as he had no money and few prospects in terms of financial independence

Luke's worry about being negatively judged by women concerned him and added to his distress of living with CFS/ME, a potentially long-term and unremitting illness. He felt pressurised at having to live up to cultural expectations which he considered was a burden for him.

"Unless I do make a recovery, I am not going to be able to work more than I am working now and therefore, if I was in a relationship, she would have to be the dominant breadwinner, or the earner of the household... it's a thought that has crossed my mind... I think again, going back to cultural expectations, I think it's still expected that the female take their role and the man go out and work, so gender stereotyping..." 3/4/49.1.

e) He found it difficult that his father didn't accept his illness for some time

Luke was aware that his parents hoped he would make a full recovery, which seemed to place pressure on him to get better, whilst being aware that a full recovery may never be possible. He also had difficulty in accepting his father didn't really understand the illness and this had caused Luke to experience some resentment towards his father over the last few years.

"I think he really struggled with it and I think he still struggles with it, like I remember when I got the diagnosis and... he didn't tell a single person... he did tell a single family member... I remember I got quite annoyed one day because one of our relatives their son had broken his arm and... he literally told everyone he knew... making phone calls to tell people... but yet you won't tell anyone that I have got this condition, so he really struggled with it... he is much better about it now but he has travelled for a very, very long time... he was supportive you know I mean he has always been supportive to an extent he just has had trouble accepting the chronic nature of the illness and you know he would like to see a recovery and yeah he very much doesn't want me to give up on a recovery because he wants me to do everything I possibly can do to you know induce that recovery while at the same time he is supportive and he does accept but he just doesn't want you know me or anyone else to be like ok well that's that then" 3/4/22.

Luke's need to be fully accepted by his father despite his illness was important to him.

5.3.6 Sparky

Sparky's Thematic Map

Sparky's experiences of living with CFS/ME were analysed and placed into six inter-related themes. Sparky's own words were used to label the themes. They were:

Theme 1: I had a virus that attacked my liver.

Theme 2: The way you can live your life for the better is to manage the condition.

Theme 3: A big part of any person's identity is their physical and mental well-being.

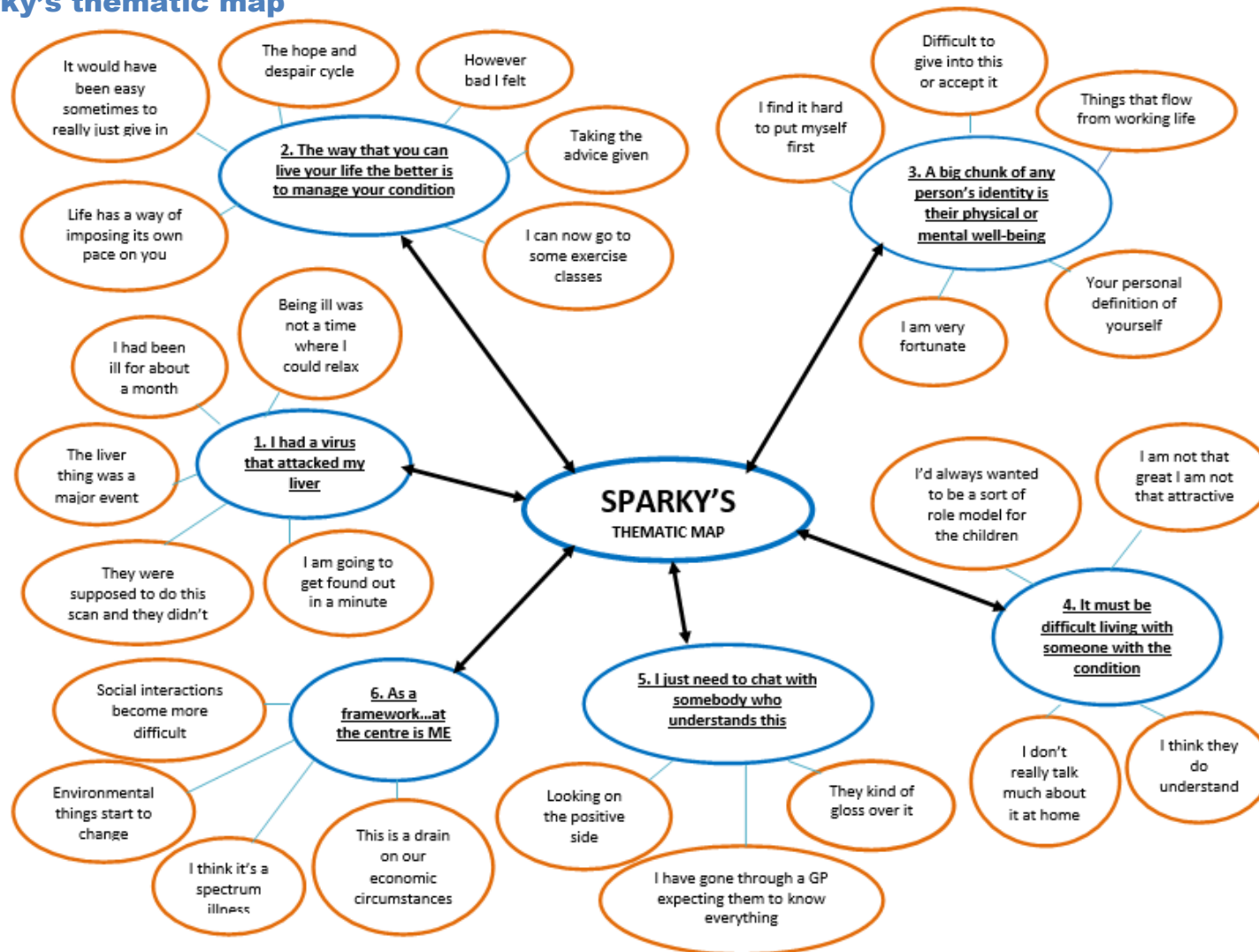
Theme 4: It must be difficult living with someone with the condition.

Theme 5: I just need to chat with somebody who understands this.

Theme 6: As a framework...at the centre is the ME.

Themes and contributory sub-themes appear on the thematic map below to provide context.

Figure 11: Sparky's thematic map



Uniqueness of Sparky's experiences:

- a) He trivialised his illness experience despite being hospitalised in an intensive care unit (ICU) in an acute hospital.
- b) No explanation ever provided for illness in ICU and therefore, faced death without known cause.
- c) Sparky was made to reapply for his own job whilst off sick.

a) He trivialised his illness experience despite being hospitalised in an intensive care unit (ICU) and faced death from an unknown cause

Despite the scientific evidence indicating the severity of his liver symptoms, Sparky was concerned that he would be accused of 'faking it', based that on the way he had been treated for his CFS/ME by health care practitioners in the past. His beliefs were so strong that he was prepared to go along with being asked to leave the acute hospital where he had been admitted to ICU. The possibility that his illness was not legitimate or that he was in some way disingenuous concerned him. There seemed to him to have been a mismatch between how ill he felt and the medical actions taken. He based this analysis on his previous feelings of illness, linked to how much worse he had felt with CFS/ME, without anyone considering the need for hospitalisation. Incongruences between the individual's needs and treatments offered was brought into contrast.

"They kept me in basically and even at that point I thought well they are going to say look you have just got a history of CFS or ME and off you go home... I genuinely can remember being in the hospital thinking, I am going to get found out in a minute, they are going to come in and say, you know, 'you need to go home', so every time you know, when you are sort of sat in the hospital waiting for the consultant to do the rounds, you think 'oh I will get myself ready because they are going to tell me to go home in a minute' and so I'd sort of got to the point where I was conditioned... to not resist... I can remember being in the hospital saying oh you know I do feel a bit weary... and they said well I am not surprised with blood readings like this and I thought well actually I have felt much worse I have felt much worse." 4/1/19, 4/1/24, 4/3/23.

b) No explanation ever provided for illness in ICU and therefore, faced death without known cause

Sparky has been and still remains, traumatised by his illness and near death experiences. Whilst he was grateful for being successfully resuscitated when in hospital, the cause of his liver problems was never fully understood and his CFS/ME still lingered on and was not healed by the medical interventions given.

"I had a virus that attacked my liver and had to be resuscitated on more than one occasion and I think the impact of that was huge and it still is huge nearly two years on... they never actually got to the bottom of why the liver had such huge damage... in the end they sort of termed it viral ... they... were obviously talking to people across other NHS Trusts to try and work out... and I was being given various medications to try... and... had an anaphylactic reaction... and had to be resuscitated... it was a really, really strange... I can remember the consultant saying to me you know, 'this is looking really bleak and have you got, you know, have you got a will'..." 4/1/8, 4/1/8.1, 4/1/22.

A cause for Sparky's liver problems was never established; meaning he almost died and didn't understand why. The fear associated with such an experience was concerning for him and with young children to provide for and only being in his 40s, the threat of possible recurrence and next time not being so lucky, was a possibility.

c) Sparky was made to reapply for his own job whilst off sick

Whilst experiencing personal loss on many levels, he was made to reapply for his own position due to a restructuring of his department. He felt vulnerable, unsupported, bullied and marginalised by his employers. Unsurprisingly to him he wasn't offered his job but wasn't informed of this for some time adding to prolonged distress and pressure of being off sick from work.

"... they then did a restructuring my post was at risk I was off work sick and I was made to apply for my own job and go for an interview and surprise, surprise, I didn't get it and I had the interview in the August they told me at the end of September I hadn't got it and then I didn't get my formal notice until the end of March 2014." 4/1/35.

The actions of his employer led Sparky to set up his own business on a self-employed basis. He did this to try and earn a living for his family and to regain some control over his working life. Based on how his employers had treated him he was fearful of applying for employment elsewhere, while trying to deal with the impact of CFS/ME on all aspects of his life.

5.3.7 Billy

Billy's Thematic Map

Billy's experiences of living with CFS/ME were analysed and placed into five inter-related themes. Billy's own words were used to label the themes. They were:

Theme 1: My wife said it was ME long before the doctors.

Theme 2: I worked in a builders' merchants.

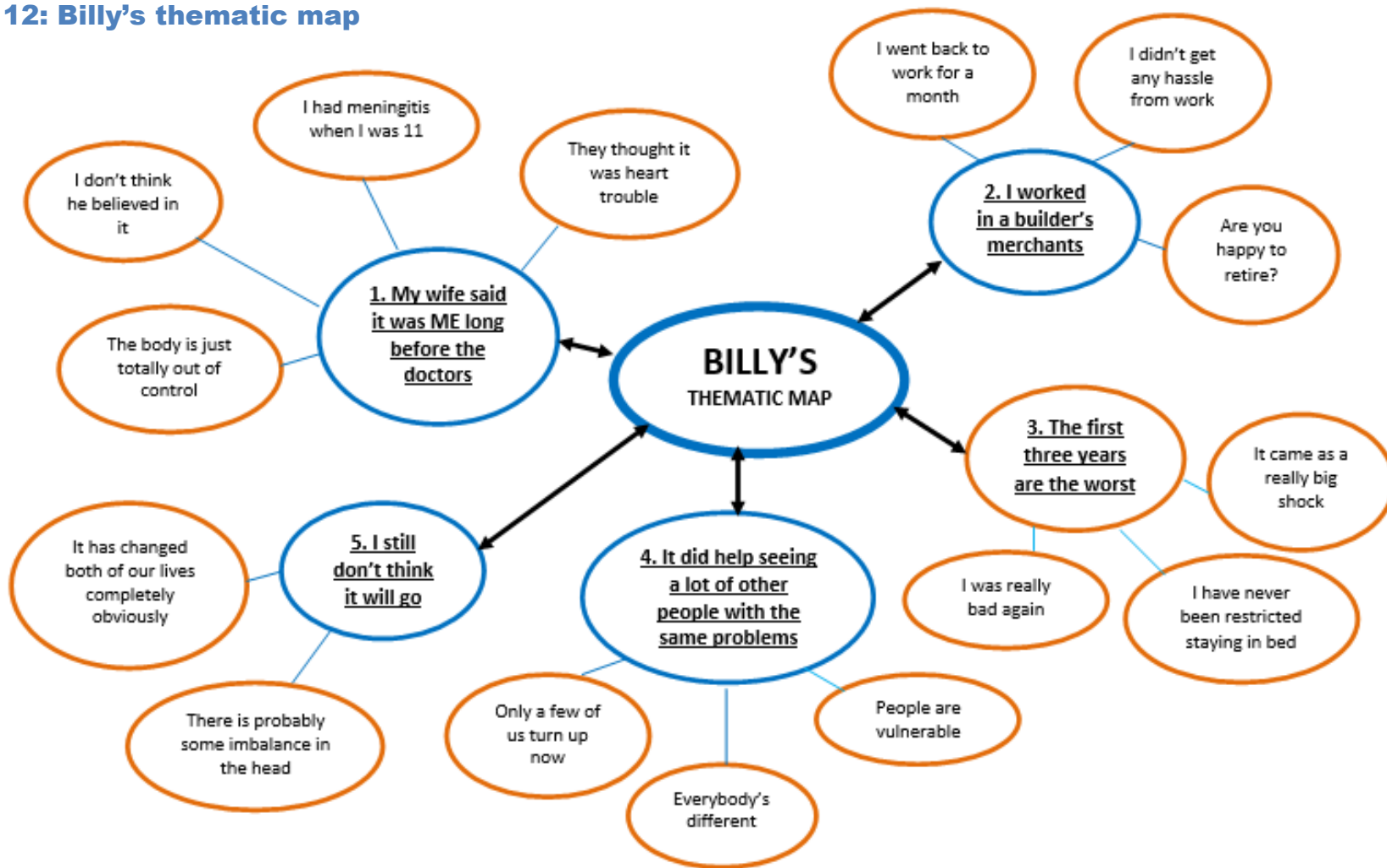
Theme 3: The first three years are the worst.

Theme 4: It did help seeing a lot of other people with the same problems.

Theme 5: I still don't think it will go away.

Themes and contributory sub-themes appear on the thematic map below to provide context.

Figure 12: Billy's thematic map



Uniqueness of Billy's Experiences:

- a) Wife knew it was CFS/ME before the medics.
- b) Became ill just before planned retirement so retiring early was less of an issue for him.
- c) Only Billy had found some benefit from attending a community based CFS/ME support group.
- d) Prevented Billy and his wife from their retirement plans.

a) Wife knew it was CFS/ME before the medics

Billy's wife challenged the GP's knowledge and authority but to no avail. This led to frustration and a lengthy journey before diagnosis, which might have been prevented if her opinion had been valued by the GP. Her concern over Billy's health was clear and he valued his wife and her care. Remembering how upset she was about him causes him some distress. Their long-term partnership seemed strong.

"...because a friend of ours, their daughter has had it for a long [time]... So my wife knew more about it than I did... my wife was telling me... it was ME long before the doctors were... she said to the original doctor 'he has got ME' and she said 'no we don't want to go down that line'..." "...it took 18 months [to be diagnosed]." 5/1/53, 5/2/34.1.

b) Became ill just before planned retirement so retiring early was less of an issue for him

The opportunity to escape from his 'job and a half' as he had described it, just before he was due to retire was appealing to Billy so he took early retirement. He reflected that the package being offered to him was acceptable financially. Thinking about the consequences of having to retire had he been younger however, caused him some distress as he acknowledged he would have been in financial difficulty.

"If I had been a bit younger I probably would have been more upset about it, a little more worried about it, because of the finance part of it, but I was close to retiring anyway so I was able to get a pension, a final salary pension, so money wasn't a problem, but if I had been younger it probably would have been more stressful." 5/1/1.

The need to retire at the time was not far off what he had anticipated in terms of his planned time to retire and he was therefore accepting of this.

c) Only Billy had found some benefit from attending a community based CFS/ME support group

Unlike the other participants in this study, Billy had found it useful to attend a voluntary, community based support group for people with CFS/ME.

"...it wasn't long after [diagnosis] something was in the paper my brother had been going through, the local paper he said 'oh there is something in here'...it did help seeing a lot of other people with the same problems... a lot of theirs was worse than mine really because a lot of their marriages and relationships broke up there was not many that stuck." 5/1/39 - 40.

The need to belong to a group of people where common experiences are shared was important and provided Billy with a sense of perspective on his own illness and its consequences. Additionally, it reminded him of how lucky he was to have the support of his wife.

"...it's a shame they are not coming [to the support group], there is only a few of us turn up now and it really is a shame... because I feel now we have been through it and know a bit about it, we can help the new people... we do try put little bits in the paper and that, but it doesn't seem to do any [good]... but then there's finance, it's not much point paying out whatever it is a month for the room and nobody is turning up, plus fund raising things, the same few turn up every time." 5/1/67.

The group however, had diminished somewhat and this saddened Billy as he felt he had experiences to share with others that could have been helpful to them.

d) Illness prevented Billy and his wife from following their retirement plans

As Billy's transition from work to retirement did not follow the planned trajectory, his hopes of travel did not transpire. Additionally, his wife stalled her retirement plans to help out financially. A more restricted life-style for both of them has had to be adopted compared to what was planned, hoped for or anticipated. However, Billy and his wife seemed to make the best of what they had.

"It has changed both of our lives completely obviously we have not been able to do things we were hoping to do ...a lot of the frustration is when we were planning to do things when we retired, but we retired and we couldn't...I wouldn't go abroad now, because in case I have one of these really bad spells, my wife would love to go to Egypt... we do try and go out as much as we can." 5/2/8, 5/1/30, 5/2/15.

5.3.8 Andy

Andy's Thematic Map

Andy's experiences of living with CFS/ME were analysed and placed into six inter-related themes. Andy's own words were used to label the themes. They were:

Theme 1: Something odd happened.

Theme 2: There are a quarter of a million people like me.

Theme 3: My tendency is not to speak about things.

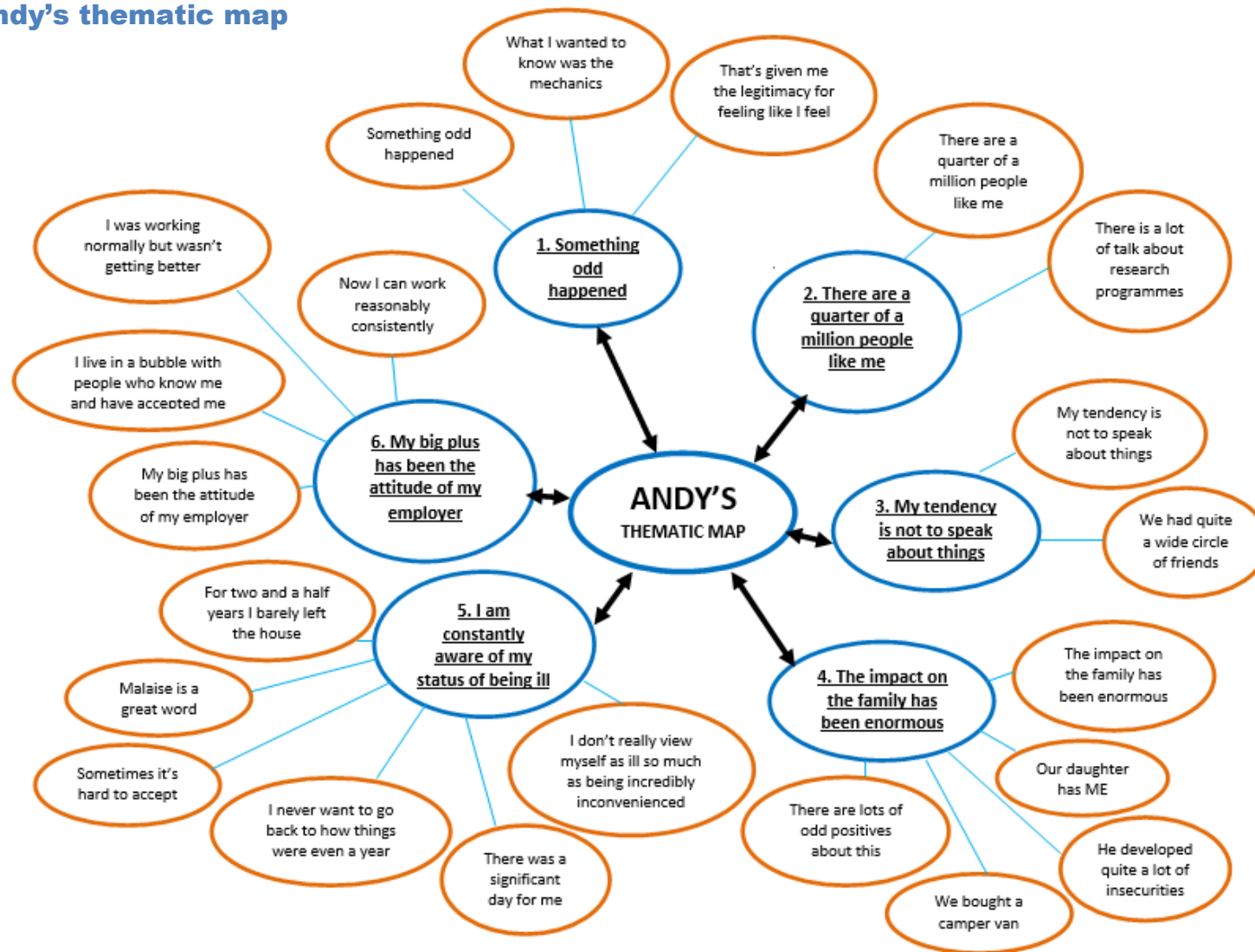
Theme 4: The impact on the family has been enormous.

Theme 5: I am constantly aware of my status of being ill.

Theme 6: My big plus has been the attitude of my employer.

Themes and contributory sub-themes appear on the thematic map below to provide context.

Figure 13: Andy's thematic map



Uniqueness of Andy's Experiences:

- a) He became the second person in his family to be diagnosed with CFS/ME; his school age daughter was first.
- b) As well as via dialogue, Andy uniquely expressed and shared some of his experiences of illness through artwork and poetry which he found cathartic.

a) He became the second person in his family to be diagnosed with CFS/ME; his school age daughter was first

Andy became ill after trying to juggle working from home, whilst also looking after his ten year old daughter who had a diagnosis of CFS/ME. Andy felt there was an element of fate about him getting the illness and considered this as some form of punishment for his lack of understanding of his daughter's needs.

"At the back of my mind it seemed pretty similar to what my daughter had but we said 'lightening can't strike twice'... It was a huge shock... I was an angry boy... I have to confess, that you know, I didn't really grasp it or believe it, or whatever it was... and I feel really bad about that now... and also at that point, I got a real appreciation of what she had gone through, so I feel a lot guilty about that..." 6/1/5, 6/1/7, 6/1/9.

Through his unique insights from looking after his daughter and then getting CFS/ME himself, he identified that the illness can affect people differently.

b) As well as via dialogue, Andy uniquely expressed and shared some of his experiences of illness through artwork and poetry which he found cathartic.

Andy was the only participant to discuss how he had recorded some of his illness experiences by using the media of art work and poetry. He did so originally, simply to vent some of his frustrations linked to the impact of living with CFS/ME. As time went by however, he acquired a degree of competence over the activity which then became a meaningful leisure occupation for him.

"What I do remember from doing that [painting in the middle of the night] was how much I calmed down in the process... and then I was able to go back to bed and go back to sleep and... so at that point I realised, well I might be able to do something here...I never realised I expressed myself so well on paper..." 6/3/26, 6/2/8.1.

The development of his interest in painting was seen as cathartic and also as a positive spin-off from being ill.

“So the early painting things helped me express despair and loss and loss of direction, all that kind of thing and then gradually, I am coming into, I could do this for long periods of time and I enjoy it now, I am going to try and do it better and... so... [painting] has become... a fairly firm hobby now. Would I have ever done this had I not had it? [CFS/ME] ... So I think that it just shows that you know good can come out of bad at the same time like I say it's not an entirely... negative thing.” 6/3/40 – 41.

“There are lots of odd positives about all of this... like for example, I would never have picked up a paint brush... if it wasn't for this.” 6/2/4.

Various aspects of Andy's illness experiences appeared in his art work. His sense of isolation and being imprisoned in his 'lived space', his own sitting room, was represented through his paintings of being inside a cave. A picture linked to his perception of the destruction of his life world appears below and uniquely illustrated the fragmented nature of his being, due to the presence of his illness:

“It was like the earth had blown up and... it's like the destruction of what I was or what I had been able to do ... so... this is my world you see its quite small.” 6/2/8, 6/3/31.

Figure 14: Andy's Bits of World Painting

"This was a world, now there's bits of world" data line number 6/3/31.



Andy's poetry was also cathartic as he was able to use his work to reflect on his progress through the illness which he found helpful as he explains:

"Come across it [poem about ME he had written] the other day and I thought well actually this neatly expressed how I was, not so much how I am now... I have moved on... yeah absolutely..." 6/2/10.

The poem could be interpreted as a play-on-words both of which are poignant. It is about 'ME' (myalgic encephalomyelitis) but might also be interpreted as all about 'me' in terms of the 'self'. Either way, the appearance of 'ME' in every verse, however interpreted, indicated the all-encompassing and stifling nature of living with the illness for Andy and resonates with his comments of there being no escape in terms of lived body, time and space and feeling imprisoned in his own home due to the illness. Additionally, the poem conveys messages of Andy feeling selfish for focussing on his own needs, the long-term nature of his illness, threats to his relationship with his wife, a lost sense of self and any future, and distress and resentment at having to endure the illness. There is a sadness and hopelessness to this poem making it difficult to read.

It's all about ME

*It's all about ME
I can't hear what you say
For it's all about ME
And not just for today.*

*It's all about ME
I know nothing more
It's all about ME
Don't walk out the door*

*It's all about ME
I'm consumed by my sorrow
It's all about ME
I can't see past tomorrow*

*It's all about ME
I've time to reflect
It's all about ME
So I've lost my respect*

*It's all about ME
I don't get out much
It's all about ME
For attention I clutch*

*It's all about ME
Can't talk about you
It's all about ME
And the things I can't do*

*It's all about ME
I can't tell you how I feel
It's all about ME
I've had a poor deal*

*It's all about ME
I can't think of much else
It's all about ME
I wish it would stop*

Andy's need to express something somewhere drove him to write poetry to get it out somewhere as he stated:

[His ME poem] *"...I may not have realised it at the time, although I do remember... what drove me to write it in the first place, was the need to express something, somewhere."* 6/3/25

He needed to express himself when perhaps he couldn't speak these words. This was helpful to him and replaced dialogue to convey and illustrate his illness experience to others. Additionally, Andy was able to reflect on and situate his stages of illness and improvement which seemed reassuring to him in terms of progress towards recovery.

5.3.9 Christopher

Christopher's Thematic Map

Christopher's experiences of living with CFS/ME were analysed and placed into four inter-related themes. Christopher's own words were used to label the themes. They were:

Theme 1: The seriousness of the illness became evident in 2007.

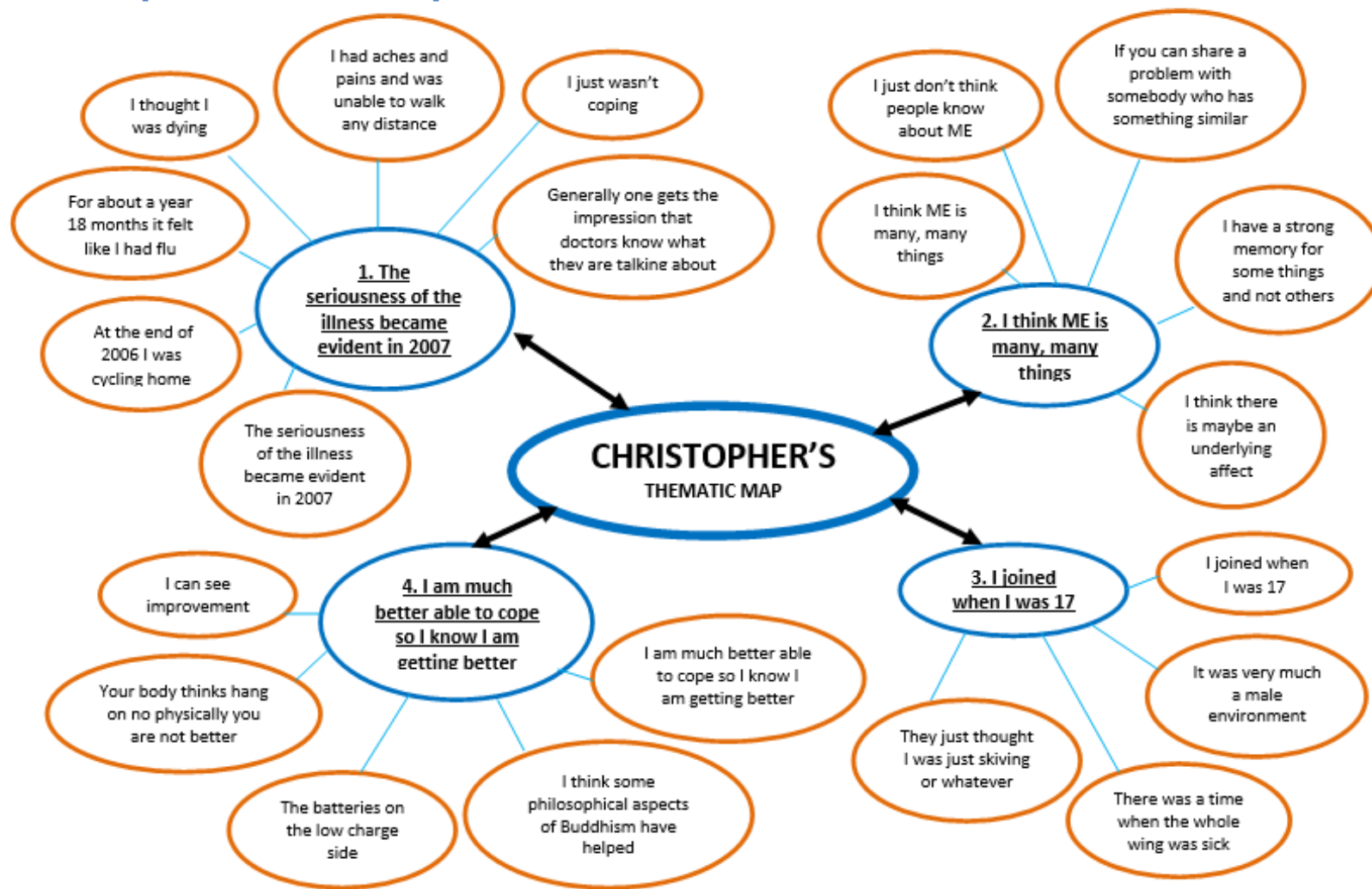
Theme 2: I think ME is many, many things.

Theme 3: I joined when I was 17.

Theme 4: I am much better able to cope so I know I am getting better.

Themes and contributory sub-themes appear on the thematic map below to provide context.

Figure 15: Christopher's thematic map



Uniqueness of Christopher's Experiences:

- a) Suspected he may have triggered CFS/ME during his time in the services, having joined when he was 17.
- b) His GP unfairly accused him of drinking heavily after taking a tot of whisky to try and help him sleep.

a) Suspected he may have triggered CFS/ME during his time in the services having joined when he was 17

At 18 and living in service barracks, a suspicious mass illness with significant fatigue is remembered by Christopher and he wonders whether this could have been the trigger for his CFS/ME. He wondered whether the battalion may all have been poisoned, but no admission is made to this effect by the service in question.

"I have been getting ill ever since I was young... I was in the [name of force] at that time and they just thought I was just skiving or whatever...I would just like to also mention that when I was 18, about 18 I would say, there was about 150... recruits... that was in the Autumn... but there was a time, when the whole wing was sick... yeah with some gastric thing and they said that 'it's nothing to do with your food we don't know what it is', but we were really sick like the whole wing... and no strength and I remember getting up one night to go to the loo and then the next thing, I was lying on the floor and it was... really strange because, it was so many people that had no energy and were fainting... well I remember there being a suspicious air about the whole thing, it felt a bit cover uppy." 7/3/11.1, 7/3/12, 7/3/16.

No cause for his illness was ever established, but Christopher continued to experience problems with his energy levels leading to a period of hospitalisation for relaxation purposes. A friend in the same battalion also went through a similar experience. Christopher's was accused of skiving when he was unable to carry out normal/expected duties and came into conflict with superior officers who felt he did not have a legitimate reason for his lack of energy.

b) His GP unfairly accused him of drinking heavily after taking a tot of whisky to try and get some sleep

Prior to diagnosis and in an attempt to try and get some much needed sleep, Christopher was labelled a heavy drinker by his GP. Whilst generally unsympathetic attitudes towards their illnesses from GPs were reported by several of the participants in this study, only Christopher had been unfairly accused of drinking heavily by his GP.

“I went to the doctor and said ‘I feel as though I am dying and I only had a little tot of whisky’ um,’ there’s something wrong’ and he said ‘you must have had a lot more than you are saying so’ and little did I know then, that one of the symptoms of ME is intolerance to alcohol, so I found that out much later... well I knew how much I’d had and I knew he was mistaken... the whisky I had around the time I went to see the doctor, was just an attempt to get some sleep because, I was starting to have um... you know waking up at night... and I felt really tired and I felt as though I needed more sleep so let’s have whisky you know... a tot of whisky...”
7/1/14.

The severity of Christopher’s symptoms following just a tot of whisky was indicative of the difficulties people with CFS/ME frequently experience due to alcohol intolerance (NICE, 2007). Prior to diagnosis however, Christopher was unaware of this possible explanation, and his GP also seemed unaware, having jumped to this judgemental conclusion.

5.3.10 Arnold

Arnold's Thematic Map

Arnold's experiences of living with CFS/ME were analysed and placed into four inter-related themes. Arnold's own words were used to label the themes. They were:

Theme 1: Maybe I should start from where I got my diagnosis.

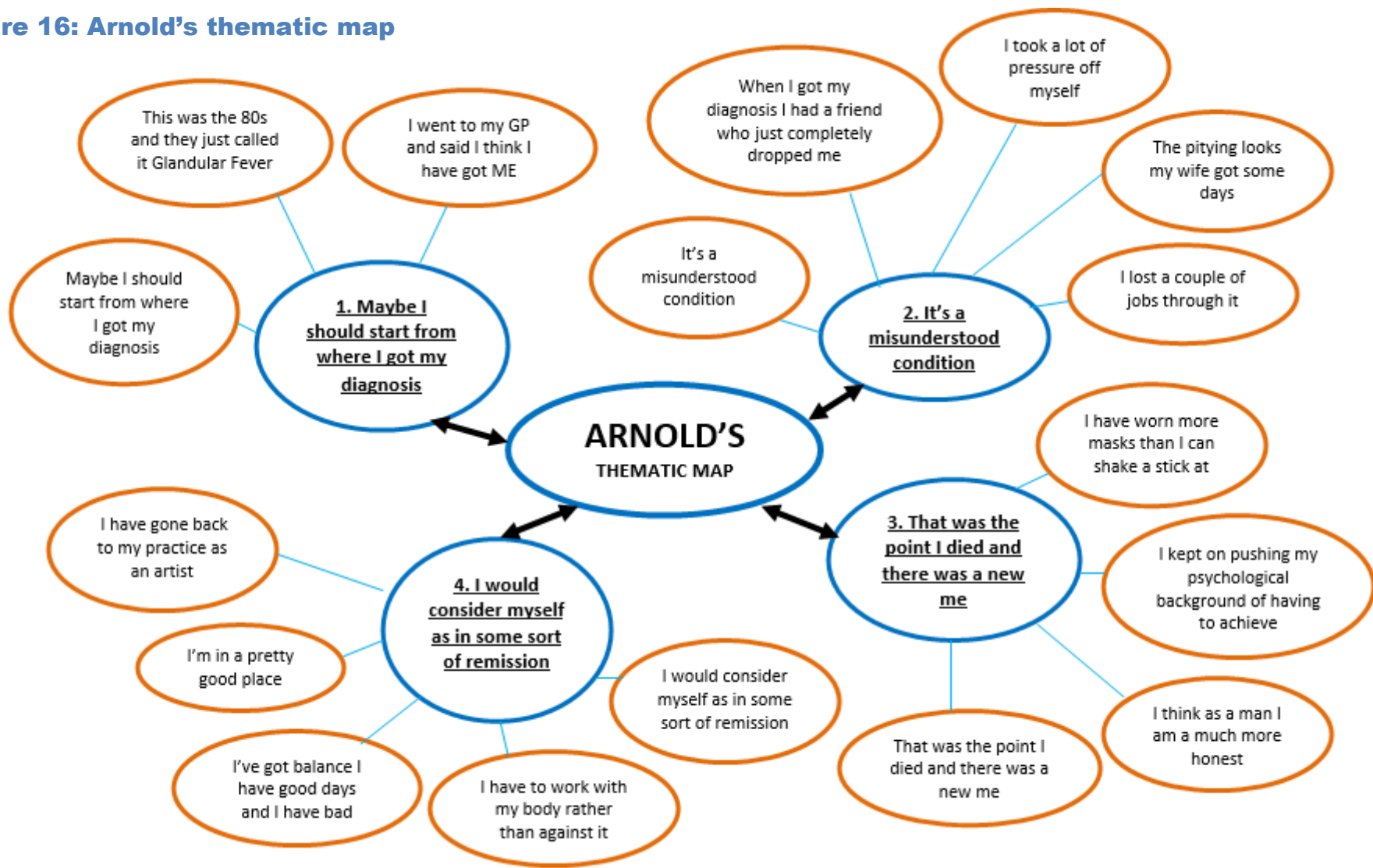
Theme 2: It's a misunderstood condition.

Theme 3: That was the point I died and there was a new me.

Theme 4: I would consider myself in some sort of remission.

Themes and contributory sub-themes appear on the thematic map below to provide context.

Figure 16: Arnold's thematic map



Uniqueness of Arnold's Experiences:

- a) Had experienced fatigue-like illness for longer than the other participants.
- b) Death of old me described as a consequence of having CFS/ME.

a) Had experienced fatigue like illness for longer than the other participants

Arnold's spoke from a horizon of having had a CFS/ME-like illness diagnosed on two separate occasions, with a period of 'recovery' in the middle of approximately twenty years. He had experienced his illness as being labelled different things including Epstein Barr Virus and more recently ME. After becoming ill for a second time in 2007, with a flu-type virus, followed by enduring fatigue, he learned that CFS/ME was linked to the Epstein-Barr virus. This enabled him to identify similarities in his two illness experiences and provided him with a unique insight into the impact of his illness over time.

"I got my diagnosis [CFS/ME] in; I would guess it was mid 2008 ...about 20 years before... I had Epstein-Barr virus; it must have been for about 7 years. The impacts of it... I would crawl from my bedroom in the flat to the bathroom some mornings, I couldn't walk... I was 26, 25, 26... I felt so ill... I didn't even care about how I felt. I would just sleep all day and I must have had the impacts of that for getting on for seven years and then I kept on getting balance issues, where you would just fall over, so I had neurological scans which came back clear... really I thought this is life." 8/1/1, 8/1/11, 8/1/12, 8/1/13.

Arnold considered himself as being in remission at the time of our meetings. Remission being described by him as his ability to return to activities and occupations he liked, wanted and had to do. He acknowledged that remission had only been possible due to the very supportive nature of the relationship he enjoyed with his wife. This he felt had enabled him not to worry about trying to run the house as well as his business, with compromised energy levels.

b) Death of old me described as a consequence of having CFS/ME

Arnold felt he would not be heard by his wife so did not communicate his difficulties to her. This led to him reaching a crisis point in terms of day to day coping, with associated thoughts of suicidal ideation.

"...I think maybe it was... a bad move to hide it from the day one... when I was seriously thinking about killing myself, yeah that was the real nadir of my existence. I couldn't go any lower... I had bumped along the lines for about six to eight weeks after that but ... that was the point I died and there was a new me." 8/2/7.

Revealing his needs to his wife and these being heard by her, he saw metaphorically, as the death of his old self, the one who hid things, and the birth of a more honest self. This catharsis seemed to coincide with his decision to accept the psychological impact of being ill and enabled him to be more open about himself and also his illness, with others.

Having presented a thematic map for each participant in section two and reported on the uniqueness of their experiences, in section three, I include a thematic map to shown a synthesis of the findings and similarities in experiences, referred to as shared experiences, which are supported with quotes from the data analysis.

5.4 Section 3: Synthesis of findings

This section is a synthesis of findings across the data corpus to identify shared/similar experiences of living with CFS/ME

Using the individual thematic analyses of the data, shared experiences of the men involved were identified. These were synthesised into four overarching, inter-related themes. The themes were named using the participants' own words, to illustrate the shared theme label and to reflect the definition and contents of the theme. The four themes were:

1. There is nothing more important than understanding what it is

Definition of the theme: Shared perspectives on becoming ill, factors felt to contribute to this and trying to make sense of CFS/ME, prior to and post diagnosis.

2. The way you can live your life for the better is to manage the condition

Definition of the theme: How participants dealt with or struggled having CFS/ME and suggestions for others with the illness.

3. I just need to chat with somebody who understands this

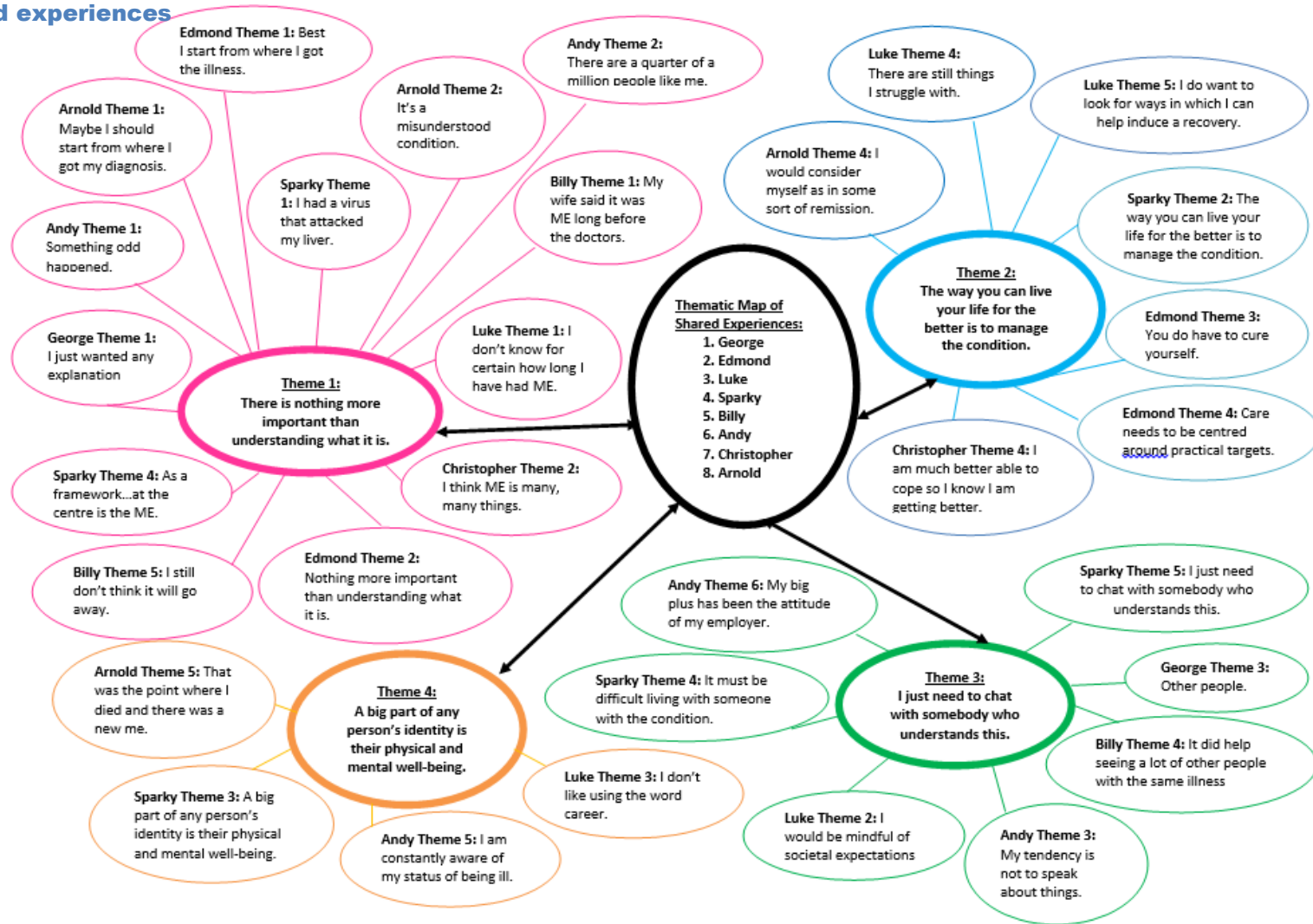
Definition of the theme: How others, including health professionals, featured in participants' experiences of living with CFS/ME.

4. A big part of any person's identity is their physical and mental well-being

Definition of the theme: Perspectives of the impact of CFS/ME on participants' self-identity and self-control and 'being-in-the-world'.

A thematic map presenting the four synthesised themes appears below, linking themes from the individual participants to the shared/similar themes.

Figure 17: Shared experiences



5.4.1 Shared Theme 1: There is nothing more important than understanding what it is

Definition of the theme: Shared perspectives on becoming ill, factors felt to contribute to this and trying to make sense of CFS/ME, prior to and post diagnosis.

Becoming ill

Prior to gaining a diagnosis of CFS/ME all participants had a need to understand what was happening to their health and why. They began to experience new and unfamiliar symptoms and noticed that they became unable to manage some of their day to day activities and occupations, seemingly without good reason. Gaining an understanding of what was happening would have enabled them to take some appropriate action to deal with the changes experienced. Edmond expressed this confusing time in his illness trajectory as follows:

“...imagine that you had to change the way that you lived entirely for the worse and this was because of an unseen and unknown force, you would want to know a bit more about that unseen and unknown, ‘cos you’d want to know whether it’s ever going to go away, or whether you can do anything about it...” 2/1/168.

Billy also explained how frustrating the impact of the illness was for him:

“...I had been very active... not only at work playing sports and all that... it was a shock to have to sort of sit down and can’t do it and I found that very... well, I don’t know about stressful, but what’s the right word, I can’t think of the right word now... frustrating that’s the right word...” 5/1/4.

Andy needed to know more precisely what was happening to him as this was not apparent:

“...what I wanted to know was, what’s the mechanics, you know, what precisely is going wrong...” 6/1/44.

Their accounts were contextualised by referring to significant periods in their illness journeys linked to disruption of their being and doing in the world, and shared by moving back and forth across time, during their research interviews.

Making Sense of CFS/ME

Symptoms experienced as they became ill included disruptive fatigue and muscle pain and general physical weakness. Some participants were concerned that something life-threatening may be happening to them. For Billy and Arnold, experiencing acute chest pains had led to emergency paramedic call outs, but nothing abnormal was diagnosed. Luke and Christopher had both feared they may have some sort of cancer, partly because of the significant fatigue they were experiencing. Some participants had attempted to understand their illness by conducting their own research, in the hope they could take some control over what was happening. For Arnold and Luke this led to them gaining an understanding of what they were experiencing by matching their symptoms with available information and the ability therefore, to make a self-diagnosis as Luke explained:

"I Googled it and I can't remember what website I went on, but there was a list of symptoms and I read the list of symptoms and I was like 'that's what I have' and so it became very clear at that point... that's what I have..." 3/2/29.

For George, who was told he may have a brain tumour, and Luke there was some relief at being given a diagnosis of CFS/ME as opposed to cancer. For Sparky however, receiving a diagnosis left him with few suggestions in terms of how to deal with the impact of his illness. For Christopher and Arnold, misdiagnoses of Fibromyalgia Syndrome (FMS) and depression were challenged by them, due to a mismatch in their symptoms but were eventually medically overturned.

Encounters linked to relationships between participants and medics and issues around gaining a medical diagnosis, appear later in this section of the findings chapter, under the third theme labelled 'I just need to chat with somebody who understands this'.

Understanding possible triggers or causes for becoming ill

An identification of possible triggers or causes of their CFS/ME was made by all participants. George, Sparky, Christopher and Arnold, when he was diagnosed for the second time, mentioned they had experienced a flu-like illness for approximately six to eighteen months before they were diagnosed. Luke, Billy and Arnold initially attributed their fatigue symptoms to working too hard, but on reflection, realised symptoms were making work a struggle, rather than necessarily being caused by work. Edmond and Andy however, attributed the possible triggers for developing CFS/ME as being linked to more acute episodes of illness. For Edmond this was following his intense exercise sessions

and for Andy, after a fall which resulted in him damaging the base of his spine. This he felt, rendered him vulnerable to developing the illness, based on something he had read about triggering CFS/ME following physical trauma. Additionally, personality factors or traits including the need for control were mentioned by Edmond, Christopher and Arnold. Edmond also considered that bad luck played a part:

“I think I’m quite an introspective person and I am inclined to worry about things it’s just my nature and I think that that is part of the profile of somebody that will get this sort of illness ... I think this sort of illness is very comparable to anorexia in that...it will strike a certain personality type... and it springs from reaction between the personality type and the environment ...with some bad luck thrown in...it’s somebody who’s used to being a quite a high achiever somebody that pushes themselves and likes that achievement...thrives on pressure...thrives on putting themselves under pressure and somebody who likes to have control over their environment and control over themselves and to a degree... somebody who is inclined to worry and they try and exert that control as a response to that.” 2/1/63 – 2/1/68.

Both Christopher and Arnold considered that the way they had been physically abused during childhood had caused them significant distress and made them more susceptible to developing CFS/ME in adulthood. Both of them had been bullied and physically abused by their strict step-father and father respectively, which had included beatings and being punched in the face. Christopher considered that such abuse by those in authority was the social norm when he was a child and that children were expected to accept the status quo. Awareness that he had not felt as tough as other boys at school, who took their punishment from teachers with pride, was apparent. Christopher had carried stressful memories with him into adult life and acknowledged that stress made him feel generally more vulnerable and sensitive, even as a middle aged adult. The need to be tough and competitive had stayed with him into adult life and included the need to adopt ‘the man up attitude’ in times of distress, a traditional and stereotypical image of masculinity.

Arnold’s father’s lack of support, attitude and treatment of him as a child, also made him want to push himself to achieve in adulthood, which became habitual and contributed to his successful career in business in the city. His success however, was also part of his downfall, as his habitual behaviour resulted in occupational imbalance, deterioration in his health and an exacerbation in his illness symptoms.

Understanding the symptoms of CFS/ME post diagnosis

Physical and mental fatigue was commonly experienced by all participants. However, for Edmond, pain behind his eyes was reported as more problematic, which he described as being like a bad hangover. Brain fog and hypersensitivities to noise and certain foods such as coffee and alcohol were commonly reported. Poor memory was reported by most participants at some point in their illness experiences. A feeling of 'drifting' indicating reduced concentration was also mentioned by some of the men. Word-finding difficulties were reported by several of the men leading to frustration and sometimes embarrassment in social and work situations. Additionally, temperature regulation symptoms were mentioned by Luke and Billy with fluctuating hot and cold extremities and numbness at times. Gut problems were an issue for George and Christopher.

Sparky, Andy, Christopher and Arnold shared similar experiences linked to primary diagnoses of possible depression. All of these men were firm in their belief that depression was not a cause of CFS/ME but rather a consequence of not being able to do what they wanted to do or be who they wanted to be. Sparky summed this up:

"The way the health service responds... is to say it might be an issue of depression... I was open to that when my GP was saying you know, 'you got a chronic illness it's bound to drag you down'... I don't think it was the other way round... and I know with depression one of the symptoms is lack of motivation. I didn't ever lack motivation it would be fair to say you know, I probably recognised at other times in my life I have gone through a patch where I have felt a bit low, but I would have never had classed it as depression and I would have just thought there's a transition or a change happening and I am not quite sure how this is affecting me, or I would just go through a bit of a rough patch or something, but my response to that has always been a positive one." 4/2/28.

Christopher offered this explanation:

"The depression is a symptom... it's not a cause of anything, no it's just a mere symptom you know... I felt the impetus behind the depression was um, not neurological or anything, it was um, physiological is that the right word?...yeah so it was because of the body going wrong you know, physically and not because I was depressed, I have never been... I am quite a positive person I think." 7/1/8.1, 7/1/9.

For Andy, an apparent lack of understanding of the illness by the medical community was baffling. For George and Edmond, some avoidance of understanding was experienced as they actively chose not to look at CFS/ME information, being fearful of what they might learn and additionally chose not to be reminded of what they already knew.

Participants trying to describe CFS/ME to assist my understanding

Attempts to describe CFS/ME were made to assist my horizon of understanding. George Billy and Andy found it difficult to describe adequately and couldn't find any particular words to use. Luke described it as having constant jet-lag. Arnold described the illness as being hit by cricket bats all the time and like most other participants, was aware of the variable nature of symptoms experienced. Edmond, Sparky and Christopher considered that the disabling, complex and holistic nature of CFS/ME made it problematic to define adequately. Sparky went on to suggest a conceptual model of CFS/ME to help others to understand the illness:

“As a framework... you know those Venn diagrams where you get circles and the circles overlap...what you could have in the overlapping bit is... at the centre is... the ME... the chronic fatigue, but the three circles represent, one represents social, one represents economic and the third one represents environmental and so ME/CFS whatever it's called, it has an impact on all three of those circles and sometimes it pulls a bit like gravity, more into one and other times it pulls a bit more... into the other... so in the three bubbles in the social, your social relationships change partly because of the energy that you can give to it but also partly because and this is where it overlaps with the environment but you don't go to football club anymore for instance.” 4/2/1, 4/2/25.

Christopher and Andy felt the invisible nature of CFS/ME also made it difficult to describe and contributed to a lack of understanding of the illness by others. The person in this situation becomes unseen (Carel, 2008).

5.4.2 Shared Theme 2: The way you can live your life for the better is to manage the condition

Definition of the theme: How participants dealt with having CFS/ME and suggestions for others with the illness.

Once a medical diagnosis of CFS/ME was given, help to deal with the impact of the illness was needed by all participants. All men in this study were at some point, referred to a specialist fatigue service, in order to access a programme of supported self-management. The timing of referral to a service varied. For some participants it happened within approximately six months, as was the case for George, but for others years passed by before any help was offered from their GPs and occupational deprivation was experienced. Trying to self-manage their illness in the absence of a cause and therefore, without a proven cure, was problematic. However, the holistic nature of the illness was recognised as important to consider. Luke usefully illustrated the impact of CFS/ME on the whole person:

“No one knows definitively what causes ME or how best to treat it, so I kind of try to take like a holistic approach and look at everything, so I kind of broke that down into sort of mental and physical and also psychological and just try to deal with those three aspects as best I could.” 3/4/1.

The need to provide some hope of recovery was important particularly for Edmond:

“Being told that the only certainty was uncertainty... is what makes you much, much worse and that should be, in my opinion, completely eliminated from the care cycle.” 2/2/106.

Recovery was so important to Edmond, that he even suggested that health professionals should lie to their patients to facilitate this process. Placebos, in terms of drugs, were also suggested. Edmond did however; speak from a horizon of considering himself cured at the time of our interviews, so whilst suggested these strategies, he had not needed to try them out to manage his own illness. He did however, along with all other participants, acknowledge the need to adapt his day to day roles, habits, routines and occupations to cope with the challenges presented by having CFS/ME. Through adaptation of occupations using pacing, planning and prioritizing and recalibrating his daily routines, Edmond felt confident he had cured himself of the illness. George, Luke, Billy, Sparky, Andy, Christopher and Arnold also provided illustrative experiences linked to the usefulness of occupational adaptation and pacing. Luke described how he had achieved this in the work place:

"I am now doing 20 hours a week which I am really feeling is my limit... I am just about ok with that... it's not necessarily 100% high energy activity all of the time, but because it's four hours a day, I do it in one large block...I am better if I break things up into manageable chunks during the day." 3/4/6, 3/4/10.

Pacing however, was not necessarily achieved without some help. Edmond, Andy and Arnold stressed the importance of practical and emotional family support, which provided them with the opportunity to follow the pacing process. Sparky had valued being able to refer to resources supplied by a specialist fatigue service, when he needed to refresh his memory of strategies shared. Andy mentioned that through being more aware of how to manage his illness, crashes in his energy levels were less of a problem for him, due to taking more care to adapt his day to day life, in an attempt to prevent these from occurring. Having a daily routine in which to situate pacing was reported as useful and enabled Sparky to achieve basic levels of physical and mental activity, even at times when he felt most unwell:

"Even when I was at my worst, I would try and at least walk round the block and I could walk round the block and come home and feel utterly drained and in pain and really distracted by it, really not very well, but I would always try and maintain some kind of movement and also some kind of focus." 4/1/52.

Employing mindfulness and Buddhist meditation were helpful for Luke and Christopher enabling them to deal with managing their illness by reducing associated anxiety. However, Edmond found Mindfulness, which employs cognitive techniques to focus the individual in the present moment, difficult to adopt. His reason for this was linked to concerns about experiencing post-exertional symptoms, which he felt could not be forestalled even if anxiety in the present moment was reduced.

For Andy, the use of home oxygen helped to reduce brain fog and he found ibuprofen helpful in managing his pain. For Billy, knowing he had ongoing access to a specialist fatigue team who believed in his illness helped him to deal with managing this. This was unlike Andy, who had felt abandoned by adult services post programme. He had also envied the ongoing support his daughter had received from children's services, making his illness he considered, more difficult to manage.

The need to accept that something was wrong with their health was commonly identified by participants as a useful shift in thinking. This enabled a reduction in worrying about the condition and its potential impacts on life, and future being, doing, belonging and

becoming. Acceptance however, was not easily achieved by all. Sparky saw acceptance as losing the battle with CFS/ME and admitting defeat:

"...and one of the things that I found a little bit difficult sometimes is, particularly in the group [fatigue programme] there was a little bit of discussion about you know, acceptance and I could easily confuse that in my mind with defeatist... and I was the one who was struggling with that... and... I couldn't always see the difference, so I thought if I am accepting this I am accepting defeat and the stubborn part of me then kicks in and says 'well I am not going to accept defeat'... that was quite an important thing... I am determined and I am tenacious... couldn't completely submit to it." 4/2/14, 4/2/46.

An increase in an ability to cope with the illness was linked to recovery and getting better. Good days and bad were still experienced and reflected the fluctuating nature of the illness. However, positive thinking was used to challenge negatively anticipated impacts and was mentioned by George and Andy. For Andy, achieving a degree of recovery was acknowledged as enabling further positive thinking:

"If you have recovered sufficiently to take that next step, but you are mentally not taking the next step... there was a significant day for me ... I suddenly said to myself 'why am I thinking like this, I feel fine so why don't I just carry on as I'm fine and then if something happens then I will start to feel ill not now, because I am not ill, I don't feel ill right now and I feel capable right now, why do I have to have this... this blinker as it were' and then from that point on, my approach is completely different." 6/3/4.

For most participants George, Luke, Sparky, Billy, Andy, Christopher and Arnold their future being, doing, belonging and becoming remained uncertain despite their attempts to manage their illness. For Edmond however, his way of "being-in-the-world" through adapting his thinking, roles, routines and occupations enabled the possibility of a familiar future way of 'being, doing, becoming and belonging' to be regained:

"Having been given a firm target that you can measure yourself against, does suddenly give you a future back, even if at first its only for the week or for the 2 weeks that I am going to be increasing what I am doing by a certain amount in 2 weeks' time, and so suddenly, your horizon has gone forward to that which is an improvement... and then once you do that successfully, you think well if I can do that successfully 3 times in that amount of time, I'll be there, and so suddenly your future rolls out in front of you again, which is very important for the psychological way that you beat the condition." 2/2/92.

Identifying improvements in health and well-being was important to all participants. This was achievable through measuring levels of doing by using a pacing formula. Not being able to measure improvements left some participants with a life world that seemed futureless, where uncertain horizons and reduced occupational potential was experienced.

5.4.3 Shared Theme 3: I just need to chat with somebody who understands this

Definition of the theme: Acknowledgements of the role of other people featured in the participants' experiences both helpful and unhelpful, social losses and gains and other peoples' understanding of CFS/ME.

The role other people played in the illness experiences of participants held some importance for all of them. Others were thought of as contributing either helpfully, being supportive of the men during their illness experiences, or unhelpfully, as was the case with one of Edmond's GPs whom he considered, had been useless. Those of importance who featured in their illness experiences included families, friends, girlfriends, health professionals, employers, work colleagues, teachers and members of CFS/ME voluntary support groups. Social losses and gains were also reported.

Families

Helpful and unhelpful accounts were shared linked to the role of family members in the participants' illness experiences. For the three youngest and single participants, George, Edmond and Luke, none of whom were in a long-term relationship, the practical and emotional support of their parents was important. Edmond also considered that his mum had prevented him from acting on thoughts of suicidal ideation and acknowledged the significant role she had played in his recovery:

"I relied on my mum, you know, unbelievably throughout this whole process. Without her I imagine I would still be ill now, undoubtedly. Her support was fantastic." 2/1/102 - 2/1/104.

For the remaining participants, all of whom were married and in long-term relationships, the role their wives played was important. The degree of support provided, practically and emotionally impacted upon the coping and recovery of the participants. Arnold for example, explained that his wife retiring meant she could provide more practical support with running the family home, freeing him to return to his valued work as an artist. This enabled him to re-engage in meaningful occupation and provided him with a renewed sense of well-being. Arnold attributed his remission from CFS/ME in part, to his wife's support:

"I think that ... the fact that I would consider myself in some sort of remission... now is aided by the fact that my wife is retired and is at home... I have got some more support, I have got that support again... and also the fact is that you know when she was at work... I was trying to run my business and...I had gone back to

my creative practice... so I was trying to do that from home as well as keep the house running and looking after a very old property.” 8/1/20.

For participants with school age children, Sparky and Andy, some regret over lost time and shared activities with their children was identified. An awareness that time could not be recaptured was also present. Andy regretted missing out on doing normal day to day activities and occupations associated with parenting:

“...what I really regret is, you know when the children get to this kind of age, those years just fly by and we have missed four years of doing normal things with them.” 6/1/66.

Communication between married participants and their wives was largely reported as improved over time due their illness experiences, with a greater understanding of the needs of the men eventually being realised. For both Billy and Andy, fatigue resulted in word finding difficulties, meaning at times, they were unable to express their point of view adequately. Despite this, their wives were able to understand what they were trying to say, indicating an extended and developed sense of communication and rapport. For Sparky however, sharing his experience through the research interviews, made him realise that the communication between himself and his wife could have been improved and possibly therefore, led to her having a better understanding of his illness.

This was illustrated in this quote from Sparky:

“...it’s interesting because one of the thoughts... I have had since last week is... I don’t talk about it much at home... I don’t talk about it hardly ever with my wife... I hardly ever talk about it with anyone which is probably why you are getting the full brunt of it all ...there are days where I have worked really hard here trying to do something for my business and I have done some childcare stuff... and I feel pretty rubbish and my wife is not a person who moans and she is very resilient and gets on with life but in doing so doesn’t particularly say... it’s been a bit tough you need to take it a bit easier or so you know sometimes I feel yeah you know I would appreciate a bit more sensitivity.” 4/3/9.

Edmond, who was single by choice at the time of the research interviews, suspected that only an established and strong, long-term relationship, would survive if one of the partners had CFS/ME.

Friends

Social losses and gains were experienced by some. At times, illness impacted upon their ability to participate in meeting up with friends and a lack of understanding on the part of some friends was experienced, leading to friendships being lost, as was the case for Arnold and Andy. Andy explained:

“We have one group of friends who... when we do meet them they never talk about it, it’s never mentioned particularly and I am pretty sure they don’t get it...we had quite a wide circle of friends and it was interesting to see the ones who pretty much dropped us and the ones who didn’t.” 6/1/36.1, 6/1/37.

Billy however, made new friends through joining a community support group for people with CFS/ME and George had gained new friends through family connections. Additionally, George was able to rekindle old friendships he had lost when he first became ill and made up for lost time by engaging with social media:

“I wasn’t on Facebook... I just wasn’t able to see my friends or get in touch with them really because I didn’t feel up to it...there wasn’t really many ways of doing it.....during the last couple of years I’ve got in touch with a few of them on Facebook to, to sort of make up for not seeing them during that time.” 1/1/67 – 70, 1/1/80.

Being present at social events but not being well enough to meaningfully participate was also problematic for some including Andy, Sparky and Edmond. This led to feelings of isolation and being treated differently by their friends. Their sense of belonging to friendships was therefore threatened and occupational alienation was experienced. Edmond discussed how he had made a conscious decision to end some friendships with friends he felt were unable to understand his health-related needs; an assertive and self-protecting action on his part.

Employers and colleagues

Both helpful and unhelpful employment-related experiences appeared in the accounts of participants, some of which appear in the ‘uniqueness’ section of the findings chapter presented earlier. Additionally, Arnold had experienced some bullying at work due to his illness and was aware of cultural stereotypes linked to the notion of the ‘male bread winner’. This drove him to push himself and to not take time off sick from work in order to avoid being viewed as weak by his employer:

“I would suspect particularly with men is, they are afraid of showing their weaknesses... I think it’s because society... has to say to you, you can’t do this

you have to be the strong breadwinner culturally... and society says you know you have got to be a male you have got to look after your wife your family and your kids you can't have a day off sick you got to keep on pushing through, what do you mean you feel tired, I feel bloody tired every day of the week, get off your ass and do it." 8/2/27.1

Sparky had also experienced negativity at work and mentioned the prejudicial views of some colleagues leading to feelings of occupational marginalisation:

"There is a prejudice against it, you know... it's one of those made up modern diseases and I have worked with a lot of people who make those kinds of comments." 4/2/6.

Conversely, several accounts were reported linked to supportive employers and colleagues. George, Billy, Andy and Christopher had all received help from people in their work places. Andy in particular and four years on from the start of his illness, continued to be pleasantly surprised by the degree of understanding shown to him by his employers and colleagues:

"...my workplace...have been absolutely fantastic in the way that they have dealt with me...I have... a very flexible job which means I can work at home as much as I want to... my big plus has been the attitude of my employer ... even now four years later... you start to think surely people are going to get tired of all of this and you know, there is still an understanding." 6/1/3, 6/1/10, 6/1/20, 6/3/18.

Helpful work place attitudes fostered a sense of personal value, ongoing meaningful belonging, through occupational participation, and reduced anxiety linked to altered work performance, despite enduring fatigue.

Health professionals

Encounters with the medical profession, predominantly with their GPs, linked to becoming ill, gaining a diagnosis and post diagnostic needs, were shared during the research interviews by all of the participants. Other health professionals encountered included specialist occupational therapists and psychologists. Consultations with specialist physicians were also mentioned by George, Edmond, Luke, Sparky, Billy, Christopher and Arnold and were related to processes of differential diagnosis. Prior to being given a diagnosis of CFS/ME, two participants were investigated for sexually transmitted diseases such as HIV/AIDS, two were investigated for cardiovascular disease, as they had experienced significant and acute chest pains, and three thought they may have some form of cancer.

Positive and negative accounts were reported in their medical encounters. Variability in the knowledge and skills of medics and GPs in particular, was identified in relation to CFS/ME. The two youngest participants in this study, George and Edmond, both recognised the limits of their GPs' abilities, which Edmond found very frustrating. However, Edmond's encounter with a specialist physician helped to restore his faith in the medical profession to some degree, as he felt he was treated and spoken with as an equal partner, which resulted in him being referred to a fatigue clinic for some much needed help:

"He really did talk to me on a level ... it was a relief to have somebody who actually knew what the current thinking was, talk to me about it in a fairly frank way...I had a couple of sessions with him ... at least it was a little bit of information, we had quite a philosophical discussion actually about you know the relationship between mind and body ...so we had quite a philosophical discussion on that ...which was a relief in itself ...cos of course this was the only subject that was interesting me...so it was good to have that discussion with him and I think he referred me to [name of specialist fatigue service]." 2/1/193 – 2/1/194, 2/1/196 - 199.

Some GPs were more amenable to listening to participants' accounts than others and considered their needs in a genuinely open manner. This made participants feel heard and their opinions and experiences validated. Other GPs appeared more threatened by participants' challenges to their authority, knowledge and skills. Some had their CFS/ME symptoms trivialised or ignored as GPs deferred to discussing diseases which appeared in the participants' past medical history, such as Andy's asthma, even if they were not a problem for the participant at the time of visiting their GP. Andy explained:

"There is an embarrassed silence about it... whenever I have gone down there before, at the top of their list you can see it on their screen, it says, asthma patient so they always ask me about 'oh how's the asthma' and I wish I'd say it out loud, but in my head I say 'well you ask me about something which I have told you before hasn't affected for 15 years, but the thing that's turned my life upside down for the last 4 you don't want to know about'... It doesn't appear on the screen." 6/2/13.

One GP was described as highly trusted by Arnold. This trust was established as Arnold had presented fatigue research findings to his GP who had then over-turned his original diagnosis of depression to agree with Arnold's self-diagnosis of CFS/ME. Importantly, Arnold considered that by using the correct language and dialogue to discuss CFS/ME a shared and different understanding of his illness was jointly achieved:

“You can use the right terminology... you know, there is that kind of peer to peer type stuff rather than a GP talking down to a lay person. I could actually use the right terminology to be thought of as an equal... because using the right terminology, right language you kind of, you know, I got treated differently.” 8/2/42

Trust and knowledge went hand in hand with being heard, and the importance of being believed was identified and summed up by Billy:

“Find someone who is going to believe you and support you more on the medical side... professional help... as a first start, because that’s what really helped coming down to [name of specialist occupational therapist] that was a big, big difference... believed.” 5/2/33.

Sparky also felt that support from a health professional especially in the early stages of the illness was very important:

“It’s helpful if the person who spots it is good natured and understands what’s going on and is sympathetic and accepting of it.” 4/2/5.

Trivialisation, lack of knowledge and uncertainty was unhelpful and frustrating for all and Edmond’s advice to health professionals working with people with CFS/ME included the following:

“Being told that the only certainty was uncertainty... is what makes you much, much worse and that should be, in my opinion, completely eliminated from the care cycle.” 2/2/106.

Others with CFS/ME

Prior to diagnosis, only Andy had met someone else with CFS/ME, due to his daughter having been diagnosed a year or so earlier. The rest of the participants came across others with the illness after diagnosis, via a variety of means, including friends of a family member, attendance at a community based, voluntary support group, or through attending a specialist NHS, supported self-management group treatment programme. Billy’s unique experiences of positively attending a support group appear earlier in the findings. Other participants had mixed views about the utility of meeting people with the condition. Luke had considered going to a support group but having investigated this possibility online, he thought better of it to protect himself from any possible exposure to negativity:

“I did think about joining like local support groups, but when I went on line to read about them it was very negative... people whinging and you know people who looked to be in a really bad way, a lot worse than I was and I didn’t want to surround myself with that energy... so I never joined one... I never thought it was right for me.” 3/2/34.

Similarly, whilst it may be generally assumed that meeting others with the same condition is a positive thing to do; the negative aspects of reminding oneself that something is wrong can be problematic. Andy expressed his doubts about attending a NHS fatigue group programme, regardless of acknowledging the need for some specialist input:

“This is going to sound awful... I didn’t want to hear people moaning... because I couldn’t deal with it...” 6/3/56.

Sparky also found the same group programme dragged him down, but some ambivalence was demonstrated as he also acknowledged that support of some sort was required and therefore, still attended:

“... one of the great things about the group is that you feel less isolated... there’s a fine balance... when I was in the group, sometimes I would get frustrated because I would think ‘this could become a little bit of a moaning shop if we are not careful for everything that’s wrong about having ME’ and then the benefit system... and you don’t want to get dragged into that.” 4/2/53, 4/3/28.

The dilemma of needing to gain support along with the need to protect themselves from negative thoughts and encounters was also common to other participants.

5.4.4 Shared Theme 4: A big part of any person’s identity is their physical and mental well-being

Definition of the theme: Perspectives of the impact of CFS/ME on participants’ self-identity, self-control and “being-in-the-world”.

For several participants, a loss of their former way of ‘being-in-the-world’ impacted on notions of self-identity and any potential for recovery. For Edmond, Sparky and Arnold an acknowledgment of the need to actively lose any pre-illness self-identity was seen as facilitating an acceptance of their condition and enabled health and well-being through a re-calibrating of their day to day lives and occupations. Sparky suggested:

“I think for me it’s about recalibrating... recalibrating your activities and out of that comes your recalibrating your friendships.” 4/2/24.

Similarly for Edmond:

“If you’re going to recover, you have to recalibrate a lot of things... and that, part of that, involves... you have to clear the slate as much as possible of your former life, I’ve found.”

2/2/33.

Rejecting a once anticipated notion of self, was upsetting for Luke who could no longer use the word 'career', as he had lost any control over becoming what he had aspired to be due to his illness:

"I don't like using the word career in this particular time in my life because of everything that's happened... but there was a time where I... had aspirations for a longer career which you know I don't really think about that too much anymore... and it's also kind of like a pointless thought to have because I know that unless this improves that's not something I can do so I am working myself up about things that I don't really have any control over... at the moment." 3/2/6.1.

Luke described his need to live in the present as *"it's like a mental safety net"* 3/4/40, to prevent further mental toll and disappointment with his life-world.

Unlike Luke, Sparky was someone who had already enjoyed success in his professional career before he became ill. This success however, was lost due to his illness. Sparky's grief over the consequences of this loss not only applied to his career, but also impacted upon his sense of self-worth and identity as a father:

"I have lost not only a job, I have lost a career and with that career I think, comes a sense of identity and self-worth... it's that feeling of value and worth... there has been a massive change and I think I mean midlife crisis it's not really that, but I think there is an identity crisis you know. I have always been conscious of what my children think of me as their dad." 4/2/31.

Additionally, Sparky was keen to be identified as an individual, rather than by his illness. This was something that concerned him about being part of a cohort of patients attending a specialist fatigue programme:

"I think... about your personal definition of yourself, your own being so... one of the things I try really hard to do is not be defined as somebody with ME or CFS... there is a whole personal thing, then there's the very sort of practical how you live your life on a day to day basis." 4/1/4.

Andy also struggled with his self-identity caused by the disruptive nature of CFS/ME which is illustrated in the quote below:

"I'm constantly aware of my status as being ill if that doesn't sound too peculiar." 6/3/2.

A desire for control over day to day life and activities was of particular interest to Edmond, who along with one of his male friends referred to this need as the male anorexia. Loss of

control was associated with loss of self-identity and Arnold used the metaphor of mask wearing which he employed to conceal his notion of illness identity from others. The need for control over his life he felt, stemmed from his all or nothing approach to being and doing. Through working with a specialist psychologist however, he was able to better understand his CFS/ME and rebuilt a more favourable sense of self:

“Everything had to be 100% or it was worth nothing... and I think from dealing with the psychologist attached to the clinic, gave me a very different take on... my understanding of my CFS/ME... talking to the psychologist at the clinic was very... very useful... it almost took me apart brick by brick and put back a new edifice, a new building.” 8/1/35 – 35.1.

Notions of emasculation due to CFS/ME, was mentioned by Edmond, Sparky and Andy. Emasculation was attributed to not being able to do all the activities they had wanted and needed to do such as exercise, mountain biking or providing financially for others. At one point in his illness trajectory, Andy was concerned that he was not having any impact on the world and represented this through his tent painting which can be seen in the image below:

Figure 18: Andy's Tent Painting *"There is no shadow... probably because I am not having any impact on the world."* 6/3/38.



Andy described how feelings of emasculation were beginning to diminish for him as he began to be able to do more for his family:

“Even a year ago, I would have still [been] thinking that I may not be able to carry on working, so there has been a considerable... improvement... and... I am stable where I am at the moment ...I am starting to do more things which makes me feel better, because you know you feel terribly oh... is emasculated the right work I am not sure?” 6/1/28, 6/1/58.

Luke was also aware of traditional cultural expectations he was unable to live up to in terms of being a young male and the associated and socially constructed norms linked to anticipated life milestones and occupations. He summed this up below:

“I think what I used to get worked up about... was... cultural expectations and how... I wasn’t meeting those and...there are societal expectations for a young man in his 20s, things he should be doing, you know working having a career, relationships, getting married, things along those lines and you know, I have not been able to do a lot of those things because of this condition, the diagnosis etc., but they are very real expectations and people do, I believe anyway, treat you differently, if you don’t meet that set criteria of what people have in their mind as being almost the norm.” 3/4/19.

Reflexivity and the study focus: notes taken from my research journal 2015

By adopting an open phenomenological stance I was able to reflect that masculinity was mentioned far less than I had anticipated. Co-creating understandings with participants about living with CFS/ME in a unique and contextualised manner, ensured that I remained open to the encounter rather than concerning myself with issues I had pre-judged, as potentially being of most relevance to the men. The exciting thing about conducting interpretive phenomenological research is the opportunity to simply ‘be with another’ and generate new understandings which was very liberating. I considered that not needing to look for or attend to pre-determined theories or models during the interviews enabled a genuine rapport to develop between myself and the men. This was both enjoyable and illuminating as we discovered new things together about the meaning of living with CFS/ME for the benefit of others and clinical practice.

For Sparky, a lack of self-esteem due to his illness, impacted negatively upon intimacy with his wife:

“I just feel less... not less warm but I can’t think of the expression... less comfortable being... there is a slight self-embarrassment almost... I am just not that you know, I am not that great. I am not that attractive... you know and all that sort of thing... and again it gets back to that you know, when people say ‘oh you

look rough' or 'you look tired' and you think yeah, yeah I'm not that sort of robust."
4/3/16.

Andy and Arnold also shared horizons of experience linked to intimacy with their partners. Both of them acknowledged that sexual intercourse was not as important in their relationships as supporting each other emotionally and practically.

Doing for participants' was collectively valued and associated with mastery particularly of their condition. This was inter-related with their 'being-in-the-world' in terms of enabling participants' to become who they wanted to be and notions of occupational identity (Jakobsen, 2001; Laliberte-Rudman, 2002 and 2008). Occupational identity provided a sense of belonging to their culture and the importance of occupation and its impact on positive health and well-being was identified.

5.5 Summary of the Chapter

Findings were presented, both unique and shared, of the meaning of the experience of living with CFS/ME for eight men of varying ages. These included what it meant for the men in terms of their self-identity, day to day lives and occupations expressed through a variety of dialogic forms. Examples of occupational disruption, deprivation, alienation, marginalisation and injustice appeared in the findings. The impact of having CFS/ME on notions of masculinity, life transitions and the positive impact of self-imposed social isolation also appeared.

The findings will now be explored further in the discussion chapter. Findings will be used to corroborate what has been identified in the background literature review in Chapter 2.

In order to acknowledge and reflect the synergy between philosophical and occupational orientations to the study, findings will be discussed in relation to the men's 'being with CFS/ME'. Their associated 'doing' or occupations, 'belonging' and 'becoming' will be discussed and contextualised as domains of their 'being'. Furthermore, the impact of their collective 'being, doing, belonging and becoming' will be discussed in relation to their subjective sense of health and well-being.

Chapter 6:

Discussion

6.0 Introduction

In this Chapter I begin by summarising how I began to understand participants' experiences of living with CFS/ME. The findings from this study are unique as they are interpretations specifically of the lives of men with CFS/ME, something which has been missing to a greater degree from the literature to date. Findings are critically discussed in relation to the previously reviewed literature in Chapter 2. This comprises the adult literature, reviewed in Step 1, in which participants were predominantly women, and also the limited amount of men's data, extrapolated from these studies, in Step 2. New knowledge is listed firstly in tabular form. This is then discussed in relation to the background literature and the wider context and framed in a novel way, to reflect the synergy between the philosophical and occupational orientations/frameworks employed. Unique findings are therefore discussed in the first instance, in relation to the meaning of men's 'being-with-CFS/ME' and secondly, their associated 'doing' or occupations. Notions of 'belonging' and 'becoming' are discussed and contextualised as dimensions of their 'being'. Additionally, their 'being, doing, belonging and becoming' is discussed in relation to their subjective sense of 'survival' and 'health'. Within these headings original findings are presented to add to the body of knowledge linked to men's experiences of living with CFS/ME.

A conceptual illustration is presented to summarise how the inter-related concepts of 'being, doing, belonging and becoming' are disrupted by the presence of CFS/ME, to assist occupational therapists and others, to better understand the lived experiences of men with the illness. Findings are also considered in terms of implications for clinical practice and how these might be addressed. The chapter concludes by exploring the strengths and limitations of the study and suggestions for future research are made.

6.1 A summary of how experiences were understood

The experiences of the participants in this study were understood by using an interpretive phenomenological methodology and by me adopting an open phenomenological stance throughout the research process. Working in a respectful, empathic partnership with

participants and seeking to 'break-open' the being of the 'other' (Gadamer, 2004), the opportunity for me to better understand men's experiences of living with CFS/ME was possible. Acknowledging my clinical prejudgements contributed to this. For example, I was mindful that troublesome fatigue may have been a possible barrier to effective communication and took care therefore not to over-tire participants throughout their involvement in the study, by suggesting a paced approach to data collection. Trust and rapport was built with the men by negotiating multiple interviews over time, and by engaging in various forms of dialogue, a fusion of horizons was made possible. Dialogue included mostly talking, attention to non-verbal body language and unexpectedly, Andy's poetry and artworks. These serendipitously produced forms of data were fascinating to discuss with Andy and authentically represented his distress, loss, anger and his fragmented sense of self, and his 'being-in-the-world' with CFS/ME.

During the research interviews Gadamer's (2004) concept of effective historical consciousness came into play for the participants and also for me. This was demonstrated as horizons of past experiences were shared and then reinterpreted in the interviews (the present) and with reference to future possible 'being'. Participants for example mentioned how our discussions had changed their interpretations of the meaning of their experiences. This was illustrated by Andy who had not realised until our encounters what his paintings really portrayed and had enjoyed exploring their meanings with me. A further example of effective historical consciousness was provided by Sparky, who through engaging in the interviews, realised he did not speak much about his illness at home. This led him to recognise a future need for more emotional support from family members.

Inner horizons in terms of beliefs, values, aspirations and motivations linked to CFS/ME and their 'being, doing, belonging and becoming' were shared by all of the men. Outer horizons linked to CFS/ME and cultural factors, what Gadamer (*ibid*) refers to as 'tradition', were also discussed. Outer horizons were expressed as the men's expectations of interactions with their surroundings and how these had played out and might do so in the future. Outer horizons expressed included, for example, the concerns Luke and Sparky had about future career possibilities due to the negative attitudes and actions of some of the employers they had encountered.

Experiences were understood hermeneutically by paying attention to the details/parts of the men's accounts and interpreting these within their broader context. For example, when George was first struggling with symptoms of fatigue he sadly lost touch with his good school friends meaning they were unaware of his illness. This was because he became ill

during the GCSE exam period and consequently the friends only saw each other if and when they went into school to sit exams at the same time. If they had been attending school routinely however, they would have learned that George was ill and provided him, he felt, with some much needed social support. Importantly, understanding the meaning of living with CFS/ME for the men involved in the study was achieved through acknowledging 'being with CFS/ME' as an holistic experience. That is, between us we did not consider that their illness was purely physical or psychological in nature in some dualistic fashion; but instead, involved and impacted upon the whole person over the course of their illness trajectory. All of these factors contributed to my understanding the meaning of living with CFS/ME for the eight participants involved and enabled rich, in-depth data to be co-created.

6.2 A critical consideration of the findings in relation to the literature

Interestingly, all but two of the findings identified previously in the literature review in Step 1 (adult literature focussing predominantly on women's experiences) and Step 2 (extrapolated men's quotes from Step 1) are supported by my study. In both steps of the review, I thematically synthesised findings into three themes, they were:

- Theme 1: difficulties with the negative impacts of becoming ill
- Theme 2: the period of time around diagnosis
- Theme 3: experiences of living with CFS/ME

Each of these themes will now be discussed critically in relation to my findings and contextualised within the wider literature.

Theme 1: difficulties with the negative impacts of becoming ill.

The impact of becoming ill on physical, social and economic domains of life prior to diagnosis was identified by several of the men in my study and also in the background literature linked to adults with the illness (Anderson *et al.*, 2012). Whilst it may be reasonable to assume that the impact of becoming ill would be experienced similarly by men and women with CFS/ME, these authors made no mention specifically of men's accounts to support such a claim. They did however; acknowledge the need for additional qualitative research to be conducted to capture self-perceptions of adults' experiences of living with CFS/ME, in order to improve health care practitioners understanding of social

marginalisation. Subsequently, in 2014, Anderson, Jason and Hlavaty published findings, reporting on the experiences of sixteen women and three men, from which, I was able to extrapolate data linked specifically to the experiences of two men, in the form of verbatim quotes. In the quotes, the suggested possible cause of becoming ill, was given by one man as a death in his family, and by the other, as the stress of coming-out as gay. These were the only two findings identified in the background literature that were not explicitly corroborated by my own. Whilst it is acknowledged in the wider literature that the causes of CFS/ME are not yet fully understood (Prochalska, Gressier and Corruble, 2012), exposure to significant emotional distress is suggested as a possible predisposing, precipitating or perpetuating element linked to an increased risk of illness development (Afari and Buchwald, 2003). Given this evidence therefore, it is reasonable to suggest more generally, that for some men with CFS/ME, death of a significant other and the possible impact of loss on many levels, including emotionally, economically and physically, may contribute in some way to illness development. Similarly, significant changes to notions of 'self' due to a move away from culturally dominant notions of 'masculinity' (Featherstone, Rivett and Scourfield, 2007) and a deviation towards un-masculine behaviour (Evans, *et al.*, 2011), as may be experienced when coming-out as gay, may contribute to increased distress and precipitate the development of CFS/ME symptoms and subsequent diagnosis for some.

Other difficulties around becoming ill and reported in the background literature were linked to beliefs about symptoms perception. These included attributing the development of physical and mental fatigue to the ageing process, in the extrapolated data of one male participant in the Arroll and Senior (2008) study. Similarly, in my own data, Billy and Christopher considered that natural ageing might have caused their symptoms and did so, in an attempt to understand negative changes to their well-being and health. Trying to normalise symptoms in this way could impact negatively on the individual, and result in a delay in gaining a diagnosis of CFS/ME. This is a matter of concern, as timely access to helpful interventions is missed (NICE, 2007), whilst day to day lives, roles, routines and occupations are significantly disrupted by the presence of chronic and fluctuating symptoms (ME Alliance, 2005).

Problems with health professionals and others trivialising fatigue symptoms during the onset of illness were reported in the background literature (Dickson, Knussen and Flowers, 2007; Larun and Malterud, 2007) and also in my own study. Illustrative of these

findings in the wider literature, was the suggestion that medical students needed to better understand CFS/ME within a biopsychosocial, rather than a biomedical framework (Stenhoff, *et al.*, 2013). Misunderstanding of CFS/ME and the consequential delegitimising of patients experiences by medics was also reported by Dickson, Knussen and Flowers (2007). These authors conducted a study into the experiences of three men and eight women and usefully included three verbatim quotes, one from each of the male participants. These data made mention of symptoms of fatigue being attributed to depression, which had also been experienced by Arnold and others in my study. Whilst the role of distress is acknowledged as potentially leading to the development of CFS/ME as mentioned (Afari and Buchwald, 2003), caution needs to be observed by health practitioners, to ensure that we do not automatically assume that depression is ontologically prioritised over a possible diagnosis of CFS/ME. In my study, Arnold firmly believed that he had experienced CFS/ME symptoms first, and as a consequence of this, his mood had become lowered, as he was unable to be his usual-self or do all he wanted and needed to do. Arnold's belief meant he had assertively challenged his GP's initial diagnosis of depression, which was then overturned to a diagnosis of CFS/ME. This I consider is an illustration of a genuine dialogue being had between patient and clinician, where both listened to, and were heard by, the other, and consequently, a fusion of horizons (Gadamer, 2004) was made possible.

The trivialisation of fatigue symptoms and the consequent stigma experienced by patients was also reported in the systematic review by Larun and Malterud (2007). Additionally, the negative impact of symptoms on day to day life was reported (*ibid*). However, whilst the review comprised twenty qualitative studies, none of these were linked specifically to men's experiences and therefore, no data were reported on to identify a male perspective. Whilst it is reasonable perhaps to assume that experiences may have been common to both men and women, based on my own pre-judgements, some caution needs to be observed in terms of the credibility of these findings. This is important to consider as participants included in many of the studies were recruited from community support groups. This may have meant therefore, that adults without a clinically confirmed diagnosis of CFS/ME and/or perhaps a variety of other illnesses were included in the review, unlike the participants in my own study.

The lack of a common dialogue or label to name CFS/ME is reported in the previously reviewed literature (Ware, 1992) and in the experiences of some of the men in my study.

The importance of dialogue to aid understanding (Gadamer, 2004) I consider, supports this claim, for people with frequently misunderstood and fluctuating symptoms of CFS/ME. Although Ware's (1992) study failed to report specifically on data linked to the experiences of the ten men included in the study sample of fifty, given the ongoing academic debates linked to the contentious nature of CFS/ME, diagnostic criteria and labelling (de Carvalho Leite *et al.*, 2011; Anderson *et al.*, 2012; Christley, Duffy and Martin, 2012; Prochalska, Gressier and Corruble, 2012; Anderson, Jason and Hlavaty, 2014; IOM, 2015), it is reasonable to assume that this is an issue for men and women experiencing enduring fatigue symptoms and findings were therefore, considered as transferable.

As a consequence of experiences linked to becoming ill, a crisis of self-identity was reported in the background literature along with the need to adapt daily activities to achieve and improve self-worth (Dickson, Knussen and Flowers, 2008). These findings supported my own in terms of loss of occupational identity (Christiansen and Townsend, 2011) and the need for occupational adaptation (Schkade and McClung, 2001) in order to accommodate the presence of fatigue symptoms. Included in the Dickson, Knussen and Flowers (2008) study were the experiences of four men with a clinically confirmed diagnosis of CFS/ME as per Fukuda *et al.* criteria (1994). These findings were therefore, considered as a more trustworthy source of data than several others in the literature review, where self-selected participants were recruited from attendees of community support groups experiencing therefore perhaps, potentially heterogeneous illnesses and health related issues as previously discussed.

Theme 2: the period of time around diagnosis

Extrapolated quotes from male participants were reported in the literature linked to the period of time around diagnosis (Cooper, 1997; Dickson, Knussen and Flowers, 2007) and were supported by my findings. Similarities in data included men, such as Andy, Christopher and Arnold, experiencing inequitable treatment of their fatigue, and their human rights being threatened as disease ontologies, including asthma, acid reflux, alcoholism and depression, were prioritised by medics during GP visits. Positive and negative challenges to medical authority (Cooper, 1997) and delays in diagnosis causing distress and 'anomie' (Dickson, Knussen and Flowers, 2007) also resonated with my findings. Although not termed as 'anomie' by the participants in my study, feelings of rejection and notions of occupational marginalisation (Christiansen and Townsend, 2011) akin to the concept of 'anomie' were identifiable. Additionally, and although not attributed

specifically to men's experiences in the literature, considering the diagnostic point as the start of illness experience as opposed to the end (Arroll and Senior, 2008) was similarly reported in my study. For Sparky, gaining a diagnosis enabled him to begin tackling living with CFS/ME and made some sense of the illness chaos he had experienced prior to this.

Theme 3: experiences of living with CFS/ME

Synthesised data linked to the experiences of adults in Theme 3, were also corroborated by my findings. Data included experiences of fluctuating health (Arroll and Howard, 2013) and specifically, for one man, feelings of loss including, loss of 'old-me', loss of career and impact on self-identity. This rigorous study had resonance with my own, as parallels between occupational identity (Christiansen and Townsend, 2011) and notions such as 'you are what you do', death of the 'old-me' and birth of the 'new-me' were also included in my findings. These were linked in particular to the experiences of Edmond, Luke, Sparky, Andy, Christopher and Arnold, whose 'being, doing, belonging and becoming' was disrupted due to the presence of CFS/ME. The importance of adapted role-restoration or discovery of new, meaningful occupations as being vital to positively influencing health and well-being, were also reported in the previously reviewed literature (Arroll and Howard, 2013). This supports the findings of my own study as illustrated by Edmond, who through his mastery of pacing, claimed he was cured of his CFS/ME. Additionally, for Andy, through serendipitously discovering his interest in painting, used originally to express chaotic 'being', the discovery of a new and meaningful occupation was made.

Acceptance of the illness and post traumatic growth (PTG) for some was included in the adult literature review (Anderson, Jason and Hlavaty, 2014) along with strategies to balance activities by using activity reduction. In my study, Edmond in particular, mentioned that living with the illness had not provided him with any significant gains in terms of personal growth. He did however discuss an acceptance of his illness and had employed activity reduction in the form of pacing, which he considered, enabled him to regain control of his occupations and recover from his illness. The Anderson, Jason and Hlavaty (2014) study however, focussed largely on the experiences of sixteen women and failed to report any data on acceptance or PTG for the three male participants. The authors however, proclaimed a feminist perspective and mentioned that medics tended to dismiss women's accounts of CFS/ME. This may therefore have been the rationale for the limits of their reporting.

An issue reported in the background literature and discussed at length by the men in my own study, was the importance of having physical, economic and emotional support from others. Support from families and friends and the need for shared decision-making with health practitioners was suggested, leading to co-ordinated action to ensure adequate treatment provision and maintenance of human rights (Dickson, Knussen and Flowers, 2007; de Carvalho Leite *et al.*, 2011). Both of these studies again focused predominantly on the accounts of women and included limited verbatim quotes from male participants. The more methodologically rigorous of the two studies by de Carvalho Leite *et al.* (2011) interestingly included a quote from one man who reported he had needed “*complete care*” to deal with his illness. This resonated with Edmond’s experiences of being severely affected by CFS/ME and his need for his mother’s care, without which he considered, he would not have survived his illness.

In summary, the findings identified in the previously reviewed literature in Step 1, are mostly corroborated by my own. Extrapolated findings from the Step 2 of the review, specifically linked to **men’s** accounts, are also supported by my own. Only two existing findings linked to the potential causes of CFS/ME by Anderson, Jason and Hlavaty (2014) did not appear in my data. These were reported as the development of the illness being linked to the death of a family member for one man, and the stress of coming-out as gay for another (*ibid*). A summary of the existing knowledge linked to men’s experiences and corroborated by my findings are listed in Table 12:

Table 12: Corroborating existing literature linked to experiences of men with CFS/ME

Corroborating existing literature
• Negative and positive experiences reported with GP and delays in diagnosis
• Disease ontology prioritised over illness
• Normal ageing process considered as a possible cause of symptoms
• Depression given as diagnosis before CFS/ME but contended by patient
• Challenges to GP authority
• Difficulties with others trivialising illness
• The need to understand what is going on with their bodies
• Loss on many levels including of control over body and life & can't do what you want to do
• Loss of self was described as death of old me
• Deligitmacy and stigma experienced
• Support from others important
• CFS/ME support group helpful
• Feelings of 'otherness' identified when in social situations
• The fluctuating and unpredictable nature of the illness
• Adaptation of daily activities improves well-being
• Restoration or discovery of meaningful occupations impacts positively on health and well-being & you are what you do
• Medical and social inequity for people with CFS/ME and notions of occupational identity and occupational balance recognised

New findings identified from my study are now presented and critically discussed.

6.3 A critical discussion of new knowledge and men with CFS/ME

I have made explicit the new knowledge generated from my study to identify my original contribution to the current dearth of literature linked to the experiences of men living with CFS/ME. In Table 13, a summary of new findings are firstly listed and then discussed within a fusion of philosophical and occupational orientations/frameworks, the relevance of which is presented in section 6.3.1 below.

Table 13: Men and CFS/ME, new experiences in summary

<u>New</u> knowledge generated by this study
• Possibility of near death or life threatening illness experienced
• No explanation given for near death
• Experience of being diagnosed in adolescence
• Trivialising own symptoms
• Memory not affected
• Cured of CFS/ME using pacing
• A 'university illness'
• Considered social isolation as positive
• Missed illness as saw it as a gap year which was enjoyable
• Relocation geographically due to economic and other support needs
• Ended a relationship with attractive woman as reminded of negative image of self/emasculatation
• Blame for delay in diagnosis accepted by self as opposed to health professionals
• Concerns would be judged as having few prospects by women impacted on relationships
• Feelings of being treated unlawfully in terms of applying for jobs; whilst off sick and having to reapply for own job due to departmental reorganisation
• Ambivalence re attending treatment programme and negative identity
• Impact of illness reduced as near to usual life transition point i.e. retirement anyway so less of a blow/loss
• Retirement plans/occupations & transition couldn't be followed
• Wife knew it was CFS/ME before medics
• Dad became ill sometime after his daughter was diagnosed with CFS/ME
• Expressed experiences via poetry and artwork
• Possibly contracted illness following mass outbreak of nausea, vomiting & diarrhoea in service barracks
• Careful use of alcohol to assist with sleep & judged as having a drink problem by GP
• Otherness experienced in social situations

In the next section of the chapter priority is given to discussing new findings framed within a fusion of philosophical and occupational orientations/frameworks. Existing findings are acknowledged in the discussion as appropriate to provide context.

6.3.1 The relevance of fusing Gadamerian and occupational frameworks

I propose that the synergy between Gadamer's philosophical framework and that of occupation is reflected in the literature and that, occupational therapy and occupational science have closer links with philosophy than we have yet to fully realise. If we assume that all understanding of human experience is dialogical as Gadamer (2004) suggested, these links are demonstrated in the following quotations:

Philosopher:

"It is true of every conversation that through it something different has come to be."
(Gadamer, 1976 p. xxii).

Links with

Occupational Therapist:

"Occupational therapy practices are highly dependent on finely crafted intersubjective processes of interrelatedness and the narrative structuring of experience and social action."
(Lawlor, 2012 p. 153)

And

Philosopher:

"Being that can be understood is language." [Spoken and written forms].
(Gadamer, 2004 p. xxxi).

Links with

Occupational Therapist:

"Reading takes time and imagination, reflection and interpretation; only then can the possibilities for meaningfulness and new understandings of life's deepest experiences be realised."
(Hasselkus, 2011 p. xiii).

These quotes illuminate the importance of dialogue and its role in enabling different and new understandings of human experience to be shared in the inter-subjective space (Gadamer, 2004), that is, the space between 'self' and 'other', by both philosophers and occupational therapists. I suggest that the relevance of Gadamer's philosophy to

occupational therapy practice and occupational science, may usefully be explored by considering Wilcock's (2006) definition of occupation which she abbreviated to: 'doing, being, belonging and becoming equals survival and health' or **d + b3 = sh**. In this definition, 'being' is considered as a component or dimension of 'doing'. However, mindful of the main research question in this study, the meaning of living with CFS/ME for the men involved, is discussed by addressing firstly their 'being-with-CFS/ME', followed by dimensions of their 'being' in terms of their 'doing', 'belonging' and 'becoming'. Presenting the discussion in this way is unique and adds to the body of knowledge linked to men's experiences of 'living/being-with' the illness and provides new ways of knowing about their 'occupations' (Whiteford and Hocking, 2012) or 'doing'. Additionally, the impact of the illness on their 'belonging' and 'becoming' and their subsequent self-perceptions of survival and health are addressed. Exploring these concepts in this way also adds to the body of knowledge in occupational therapy and occupational science advocated by Hammell (2014) who suggested that:

"The configuration of doing, being, becoming and belonging is often named in the occupational therapy literature, but there has been little apparent effort to explore the intellectual origins, theoretical parameters, or practical relevance of these concepts to either occupational science or occupational therapy." (Hammell, 2014 p. 40).

By framing the meaning of living with CFS/ME in this original way, I pay attention to the following concepts in order:

Being, doing, belonging and becoming = survival and health or **b + d + b2 = sh**.

Choosing to prioritise 'being' re-orders the dimension of focus for occupational therapists and shifts the importance of our need to understand men's experiences of 'being-in-the-world' with CFS/ME, in order to subsequently better understand how this impacts upon their 'doing/occupations', 'belonging', 'becoming', 'survival' and 'health'. New knowledge will now therefore, be critically discussed within this conceptual framework.

6.4 Prioritising 'being-with-CFS/ME' before 'doing, belonging and becoming'

Due to the contentious and heterogeneous nature of CFS/ME (Fry and Martin, 1996; Prins, van der Meer and Bleijenberg, 2006; Prochalska, Gressier and Corruble, 2012), I considered that the importance of focusing on 'being' with the illness before 'doing' should be a priority for occupational therapists and other clinicians, to ensure occupationally just practice (Durocher, Gibson and Rappolt, 2014). As mentioned in Chapter 1, CFS/ME has been, and still is, misunderstood in our culture by some health care practitioners and the general public (NICE, 2007). The importance therefore, of achieving Gadamer's Level 3 dialogue (Gadamer, 2004) is vital to ensure patients feel truly heard in equal partnership, particularly with clinicians. Entering into a partnership to explore the individual's 'being' I believe can facilitate trust and rapport-building and legitimation of individual accounts. Additionally, paying attention to an individual's 'being' first, I suggest, enables practice to be truly client-centred in the spirit of shared care (Coulter and Collins, 2011), a value at the heart of our humanistic profession (Wilcock, 2006) and resonant with Gadamer's humanistic philosophy (Grondin, 2003). For these reasons 'being-with-CFS/ME' and addressing its disruptive nature will now be discussed.

6.4.1 'Disrupted being' with CFS/ME

For all of the men in this study their day to day existence had been significantly disrupted at some point during their illness trajectory (Gerhardt, 1990). All of them, apart from Luke had experience of being severely ill with CFS/ME as described in the NICE Guidelines (2007). This had meant that their 'being' became unfamiliar to them; they felt different in terms of their physical bodies and also became aware that their cognitions and emotions were changeable and unreliable at times. This sense of unfamiliarity may be considered as 'occupational alienation', where a sense of estrangement from others and the 'self' is experienced (Christiansen and Townsend, 2011). These feelings caused stress and fear for some and was described by Edmond as a sense of 'otherness'. Otherness was linked to an altered notion of self-identity. Their usual 'self' then seemed inaccessible as they were unable to identify the sense of 'self' held prior to becoming ill. Wanting familiarity with their usual self but not being able to achieve this led to feelings of unhappiness and low mood. Several of the men were keen to stress that their mood was lowered as a consequence of being ill rather than because of having depression in the first instance which also supports background findings (Dickson, Knussen and Flowers (2007). Their desire to change their altered sense of 'self' was difficult as the presence of troublesome and unpredictable symptoms (NICE, 2007) took away their control of their bodies,

emotions and cognitions. For Andy, this resulted in an embodied sense of an illness identity, something reported in the literature by others with troublesome long term conditions (Carel, 2008). His illness, he felt, defined who he was rather than being his usual 'self'. Loss of 'self' for most of the men had meant at times feeling lonely and socially isolated.

Uniquely, trivialisation of his being with CFS/ME was made by Sparky who despite being seriously ill and admitted to an intensive care unit, still felt he would be "*found out*" that it was only CFS/ME and be asked to leave. His culturally embedded notion of being ill enough to be admitted to ICU was at odds with his 'being-with-CFS/ME'. This is interesting as no definitive cause for the severity of his illness was ever provided meaning uncertainty surrounded his 'being' and caused him some ongoing apprehension in day to day life.

6.4.2 'Emasculated being'

Guilt was experienced for not being able to fulfil role expectations of self or others and included difficulties with being a good parent for Andy and Sparky in particular, a good husband or a reliable employee. Findings were linked to concerns about not being able to be a 'bread winner'. This role links strongly with socially constructed meanings of masculinity and its associated social responsibilities (Evans *et al.*, 2011). These meanings resonated with the concept of "*precarious masculinity*" (Featherstone, Rivett and Scourfield, 2007, p. 125) where notions of being 'less male' may prevail and valued roles are threatened. More specifically, Edmond, Sparky and Andy had experienced feelings of emasculation when comparing themselves to traditional and dominant constructs of masculinity (Connell and Messerschmidt, 2005). This culturally embedded notion meant that even if they were unable to conform to this they still judged themselves by it and, as described in the masculinity literature, considered others might do the same (Conrad and White, 2010). Feelings of emasculation were mentioned by only three of the men. However, based on my pre-judgements I had expected this to be discussed by more of them.

6.4.3 'Traumatised being'

New meanings linked to 'being-with-CFS/ME' included the horizons of George, Sparky, Billy, Luke, Christopher and Arnold who had all potentially faced death due to the type and severity of the symptoms they experienced and possible alternative diagnoses. The impact of significant illness experience without diagnosis can be particularly stressful

(Charmaz, 1997). Being close to death and surviving such a trauma was still distressing for the men even many years after the events. The possibility therefore that some of the men may have been suffering with Post Traumatic Stress Disorder (PTSD), I consider, should be acknowledged. Whilst there is emerging evidence linked to the association of PTSD in people with chronic pain (Brennstuhl, Tarquinio and Montel, 2015) evidence of its presence in people with CFS/ME is lacking. Interestingly however, people with CFS/ME may frequently experience associated chronic pain (NICE, 2007). This evidence may therefore have some relevance to men with CFS/ME. Additional literature linked to an increased risk of PTSD development in adults who were bullied during childhood (Idsoe, Dyregrov and Idsoe, 2012), resonated with the experiences of two of the men in my study. Both Christopher and Arnold had been physically assaulted in childhood by their step-father and father respectively. Assaults included being so severely punched in the face to the point where there was blood loss. Christopher had speculated during his interviews as to whether this had made him more susceptible to developing CFS/ME in adulthood. Interestingly, he had also noticed that in the presence of his step-father more recently, he still flinched as he walked past him. Christopher's reactions may perhaps be indicative of some degree of PTSD. For Sparky, the need to be admitted to ICU had caused him a degree of psychological trauma. He also experienced some distress and guilt at not being able to be the parent he wanted to be some four years after the traumatic event. Some evidence to support the development of PTSD in men, such as Sparky, who harbour feelings of guilt, appears in recent literature (Lancaster, Melka and Rodriguez, 2011). Furthermore, the development of PTSD in people with chronic health conditions who have experienced significant trauma is also reported (Sledjeski, Speisman and Dierker, 2008). This evidence I consider may usefully be explored further in terms of the possible existence of PTSD in men with CFS/ME.

6.4.4 'Authentic' and 'inauthentic being'

An awareness of 'authentic' or 'inauthentic being' was explored in the dialogue shared with the participants. For Arnold the meaning of 'inauthentic being' was linked to his description of wearing many masks over the years in various social situations, but particularly in his work setting. Through employing effective historical consciousness (Gadamer, 2004), Arnold reflected that he had frequently been someone different to his authentic self because of CFS/ME, but this was now no longer the case. Inauthentic being was adopted at times to conceal how ill he was from his partner and also his friends, to prevent them from being worried about his health or perhaps, judging him as not being able to cope with daily life. After many years of struggling with the illness however, Arnold

had developed self-confidence and resilience enabling him to be more authentic in his day to day 'being'.

6.4.5 'Being-in-the-world' without adequate dialogue

Apart from the much publicised issue of inconsistent labelling of the illness cited in the background literature in Chapter 1 (Cohn, 1999; Prochalska, Gressier and Corruble, 2012), difficulties were expressed by participants when they were asked to describe CFS/ME. Finding what they considered to be 'representative dialogue' was a struggle. For George there were no words and for others like Edmond the illness was likened to the metaphor of an unknown force or a beast to be battled. Others, like Christopher, acknowledged that the complexity of the illness made it difficult to accurately and adequately describe. Given the historic controversy linked to the illness (ibid) this is perhaps not surprising. In Gadamerian terms culturally embedded language shared with others facilitates understanding (Gadamer, 2004). This was, and is still, not the case for people with CFS/ME. Interestingly and in the absence of access to adequate verbal dialogue to describe the illness, the use of poetry and artworks such as Andy's might be a more appropriate form to adopt. The content of Andy's poem in Chapter 5, sub-section 5.3.8 expresses what Christiansen and Townsend (2011) described as 'occupational alienation', desperation and the all-encompassing nature of his experience of illness. As Gadamer (2004) proposed and Andy had discovered, nothing more truthfully represents human experience of 'being' than artworks. In hermeneutic terms (Cohen, Khan and Steeves, 2000), Andy's paintings invite the interpreter to describe what they see when looking at the parts and by stepping back to view the whole. His tent picture in Chapter 5, sub-section 5.3.8 for example, is a poignant illustration of how his sense of 'being' is missing, represented by the absence of his tent's shadow as compared to others. Additionally, his 'Bits of the World' painting in the same sub-section of the thesis, clearly represents his fragmented sense of self and his life-world in a much more potent way than perhaps words alone could do. The use of artworks in this way contributed importantly to Andy's constructing and reconstructing his sense of self through occupation (Carlson *et al.*, 2014). The use of artworks is reported in the academic literature as useful in terms of exploring the subjective meaning of well-being for women with CFS/ME (Reynolds, Vivat and Prior, 2008). However, the use of artwork linked to men's experiences has not yet been reported in the literature.

Having firstly explored the men's 'being-in-the-world' with CFS/ME, their 'doing' or occupations will now be discussed.

6.5 'Doing-with-CFS/ME'

'Doing' considered inter-changeably as occupation, was significantly disrupted by unanticipated and fluctuating fatigue for all of the men in the study. 'Disrupted-doing' will therefore now be considered as a dimension of their 'being-with-CFS/ME'.

6.5.1 'Disrupted doing'

Having CFS/ME meant 'reduced-doing' and/or 'loss-of-doing' usual occupations. This resulted in a threat to occupational well-being summarised as the satisfaction derived from participation in meaningful occupations (Christiansen and Townsend, 2011). 'Lost-doing' impacted negatively on 'being' and sense of 'self' and resonates with Wilcock's concept of "*being through doing*" (Wilcock, 2006, p. 113). 'Lost-doing' also equated to lost control over routines and daily life. All of the men in this study experienced 'lost-doing' in the form of occupational deprivation summarised as a prolonged lack of access to 'doing' caused for example by illness (Christiansen and Townsend, 2011). When usual and taken for granted 'doing' became inaccessible, they were alerted to the need for 'doing' to be different. Reed, Hocking and Smythe (2010) summed up this experience well when they suggested that: "*Disruption reveals things that are usually overlooked*" (Reed, Hocking and Smythe, 2010 p. 140).

Expectations of 'self' in terms of abilities 'to do' were challenged and expectations of others such as teachers, employers, family and friends could not be met. Perceptions of 'doing- nothing' were experienced as the men compared their 'doing' to occupational performance, participation and engagement (Christiansen and Townsend, 2011) prior to becoming ill. For Edmond and Arnold doing too much however meant becoming ill in the first place.

The need to do something to take back control of occupations was reported, but what to do was not clear as the fluctuating nature of their illness caused confusion and uncertainty. For Christopher, his attempt to self-manage his fatigue had led to negative judgement by his GP who accused him of having a drink problem due to taking some alcohol in order to help him sleep. This sceptical horizon (perspective) of the GPs and negative judgement of Christopher had led to a poor rapport between them. Rather than challenging his medical authority however, Christopher changed his GP to avoid any conflict.

For some of the men trying to do what they normally did, did not assist with coping with symptoms, and some adaptation, referred to as a 're-calibration of doing' by Sparky and Edmond, was therefore needed. As naturally occupational beings (Reed, Hocking and Smythe, 2010), the need for occupational adaptation to achieve mastery in day to day life was acknowledged in the literature by Schkade and McClung (2001). These same authors claimed that adaptation is most needed at times when an individual must transition in terms of life roles and stated that: *"The greater the transition the more at risk this process is for disruption"* (Schkade and McClung, 2001 p. 2).

If we consider therefore the unanticipated and fluctuating transitions caused by the illness for the men, it is easy to understand the disruptive nature of living with CFS/ME on both their 'being' and their 'doing'. Such experiences resonated with the wider literature and notions of biographical disruption, summarised as, an interruption in day to day life caused by the presence of illness (Bury, 1982). In terms of disrupted transitions, Billy had however, reflected that having to retire earlier than planned was not as disruptive as it might have been, as he was close to retiring anyway when he became ill with CFS/ME.

6.5.2 Restoration of 'doing'

The need for the men to restore usual 'doing'/occupations but accepting that pre-illness levels of 'doing' may not be possible, is identified in the findings. The importance of changing the tempo of the occupations was evident in some of the men's accounts. For Edmond, despite experiencing occupational alienation and deprivation (Christiansen and Townsend, 2011), after being confined to sitting in an armchair for several months, he decided to take action and returned to an occupation he thought he could manage. By employing effective historical consciousness (Gadamer, 2004) he was able to prejudge what he might manage in the present, and how this may make future restoration of increased occupational participation possible. He chose something he had enjoyed a great deal as a boy - that of painting war figurines. The importance of identifying a meaningful occupation for people with CFS/ME is supported in the background literature (Arroll and Howard, 2013) and despite being confined to the house because of the severity of his symptoms, was also important to Edmond. Similarly, all the men had tried to in some way break down their occupations into manageable parts in order to achieve something meaningful despite their limitations. Reed, Hocking and Smythe, (2010) suggested that: *"The meaning of occupation is influenced by the balance between the challenge the occupation presents and the performer's skills, a sense of choice and control, and whether the environment facilitates easy attention to the occupation"* (Reed, Hocking and Smythe, 2010 p. 141). Having CFS/ME therefore, meant the men had to

weigh-up all of the elements in the above quote in order to restore some way of achieving a degree of 'doing'. This led to 'adapted doing' in order to get the challenge 'just right' for success.

Interestingly for Edmond, adaptation had equated to a cure as once he was taught a formula for pacing he adapted his 'doing' and incrementally increased this until he was achieving levels of activity comparable to his pre-illness ability. This process, he estimated, took about two years and is illustrative of how he regained health and well-being via occupation. Christopher also used the amount of time spent 'doing' occupations as a measure of moving towards getting better or 'harmonious-being' (Gadamer, 1996). Additionally, Luke and Christopher employed the use of Buddhist meditation and mindfulness techniques (Davis and Hayes, 2011) to successfully help reduce anxiety and facilitate access to 'doing'. The use of these techniques requires the person to suspend effective historical consciousness and focus on the present moment. These were coping strategies not favoured by Edmond however, as past experiences of post exertional fatigue linked to cognitive tasks such as mindfulness was anticipated and therefore avoided.

6.5.3 Discovering new 'doing'

Discovering new 'doing' was identified by some of the men and supported in the wider literature (Arroll and Howard, 2013). Prior to becoming ill meaningful 'doing' for Billy had included reading novels. However, as fatigue symptoms developed, he found this mentally too tiring. He therefore invested in an electronic tablet and now enjoys listening to eBooks instead. For Andy, he discovered by accident that he enjoyed painting. Originally he had picked up a paintbrush in the middle of the night to express his frustration of living with CFS/ME. What had therefore started as a cathartic outlet for anger and frustration became a valued leisure occupation over which he developed some mastery and enjoyed occupational flow (Csikszentmihalyi, 1997; 2002). For Andy, discovering a new and meaningful occupation was an "*odd positive*" of having CFS/ME. Hasselkus (2011) discussed how through chaos, or what Gadamer (1996) would term 'chaotic-being' and inter-changeably 'illness', creativity can emerge, much like the experiences of Matisse the artist when he became ill and found purpose through painting.

The need 'to do' was important for all of the men and how time was used and temporal aspects of 'doing-with-CFS/ME' was important. The need to alter the amount of doing or to change the tempo and pace of 'doing' to restore some form of personal and subjective

occupational balance was acknowledged (Pemberton and Cox, 2011). To do things differently therefore impacted positively upon their 'being' and connectedness with others. This connectedness or 'belonging' will now be discussed.

6.6 'Belonging-with-CFS/ME'

Connectedness or disconnectedness to others can impact positively or negatively on our sense of 'being' and also our opportunities for 'doing' and will now be discussed.

6.6.1 The need for us to belong

The need for us to belong and be connected to others was understood in the findings and corroborates the existing literature (Cooper, 1997; Dickson, Knussen and Flowers, 2007; Larun and Malterud, 2007; de Carvalho Leite *et al.*, 2011). Before diagnosis however, connectedness with others was problematic at times due to difficulties in explaining and understanding symptoms. Symptoms were generally invisible and this led to misunderstanding of the illness by others including friends and family members. Such disconnectedness was reported as carrying more of a burden for some than the illness itself (Dickson, Knussen and Flowers, 2007). Disconnectedness to authority figures was reported by all of the men and included teachers, employers and health care practitioners. This was linked to perceived challenges to medical authority and being doubted in terms of illness legitimacy which was commonly reported in the background literature (Ware, 1992; Cooper, 1997; Dickson, Knussen and Flowers, 2007; Larun and Malterud, 2007; Anderson *et al.*, 2012). The contentious nature of the illness contributed to disconnectedness in terms of occupational marginalisation and injustice (Christiansen and Townsend, 2011) for the men as negative judgements were made by people such as prospective or existing employers. These findings supported the background literature (de Carvalho Leite *et al.*, 2011; Anderson *et al.*, 2012; Anderson, Jason and Hlavaty, 2014) where it was mentioned that medical and social inequity existed for people with CFS/ME.

Specifically in this study however, the importance of parents and especially the role of their mother for George, Edmond and Luke, was imperative. None of these young men were married and therefore when practical and emotional support was needed their mothers played a key role. For Edmond in particular, being ill gave him the opportunity to connect with his mother which he had missed once he became well again. Missing being ill was uniquely reported by Edmond for this reason. For the married men, connecting with their wives was important. Billy, Andy, Christopher and Arnold considered that their partners were supportive and that their relationships and communication had improved as

a result of their illness experiences. Andy, Sparky and Arnold had discussed that their sex lives had been negatively impacted upon by their illness but that the emotional closeness and practical support of their wives meant more to them than their physical relationships. Interestingly, since the completion of the background literature review, two papers have been published linked to couples' experiences of the impact of CFS/ME on their relationships. Data reporting men's experiences were included in both papers. These findings were corroborated by my own, in that, the importance of relationships with 'significant others' was acknowledged as enabling coping and, for couples who have been together for some time, the quality of their relationships may be improved through building a sense of shared resilience (Brooks, King and Wearden, 2014; Lingard and Court, 2014).

Connectedness with children was very important for Sparky and Andy and some grief was expressed about the lost years of connectedness that could not be recovered. For Andy, being diagnosed with CFS/ME approximately a year after his young daughter meant he began to better understand what she had gone through to deal with her illness. This sharing of common 'being' and 'doing' had strengthened their 'belonging' which he considered as positive.

In terms of 'belonging' and connecting to others outside the family unit however, Sparky and Luke had experienced particular problems with employers leading to rejection because of their illness. Both perceived that they had been treated unfairly by employers and connecting to this domain of their lives was therefore threatened. Conversely Andy had been treated well by his employers and he praised their support and flexibility in enabling his successful part time return to work. Although Andy had considered moving departments at work he had some concerns that the strength of connectedness he had with his team might not be achieved with a new group of colleagues who may not understand his illness.

Connectedness with others at university was something that was not possible for a year or so for Edmond and his connectedness to other students and especially his sporting friends was sadly lost during this time as shared 'doing' through sport was not possible due to his illness.

6.6.2 Choosing not to belong or 'opting out'

Not wanting to 'belong' or connect with others was mentioned by participants in this study. For example, connecting with others with CFS/ME was not always seen as positive as fear of being defined as 'one of them' (with CFS/ME) potentially loomed large for those

attending any sort of support group gathering or treatment programme. Whilst positive gains for connecting to others in these settings were experienced by Billy, for others, such as Sparky and Andy, attending such groups led to feelings of ambivalence. These were caused by the men acknowledging they may benefit from some form of help and support but not wanting to be labelled with what CFS/ME meant or fully accept, being ill.

The decision to opt out of connectedness was also discussed by Edmond and included the need for social isolation, which he saw as restorative. Opting out of connectedness in this way meant he was able to use his limited energies to focus on his own recovery in terms of 'being' and 'doing'. This is an interesting finding which is supported in the work of Charmaz (1997), who pointed out that isolation can reduce distractions from others and enable a tolerable pace of life to be followed. Andy also mentioned the need to adopt a similar approach to coping, by focussing purely on his own occupational needs. He did however; consider this as selfish when compared with his usual way of connecting to others. These findings are counter to usual reports of the negative impacts of ongoing social isolation for people with health-related needs (Martz and Livneh, 2007).

Edmond had also opted out of his relationship with an emotionally needy and physically beautiful girlfriend. Ending this relationship meant he was not reminded of how emasculated she made him feel, as prior to his illness, he had been proud of his physique and fitness levels. Ending his connectedness with her meant he was protecting himself from experiencing this distress.

Additionally, for Luke, the meaning of being closely connected to his parents was negative as he considered this as being dependent on them when he wanted independence. Conversely for George and Edmond, connectedness and dependence on their families meant they were provided with freedom from adult responsibilities, which enabled them to recover with emotional, practical and financial support. For Edmond, this time of dependence he considered as his gap year from university, which held accompanying socially constructed connotations of enjoyment and relaxation; something he needed to escape from his illness experience.

6.7 'Becoming-with-CFS/ME'

Our way of 'being-in-the-world', what we do and who we are connected with, impacts on our potential to become in some way different. 'Becoming' is linked in the literature to personal transformation and a sense of planning for the future and moving forwards in life (Wilcock and Hocking, 2015) and what Gadamer (2004) might refer to as future horizons of 'being'. 'Becoming' however, may be disrupted by the presence of CFS/ME and will now be discussed.

6.7.1 'Unplanned becoming' as negative

'Becoming-ill' for the men in the study was not planned. For these men planned and potential 'becoming' did not necessarily materialise. Instead their life became something they did not anticipate and usual transitions were disrupted. Transitions are linked to role changes in life (Maley *et al.*, 2016). For Billy this meant that his planned role change from work into retirement happened earlier than predicted. Interestingly, Billy considered that this was less disruptive to him than it might have been if he had been younger as he had almost reached the culturally determined retirement age for males in the UK. Disruptions to usual transitions were more significant however for George and Edmond. For George, becoming ill during his GCSEs and then trying to access 'A' levels and higher education was difficult. For Edmond, the transition from school to university had been particularly significant so much so that he considered CFS/ME to be an illness linked to the transition of going to university:

*"...this was a university problem... going from school it's an **unbelievable** work load...and it's an **unbelievable** expectation and it's incredibly difficult because suddenly you go from a school environment where everything is more or less spoon fed to you and suddenly you have to stand on your own 2 feet academically..."*

2/1/77.1 – 2/1/79 (P2/Edmond, interview 1).

Other forms of unanticipated 'becoming' were also problematic. For Arnold this included 'becoming-ill' again after a remission of several years and for Sparky, 'becoming-an-active dad' was not possible due to symptoms experienced. For Luke, his hopes of 'becoming-a-successful-lawyer' or an eligible partner were lost as the impact of the illness became evident. Instead, 'becoming' was uncertain as the fluctuating nature of CFS/ME prevented anticipated or planned 'becoming' from being possible.

6.7.2 'Unplanned becoming' as positive

'Unplanned becoming' however was not always considered as negative. Through illness experiences for some, the opportunity to become more knowledgeable about CFS/ME

and more confident and resilient in terms of living with the illness was presented. This supported the concept of post traumatic growth reported in the existing literature (Arroll and Howard, 2013). Moving forwards in this way and making sense of experience through growth has been linked with notions of non-religious spirituality (Maley *et al.*, 2016). Finding hope and 'becoming-more-positive' about future 'being-in-the-world' despite CFS/ME was also indicative of 'becoming-more-resilient' and accepting of the illness (Van Damme *et al.*, 2006). For Arnold, this was demonstrated through him 'becoming-an-expert-patient' and wanting to give something back to others by contributing to healthcare education programmes for people with CFS/ME. Having a sense of hope was indicative of what Gadamer (2004) referred to as an inner horizon. Hope can be considered as providing a sense of 'well-being'; a sense of satisfaction with life (Van Damme *et al.*, 2006) which I consider in turn may ensure survival and contribute to the individual's subjective sense of 'health'. The inter-related notions of survival and health for the men involved in the study will now therefore be discussed.

6.8 Survival and CFS/ME

All of the men in this study had faced threats to their survival, either perceived or actual, to a greater or lesser degree. These findings supported the background literature linked to the meaning of survival for one man who mentioned that having the illness was metaphorically akin to a 'death trap' as he had no recognisable life to speak of (Dickson, Knussen and Flowers, 2008). For the men in my own study perceived threats to survival were experienced through suggestions of potentially life-limiting causes being given for their fatigue such as AIDS or cancer.

For several of the men, survival meant the need for help with basic requirements for sustaining life, such as, food, warmth and shelter (Maslow, 1943). This understandably, was when they were at their most severely affected by CFS/ME and confined to the house, or maybe even to just one room, due to functional limitations, like Andy, Christopher and Edmond. Edmond considered that without his mother providing for these basic needs, he may not have survived his illness. Interpreting what this meant for Edmond seemed to be that he would not literally have starved to death, but rather, would have taken his own life in the absence of his mother's practical and emotional support.

Support needs for the survival of the other men were also understood to be primarily emotional in nature. For Arnold this had included support from his wife, a close and

empathetic male friend who had survived cancer, and also a supportive GP. Arnold's survival had been seriously threatened by the impact of CFS/ME on his 'being, doing, belonging and becoming', which had led to feelings of desperation and physical collapse. It was at this point of crisis that he expressed his horizons of experience realising he either needed help to go on living or alternatively terminate his existence. The importance of strong connectedness to others I consider saved his life and also Edmond's.

Literature from the USA linked to the causes of death in people with CFS/ME indicated that the mean age of those who died from suicide was younger than those in the general population (2005). Additionally, and more recently, a substantial risk in mortality from suicide has been identified in people with the condition as compared to the general population of England and Wales (Roberts *et al.*, 2016). The meaning of living with CFS/ME therefore poses a potential threat to survival and health for the men involved and health and CFS/ME will now be discussed.

6.9 Health and CFS/ME

Many definitions of health appear in the literature dating back to Frank's from 1790, linked to "*freedom from want and social deprivation*" (Wilcock and Hocking, 2015 p. 8), including the WHO definition from 1948 and mentioned in Chapter 2, sub-section 2.10, through to Huber *et al.*, in 2011 who defined health as:

"Ability to adapt and self manage in the face of social, physical and emotional challenges". (Huber *et al.*, 2011 p. 3).

Gadamer (1996) suggested that health was:

"A condition of being involved, of "being-in-the-world", of being together with one's fellow human beings, of active and rewarding engagement in one's everyday tasks". (Gadamer, 1996 p. 113).

All of the above definitions have resonance with the philosophical and occupational orientations of this study and the meaning of health for the eight men involved. Gadamer's (1996) definition links closely with the notions of 'being', 'doing', 'belonging' and 'becoming' with CFS/ME as already discussed.

Health for the men in the study was considered as a positive concept, culturally embedded and something that became inaccessible as they became ill. For Gadamer,

becoming ill was considered as a moving away from 'harmonious-being' and towards that of 'chaotic-being' termed as illness (Gadamer, 1996). The unpredictable and fluctuating nature of symptoms of CFS/ME both before and after diagnosis meant that 'chaotic-being' in Gadamerian terms (ibid), was experienced by all of the men. This supported the notion of 'yo-yo' health as reported in the background literature review (Arroll and Howard, 2013) of the study.

In 2007, Wilcock claimed that occupation and health were inseparable. Considering 'doing' as a domain of 'harmonious being', I suggest, supports Wilcock's thinking. To support this claim further, we need to assume that health and illness sit on a synonymous continuum with 'harmonious-being' at one end and 'chaotic-being' at the other. With this in mind, as a person becomes ill with CFS/ME, their 'being' becomes disrupted in addition to their 'doing', 'belonging' and 'becoming'. This means that to a greater or lesser degree, they begin to move towards 'chaotic-being'. At this point for some people survival may become threatened for the reasons already discussed. A move away from 'chaotic being' may be possible by adapting their 'doing'/occupations in order to move towards 'harmonious-being' defined as health (Gadamer, 1996). The experiences of men with CFS/ME in this study support this reasoning. Edmond in particular perceived 'adapted doing'/occupation as a cure for his CFS/ME and therefore restoration of health/'harmonious-being' (ibid). With this in mind I agree with Wilcock (2007) that occupation and health are inseparable as they are conceptually defined collectively by whatever the individual considers 'harmonious being' to be. In order to understand the individual's definition of health, I suggest that the use of philosophical hermeneutics (Gadamer, 2004) has a part to play in both clinical practice and research into the lived experience. If this methodology and its associated dialogue were more frequently adopted by occupational therapists, our encounters with those we serve may be more authentically shared. Furthermore, the voices of our service users may be more clearly heard and their definitions of 'being-in-the-world' better understood. Through approaching our work in an openly phenomenological manner (Cohen, Khan and Steeves, 2000) and then paying attention to the individual's definition of 'health', the meaning of occupation as a dimension of 'being' may then be more usefully explored. This would contribute to the body of knowledge about the science of occupation and inform practice-based evidence to better meet the needs of men with CFS/ME.

6.10 A summary of new and original contributions made to the knowledge-base




Significant disruptions to the men's day to day lives and occupations were discovered preventing them from 'being' and 'becoming' who they wanted to be, and 'doing' all they wanted and needed to do. Additionally, their sense of 'belonging' or connectedness to others was also disrupted. Connectedness was generally considered as helpful and for some imperative to their survival. Uniquely however for some, a conscious decision to disconnect was seen as important to focus on survival needs and re-establish 'harmonious being', defined by Gadamer as health (Gadamer, 1996). Loss of self was identified as part of the meaning of living with an unknown and unknowable illness. Success in coping was linked to acceptance of their illness and development of resilience and confidence to live and 'be' in an authentic mode. Occupational adaptation (Schkade and McClung, 2001), contributed to better managing the illness and facilitated a moving towards 'harmonious-being' known inter-changeably as 'health' (Gadamer, 1996). For one of the men, occupational adaptation in terms of change of tempo in pacing and re-engaging in meaningful and manageable occupation had enabled him to obtain a 'cure'. This he defined by measuring his participation in occupations over a period of two years.

By fusing philosophical and occupational orientations/frameworks a better understanding of living with CFS/ME and the impact of this on the men's day to day occupations was achieved. This understanding influenced my prejudgements linked to the men's experiences via a fusion of horizons (Gadamer, 2004) achieved during the research process. Shared horizons informed suggested implications for practice which are now explored.

6.11 Implications for practice

The need to attend to the 'being, doing, belonging and becoming' and self-perceptions of 'survival' and 'health' of men with CFS/ME has been discussed and the implications for practice are now presented. A conceptual illustration is provided in Table 14 below to demonstrate how the inter-related concepts of 'being, doing, belonging and becoming' are disrupted by the presence of CFS/ME. This I suggest, may assist occupational therapists and others, to better understand the lived experiences of men with the illness and illustrate its all-encompassing nature. Each of the illustrated concepts is discussed and linked to the wider literature. Additionally, suggestions are made which may assist in addressing identified issues in practice.

Table 14: A conceptual illustration of the impact of having CFS/ME

BEING	DOING	BELONGING	BECOMING
<p>Defined as: "To know oneself." (Hasselkus, 2011, p. 25). Understanding 'being': "Being which can be understood is language." (Gadamer, 2004, p. xxxxi). Assumption linked strongly to roles: "Being a parent, being a child, being an employee, being well or well-being." (Wilcock, 2006, p. 115). BEING ILL WITH CFS/ME Being is disrupted and leads to:</p> <ol style="list-style-type: none"> 1. Unable to know oneself as previously/loss of identity 2. Roles are disrupted 3. Being becomes misunderstood by others 	<p>Defined as: Action, participation, accomplishments (Wilcock and Hocking, 2015). Referred to in this study inter-changeably as occupation and a dimension of being. Assumption: "Human beings are occupational in nature in order to survive." (Wilcock, 2006, p. 78). DISRUPTED DOING BECAUSE OF CFS/ME and leads to:</p> <ol style="list-style-type: none"> 1. Reduction and/or loss of occupation 2. Reduction in mastery and flow 3. Altered occupational identity 4. Occupational deprivation 	<p>Defined as: A connectedness to others, places and things (Wilcock and Hocking, 2015). Assumption: Connectedness is positive but not necessarily so for men with CFS/ME. DISRUPTED BELONGING BECAUSE OF CFS/ME and leads to:</p> <ol style="list-style-type: none"> 1. Unable to belong 2. Interdependence as positive (support) 3. Interdependence as negative (loss of freedom) 	<p>Defined as: A development or moving towards something a personal transformation (Wilcock and Hocking, 2015). Assumption: "Becoming is an ever incomplete process, throughout life they are always becoming different, for better for worse." (Wilcock, 2006, p. 148). "Becoming is about what people believe they can contribute to their own growth and what they can offer the community...its provision alters their place within societal structure" (Wilcock, 2006, p. 149). DISRUPTED BECOMING BECAUSE OF CFS/ME and leads to:</p> <ol style="list-style-type: none"> 1. Loss of access to belonging, doing and being 2. Loss of opportunity for personal growth 3. Unable to contribute to society 4. Loss of place in society 5. Threat to survival and health
<p>DISRUPTED BEING IMPACTS ON DOING</p> 	<p>DISRUPTED DOING IMPACTS ON BELONGING</p> 	<p>DISRUPTED BELONGING IMPACTS ON BECOMING</p> 	

6.11.1 Being and attending to 'being' needs

As a matter of priority, I suggest that for men with CFS/ME, attending to their 'usual-being' termed by Gadamer (2004) as 'being' and by Hasselkus (2011) as how an individual 'knows oneself', provides an opportunity for occupational therapists to establish truly client-centred practice (Hammell, 2004; Christiansen and Townsend, 2011; Hasselkus, 2011; Gopinath, 2015). If we acknowledge that 'being' is disrupted by CFS/ME, the importance of exploring and understanding how this impacts upon identity, roles and expectations of self and others, is, I consider, the logical starting point in any therapeutic encounter. This approach, I suggest, is preferable to focusing initially on 'doing' (occupations) or attending to pre-determined occupational domains as included in some published models linked to practice (Law *et al.*, 1998; Turpin and Iwama, 2011). Discovering how CFS/ME has disrupted the self-identity, beliefs and values of the person via a Gadamerian Level 3 encounter (Gadamer, 2004) would enable the authentic 'self' and 'other' to emerge, thus contributing to a fusion of horizons (*ibid*) and a more positive therapeutic encounter for men with CFS/ME. This is achievable via the more usual method of patient-therapist interaction employed in clinical practice, that of talk and observation of non-verbal dialogue, and supports the importance of establishing effective communication between patient and therapist in CFS/ME rehabilitation, as emphasised in the literature (Gladwell, *et al.*, 2014).

Additionally, I suggest that the use of artwork and poetry as dialogue, also have their place in occupational therapy practice and potentially enable us to better understand 'being-with-CFS/ME'. Whilst the use of artwork to capture experiences is recorded in the literature linked to with women with CFS/ME (Reynolds, Vivat and Prior, 2008), the use of artwork and/or poetry might also be useful when working with men. I suggest that these forms of dialogue may be particularly helpful to employ with those who are severely affected, as authentic communication between patient and clinician may be achieved without the burden of having to explain experiences at length. As Andy found, these media may provide a more immediate and accessible way to express 'being-with-CFS/ME' and facilitate a cathartic release of feelings of anger, frustration, loss and distress, enabling initial trust-building and rapport with those who are severely affected, and are acknowledged as hard to access in the wider literature (McDermott *et al.*, 2014). Consequently, in difficult circumstances when fatigue may prevent verbal dialogue from being had, and health is defined by the individual as chaotic, a supportive bridge between therapist and patient may still be established through using these forms of dialogue.

These media may also assist with reducing feelings of occupational alienation and occupational deprivation as defined by Christiansen and Townsend (2011).

Dialogue recorded in the form of artwork and/or poetry may also enable the patient and the therapist to reflect on changes to their 'being-with-CFS/ME' over time. This could be achieved through a series of paintings or poems to capture a moving away from 'being-severely-affected' by the illness and a moving towards 'harmonious being/health' (Gadamer, 1996) and some degree of recovery from CFS/ME. In support of this suggestion, the need to capture data linked to self-perceptions of recovery is advocated in the wider literature (Adamowicz, Caikauskaite and Friedberg, 2014). Revisiting artworks and poetry over time is something Andy reflected on as useful in his interviews. These forms of dialogue I suggest therefore could be used as an alternative type of illness diary and as an innovative data collection method, instead of employing more traditionally used written diaries (Mason, 2002) as a possible data collection tool in qualitative studies.

In terms of 'being-with-CFSME' there is also, I consider, a need for CFS/ME practitioners to be trained in recognising the symptoms of PTSD (Bisson, 2007) to ensure both men and women receive the correct support if necessary. The importance of acknowledging that the patients we work with may have experienced significant life trauma, in addition to the stress of having a chronic illness of uncertain aetiology (Charmaz, 1997) may mean they are at higher risk of developing PTSD (Sledjeski, Speisman and Dierker, 2008). Being aware of red flags for diagnosing PTSD is an easy change of practice to make and should I suggest be disseminated through fatigue teams to ensure any identified needs are addressed as appropriate.

By attending initially therefore, to how 'being-with-CFS/ME' is experienced and impacts upon the individual's sense-of-self, roles, beliefs and values as a priority, would I suggest, enable occupational therapists to better identify how 'disrupted-being' impacts on 'doing'. This is therefore, recommended as the entry point in our clinical encounters to improve client-centred practice and our understanding of living with CFS/ME.

Furthermore, capturing 'being' using artwork as dialogue in particular, therapists may be able to help the patient to identify what Andy described as "*odd positives*" of living with CFS/ME' through the discovery of a new occupation. The importance of this for men and women with CFS/ME was reported in the background literature (Arroll and Howard, 2013). Engaging with artwork and/or poetry to express 'being' therefore may also provide insights

into 'disrupted-doing' and some hope for future restoration of 'usual-doing' or 'new-doing'. This may be achieved via some form of occupational participation and engagement in an adapted way (Schkade and McClung, 2001) to accommodate 'lost-doing' and facilitate a paced recovery. The consequence of 'disrupted-being' and the subsequent need to attend to 'doing' is now discussed.

6.11.2 Doing and attending to 'doing' needs

If we assume that humans are by nature occupational beings (Wilcock, 2006), how CFS/ME impacts upon 'doing' is naturally a matter of concern for occupational therapists. I suggest that 'disrupted-being' impacts negatively on 'usual-doing' and mastery of activities, and leads to 'disrupted-doing'. The importance of identifying 'disrupted and lost-doing' due to 'being-with-CFS/ME' is therefore, acknowledged as important for occupational therapists to understand, as 'doing' has more usually been the focus of occupational therapy practice (Hammell, 2004). Like Hammell (*ibid*), I suggest that 'doing' should be considered as a dimension of 'being' and needs to be explored in this context for men and women with CFS/ME. If 'doing' is disrupted, it is reasonable to assume that mastery over activities/occupations and occupational identity (Christiansen and Townsend, 2011), (influenced by what we do and/or don't do) are impacted negatively, and therefore, changed to a greater or lesser degree. If 'doing' or occupational disruption is prolonged, occupational deprivation (Christiansen and Townsend, 2011) may then be experienced.

In terms of CFS/ME, the value of occupational adaptation (Schkade and McClung, 2001) may address the issue of occupational deprivation (Christiansen and Townsend, 2011). This may include purposely reducing activity levels (Anderson, Jason and Hlavaty, 2014) and matching activities to levels of ability during illness (Dickson, Knussen and Flowers, 2008) to enable a restoration of 'meaningful-doing' or discovery of new occupations in the process (Arroll and Howard, 2013). Despite the presence of CFS/ME, the importance of assisting the individual to identify meaningful occupation and levels of occupational participation and engagement prior to becoming ill (Pemberton and Cox, 2013), should not be underestimated and can be used to guide therapeutic interventions as per NICE Guidelines (2007).

Occupational adaptation (Schkade and McClung, 2001) can also provide hope of recovery to some degree, and for some, may even possibly enable a full recovery back to 'harmonious-being/health'; as reported by Edmond, having become expert at employing

pacing strategies. The use of pacing to change the tempo of activities/occupations is supported in the literature linked to developing self-management strategies for coping with the impact of chronic illness and its integration into daily life (Schulman-Green, *et al.*, 2012). I suggest however, that an understanding of 'disrupted-doing' and an acknowledgement of the need for 'adapted-doing' is firstly required, to enable re-engagement with 'meaningful-doing'. To engage with 'adapted-doing' a degree of acceptance of the illness is suggested, enabling perhaps, some hope of coping despite ongoing symptomatology (Van Damme *et al.*, 2006). Caution is advised however, regarding a guarantee that pacing will enable a full recovery as the causal mechanisms of the illness are still not fully understood (NICE, 2007). In the wider literature therefore, it is recommended that assessments of fatigue levels and function are adopted in addition to attending to self-perceptions of moving towards recovery/health (Adamowicz, Caikauskaite and Friedberg, 2014).

Additionally, and if not already employed, the introduction of poetry and artwork as 'therapeutic-doing' into services for people with CFS/ME could be beneficial. Apart from enabling the expression of 'being-with-CFS/ME' as mentioned in section 6.11.1 above, these activities may be paced in terms of time-use and despite this, enable occupational flow (Csikszentmihalyi, 1997; 2002) to be experienced.

For Andy, through revisiting images of 'disrupted-doing', expressed in his poems and paintings during the research interviews, he was able to reflect that he had made progress towards 'meaningful-doing' which he equated with becoming well. I suggest therefore, that poetry and particularly artworks, used for this purpose, may provide a potentially powerful visual record of positive transformation for patients and reflect a move towards subjectively defined notions of well-being and health.

Not being able to do all the individual needs, wants and has to do may result in a reduction in their sense of connectedness to others as shared occupations ('doing') becomes inaccessible due to fatigue. This results in 'disrupted-belonging' for those with CFS/ME which is now discussed.

6.11.3 Belonging and attending to 'belonging' needs

If we assume that a sense of connectedness to others, places and things is important (Wilcock and Hocking, 2015) and that we achieve these in part through 'doing', acknowledging CFS/ME prevents 'doing' therefore, logically disrupts 'belonging/connectedness'. The importance of connectedness with others for the men in

this study was discussed at length during their interviews. Sceptical attitudes towards their illness were encountered by some men in the study, not only from health practitioners, but also from friends and families as was consistent with the background literature (Cooper, 1997; Dickson, Knussen and Flowers, 2007; Larun and Malterud, 2007; de Carvalho Leite *et al.*, 2011). In terms of health practitioners, I suggest that the adoption of a communication checklist based on Gadamer's criteria for a Level 3 encounter (Gadamer, 2004) could be used to facilitate genuine dialogue with patients (Tuck and Human, 1998) to assist with feelings of 'connectedness' with practitioners. The principles of such an encounter are humanistic and simple to follow without the need for detailed knowledge of underpinning theory or associated tools. The principles being: work in partnership with patients, be open to their viewpoint and value these without over-powering professional judgements dominating treatment interventions (*ibid*). These principles are also consistent with adopting an open phenomenological stance in a dialogic encounter (Cohen, Khan and Steeves, 2000; Gadamer, 2004; Finlay, 2011). Additionally, despite the ongoing contentious nature of the illness (Prochalska, Gressier and Corruble, 2012) adopting these principles would ensure that dignity and respect are afforded to men with CFS/ME and facilitate 'connectedness' for therapeutic purposes. The anticipated and hoped for outcome of this would be a reduction in exposure to occupational marginalisation (Christiansen and Townsend, 2011) for men with CFS/ME from sometimes dismissive practitioners in health and social care systems.

In terms of friends and families, as practitioners, I consider we could at times, take into account their needs more comprehensively. Their role in being connected to and supporting the men in this study was imperative, which was supported in the wider literature by de Lourdes Drachler *et al.* (2009) and without it, threats to survival were acknowledged. Provision for families and friends to be able to discuss their role in supporting the men with CFS/ME is currently provided by the service in which I work through information sharing events. However, there may be a need to run regular carer-specific education or question and answer sessions, to maintain their support and/or a need to develop educational resources such as information films, as suggested in the literature by Hanon *et al.* (2012). Additionally, perhaps for families such as Andy's, support for families where both a parent and a child have been diagnosed with CFS/ME might be useful and is worth considering as an offer of support from health practitioners.

Identifying valued 'connectedness' and where 'connectedness' may be breaking down may assist in maintenance of 'being, doing and becoming' and consequently, 'survival' and 'health'. An example here might be between an employer and an employee with

CFS/ME. A sense of being valued and a 'connectedness' to the workplace for example, may assist with maintenance of occupational identity (Christiansen and Townsend, 2011) and self-esteem by re-establishing mastery in a work role, despite the presence of CFS/ME.

Uniquely, feelings of 'connectedness' or 'belonging' were viewed as negative by one of the younger men in my study, Luke, as he wanted to develop his independence and disconnect from his parents. I suggest that the need to explore the individual's 'belonging' needs are important in practice, to ensure an acceptable degree of support is offered and tailored to meet individual requirements.

In terms of day to day life, the need for men with CFS/ME to opt out of 'belonging' has its place. The possibility of recovery in a quiet and non-distracting environment should therefore, be discussed as a potential coping strategy, transferable also I suggest, to women with the condition. However, the inability to achieve a sense of 'belonging' to people, places and things I suggest, disrupts our 'becoming' who and what we want to become and will now be addressed.

6.11.4 Becoming and attending to 'becoming' needs

The need for practitioners to be mindful of the potential risk to planned life transitions around the time of diagnosis and throughout the individual's illness trajectory is important. This suggestion is supported in the wider transitional literature (Maley *et al.*, 2016). Transitional points for men with CFS/ME may be when most therapeutic intervention is required and assistance with occupational adaptation is needed (Schkade and McClung, 2001), as 'being, doing and belonging' are all likely to be disrupted. Identifying and assisting with the formulation of adapted and planned 'doing' through pacing, may help the person to cope with such disruptions. Although the importance of supporting adolescents with CFS/ME into early adulthood is acknowledged in the literature (CFS/ME Working Group, 2002), I suggest that more attention could be paid by practitioners working in adult services, to better support men, and possibly women, with CFS/ME during identified times of significant life-transitions. By doing so, practitioners may be able to minimise 'disrupted-becoming' and consequently facilitate desired 'becoming' for the individual, despite the troublesome presence of CFS/ME.

6.12 Strengths and limitations of the study

The study uniquely focused on the meaning of living with CFS/ME for eight men with CFS/ME. This is one of its main strengths as in-depth rich data of this kind has not to date been published. Other strengths will now be presented.

6.12.1 Strengths of the study

This study was conducted in a rigorous and auditable way to address a gap in the current literature. New and original data were generated and a unique way of discussing these was employed by fusing philosophical and occupational orientations/frameworks to address the research question. This provides a framework not only for research but makes findings meaningful in terms of application to practice. Additionally, the production of findings using an interpretive phenomenological approach contributes to the notion of practice-based evidence (Staniszewska *et al.*, 2010; Finlay, 2011) as opposed to evidenced-based practice (Curtin and Fossey, 2007). The important distinction for me is that the process of gathering the evidence of the meaning of experience was data-driven as opposed to being theoretically-driven by some predetermined concept.

Additional strengths of this study lie in the closeness of the findings to the experiences of the men involved. This was ensured by using their own words to label and categorise themes and sub-themes and interpreted meanings of experience. In this way a representative interpretation of their experiences was made, what Gadamer (2004) considered as a truth in terms of human experience and Grondin summarised as: *“By truth we mean simply a meaningful account that corresponds to things”* (Grondin, 1994, p. 141).

6.12.2 Limitations of the study and ideas for future research

In this study the voices of eight Caucasian male participants were represented. A limitation of the study is that no black and minority ethnic males (BME) were included which is reflective of the demographics of the geographical area targeted for recruitment. A further limitation is linked to the fact that all of the men included were heterosexual. Bearing these limitations in mind further research to address the experiences of men from BME demographics and homosexual and transgendered men may be useful to explore.

Whilst analysing the data it occurred to me that a further limitation of this study may be linked to me missing the relevance of engendered experiences for some of the men involved. In my defence however I naturally interpreted the data from the horizon of being a culturally engendered female. My prejudgements therefore, included a female perspective of 'being-in-the-world' as just that. After further reflection however, I reminded myself that I had thought that the men would talk about masculinity much more than they actually did. I wondered therefore, whether they had found this a difficult issue to discuss with a female researcher. Suggestions for further research might usefully include qualitative studies being conducted by male researchers to specifically explore gender issues linked to men's experiences of CFS/ME.

In terms of interpretive phenomenology, any other researcher regardless of gender would understandably interpret my data in their own way based on their own prejudgements. With this in mind it occurred to me that it might be interesting to make these data available to male researchers, to provide their interpretations and add to the richness of what we might discover about the experiences of the men involved in the study. I therefore plan to discuss this possibility with academic male peers to determine whether any of them would be interested in conducting some form of secondary data analysis subject to appropriate ethics approval. Additionally, longitudinal studies into the impact of the condition for men may usefully add to the body of knowledge linked to enduring fatigue along with studies into the experiences of children of men with fatigue, their partners, families and friends to gain a perspective on their experiences also.

A further limitation of this study was linked to the fact that no grey literature was included and this may have excluded data of relevance. This decision was made in order to include only high quality and peer reviewed data in the review linked to the contentious issue of CFS/ME and therefore avoid unpublished data of potentially poor quality.

In the data analysis phase of this study 112,000 words were generated from the interviews. These data however had to be focused and reduced to present a work that addressed the requirements of this award. It may be considered that data were unable to be fully reported upon which would have been possible with a greater word count allowance. It is proposed that raw data may be used as the focus of additional outputs from this study. This could include a dedicated paper linked to the full set of artworks provided by Andy for example.

Other suggestions for future research include the possibility of exploring inter-professional epistemologies and how and when an individual's 'being' is attended to and/or the given dimensions of 'being', in terms of 'doing', 'belonging' and 'becoming'. Would, for example, sociologists or anthropologists emphasise the importance of exploring 'belonging', or perhaps psychologists focus on 'doing', reframed as 'behaviour'? This is where I consider that using a combination of philosophical and inter-professional frameworks/orientations may add to the body of knowledge linked to occupational science.

Despite these identified limitations I suggest that something new has been learned about the experiences of men living with CFS/ME and as a consequence further research has been proposed and implications for practice suggested. These suggestions can be used to support men living with CFS/ME to better manage their 'being, doing, belonging and becoming' despite their illness and therefore, I consider, influence their chances of survival and restoration of 'doing' and harmonious health.

6.13 Chapter summary

In this chapter, the meaning of living with CFS/ME and its disruptive impact on the lives and occupations of the eight study participants was explored. The findings were discussed critically in relation to the previously reviewed and wider literature. Philosophical and occupational orientations/frameworks were fused and the need to understand 'being-with-CFS/ME' was suggested in order to then understand the men's disrupted 'doing, belonging and becoming'. These inter-related concepts were discussed in terms of the men's survival and health. Accessing 'being' therefore, was emphasised as the starting point for understanding experience and subsequently meaningful occupations or 'doing'. 'Chaotic-being' was defined as 'illness'. 'Harmonious-being' was defined as 'health' and occupation was acknowledged as inseparable from this. Implications for practice were discussed and suggestions made for addressing these. The strengths and limitations of the study were considered and suggestions made for future research. In the next and final chapter, the study conclusion is drawn.

Chapter 7:

Conclusion

7.0 Introduction

The contents of this chapter provide the conclusion to the study. The aim of the study and the research question are revisited and my original contribution to the knowledge base linked to men's experiences of living with CFS/ME is summarised.

7.1 Revisiting the aim of the study and conclusion

In this study I set out to explore the meaning of living with CFS/ME for men and how the illness impacted on their day to day lives and occupations. A pragmatic decision was made to focus on men, as a dearth of literature linked to their experiences was identified, as opposed to those of women. The research question posed was:

'How is CFS/ME experienced by men living with this condition?'

Eight men of varying ages who had a clinically confirmed diagnosis of CFS/ME were recruited to the study. To address the research question an interpretive phenomenological approach based on the work of Gadamer (2004) was adopted. Unstructured, in-depth interviews were conducted and paced over time to accommodate any presence of fatigue symptoms, and rich data co-created for us to understand experiences.

Findings identified in the background literature linked predominantly to the experiences of women were corroborated by my own, including reports of variable attitudes towards obtaining a diagnosis, misunderstanding of symptoms, stigmatised feelings and trivialisation of the illness by others, including health care professionals, family members, friends, employers and teachers. New knowledge generated included; distress experienced due to fearing life threatening causes of fatigue; difficulties with life transitions due to disruptive symptoms; feelings of emasculation and role loss; the need for social isolation to promote recovery and; the value of occupational adaptation in the form of pacing used to assist recovery and a return to health.

Uniquely, this study generated in-depth accounts of men's experiences of living with CFS/ME, where previously none had existed, which were co-created with participants, via various forms of dialogue including artworks and poetry. Findings included the importance of identifying the subjective nature of 'being-with-CFS/ME' for the men, which is suggested as an entry point into hearing and sharing their perspectives or 'horizons' of this contentious illness, in a genuine way. Whilst acknowledging that occupational therapists are skilled in identifying and addressing meaningful 'doing', the importance of paying greater attention to men's 'being' is suggested. Additionally, based on Wilcock's (2006) assumption of the close relationship between 'being' and culturally embedded constructions of 'the self', attending to 'being-with-CFS/ME' can enable a greater understanding of the self-identity of men with the illness. More specifically, for men with CFS/ME however, the potential presence of 'emasculated-being' and its possible impact on roles and occupational identity should be considered.

Employing Gadamer's (2004) existentialist concept of 'being' and considering occupation as a dimension of this, it is suggested, can assist occupational therapists and occupational scientists to explore the impact of CFS/ME on culturally embedded roles and disrupted access to meaningful occupations for men with the illness. Additionally, through adopting this approach, possible experiences of occupational alienation, deprivation, injustice and/or marginalisation (Christiansen and Townsend, 2011) may be identified. By considering occupation as a dimension of 'being' therefore, the potential to better understand the complex needs and experiences of men with CFS/ME is possible, facilitating the provision of tailored and client-centred occupational therapy interventions. Interventions may usefully include facilitating a restoration of meaningful 'doing' through adaptation of occupations, in terms of reduced tempo/pacing to make participation achievable. It may also mean assisting service-users in identifying new occupations of meaning, such as artwork for some, which are compatible with available energy. These may be perceived by the individual as 'just right' in terms of the challenges to participation and engagement imposed by fatigue severity. In Gadamerian terms (Gadamer, 1996), these occupational therapy interventions have the potential to assist the individual in their desire to move away from 'chaotic-being' or illness, towards 'harmonious-being' considered as 'health' and therefore, support their 'belonging' and 'becoming' and their well-being and survival. Exploring 'doing' as an embedded dimension of 'being', may also be useful when exploring the experiences of women and children with CFS/ME and perhaps, when working with people with other contentious and misunderstood health conditions, such as chronic pain.

As the cause of CFS/ME currently remains unknown, the need to pay attention to potential triggers for illness development is important. These include stressful life events (NICE, 2007) and it is suggested therefore, that occupational therapists should be aware of the possibility that 'traumatised being' may have been experienced by men with CFS/ME. This may require additional training for occupational therapists to identify the possible presence of PTSD and subsequent signposting to, or provision of, appropriate interventions.

Although a cure for CFS/ME cannot be guaranteed and the illness is still viewed sceptically by some, occupational therapists, in partnership with service-users, other health and social care professionals and educational and employment providers, can provide timely, flexible and tailored support to men with CFS/ME in order to re-establish a sense of control and agency over their frequently chaotic and stressful lives. This way of working lies at the core of our profession and is a fundamental driver to our mission to provide equitable and humanistic services to all. Additionally, adopting a Gadamerian approach to health-based research (Stenner, Mitchell and Palmer, 2016) and clinical practice can be beneficial to those we seek to better understand and therefore, more usefully serve. Finlay (2011) summed up this ontological stance linked to the motivation to conduct meaningful research to inform practice:

"I want research with the potential to contribute something to my practice, to help me to better understand the therapeutic process and my clients' needs. I seek research that enables them to make sense of their own experiences and have this witnessed. I also want to spread the word to others. All of this, I argue, can be made possible through recourse to phenomenology, with its enriching and transformative possibilities. For me, phenomenology has become more than a research methodology. It is for me a way of being." (Finlay, 2011 p. 12).

This stance Finlay (2011) considered supports the concept of 'practice-based evidence' as opposed to 'evidenced-based practice'. This conceptual shift has the potential for practice to be truly client-centred (Gopinath, 2015) and therefore, enable the establishment of an equal partnership between 'self' and 'other'. Additionally, the demonstration of mutual respect and dignity has the impact of reducing power differentials between the clinician or researcher and the patient or participant.

In summary, although a cure for CFS/ME cannot be guaranteed we can provide hope and timely, flexible, tailored support to patients by addressing their 'being, doing, belonging and becoming' needs. By doing so we may also assist them in maintaining their survival

and contribute to well-being and health. This aim is at the core of the occupational therapy profession and is what makes our practice of value not only to men with CFS/ME but also potentially to others with contentious illnesses.

The importance of identifying that the voices of men with CFS/ME needed to be heard, has contributed to new and original ways of knowledge generation to aid our understanding of their experiences. For this reason, I consider that the strengths of the study outweigh its limitations and can usefully inform the practice of occupational therapists and others, who genuinely want to support the 'being-in-the-world' of men with CFS/ME and therefore, their survival and health. The challenges of these men loom large, but as Finlay (2011) suggested, by adopting interpretive phenomenology as a way of practicing, both professionally and in research settings, we open ourselves up to the possibility of better understanding the needs of others. Only then can we consider ourselves to be equal partners in our shared encounters and provide truly client-centred practice to frequently occupationally marginalised men with CFS/ME.

7.2 Conclusion summary

The experiences of men with CFS/ME were acknowledged as under-reported in the academic literature and were therefore, specifically explored in this study. New understandings of the meaning of living with CFS/ME were identified. These included difficulties with living with an illness of unknown origin and uncertain prognosis which impacted upon how the men were treated by health practitioners and others. The contentious nature of CFS/ME negatively influenced their 'being-in-the-world' as illness experiences were trivialised, disrupting their occupations and their sense of self. The importance of health professionals entering into a genuine dialogue with the men is advocated to demonstrate an acceptance of their illness. Through shared dialogue and rapport development, access to beliefs, values, fears and expectations of living with and beyond CFS/ME, considered as 'chaotic-being', can be understood. Through attending to their 'being' as a priority, then their 'doing', subjective notions of 'belonging', 'becoming', 'survival' and 'health' may also be understood. By understanding these issues occupational therapists may assist with restoration and discovery of new and meaningful 'doing' or occupations. This may be achieved by assisting the men with adapting their occupations and the use of pacing strategies. As a consequence, a move from 'chaotic-being' or illness, towards 'harmonious-being' or health may then be achieved for men with CFS/ME.

Appendices

Appendix A

Audit Trail of the Literature Searches

Completed April, 2014.

Source:

PROQUEST

06/03/14

4 Data Bases:

ASSIA 1987-2014

BNI 1994-2014

Social Services Abstracts 1979-2014

Sociological Abstracts 1952-2014

CFS AND Men

- n = 0

CFS/ME AND Men

- n = 5 abstracts read/scanned
- n = 5 rejected (reasons: biomedical/quantitative/treatment related)

CFS/ME with filters applied

(to exclude: FMS, children, child abuse, just women, PTSD, MS, rape, feminist studies, lesbians and women's health)

- n = 460

CFS/ME with filters applied (n = 460) AND experiences

- n = 79 abstracts read/scanned
- n = 65 rejected (reasons: treatment trials, biomedical, genetic for example)
- n = 14 of possible use
- n = 5 rejected further scrutiny (reasons: did not meet criteria or poor quality n = 1)
- **n = 9 of use**
 1. Anderson *et al.* (2012)
 2. Clements *et al.* (1997)
 3. Cornes (2013)
 4. Guise *et al.* (2010)
 5. Taylor (2005)
 6. Tuck and Human (2006)
 7. Ware (1992)
 8. Whitehead (2006a) quest
 9. Whitehead (2006b) identity

PROQUEST no duplicates Total number of papers of use n = 9

Source:

EBSCO

20/04/14

7 Data Bases: No date restrictions

AMED

CINAHL Plus

MEDLINE

PsychARTICLES

PsychINFO

SocINDEX

SPORTDiscus

CFS/ME AND Men

- n = 1 abstract read/scanned
- n = 1 rejected after further scrutiny (reason: biomedical)

PVFS

- n = 59 abstract read/scanned
- n = 1 of possible use
- n = 1 rejected after further scrutiny (reason: biomedical)
- n = 0

CFIDS

- n = 75 abstracts read/scanned
- n = 1 possible of use
- n = 1 rejected after further scrutiny (reason: biomedical duplicate of the paper identified in the PVFS search above)
- n = 0

CFS/ME AND Qualitative Research

- n = 12 abstracts read/scanned
- n = 11 rejected after further scrutiny (reasons: experiences of health workers or just women)
- **n = 1 of use**
 1. Whitehead (2006a)

CFS/ME AND experiences

- n = 34 abstracts read/scanned
- n = 30 rejected after further scrutiny (reasons: experiences of health workers or just women)
- **n = 4 of use**
 1. Arroll and Senior (2008)
 2. Whitehead (2006a)
 3. de Carvalho Leite *et al.* (2011)
 4. Whitehead (2006b)

CFS/ME AND occupation*

- n = 12 abstracts read/scanned
- n = 11 rejected after further scrutiny (reasons: models of practice, theoretical papers)
- n = 1 of possible use
- n = 1 rejected after further scrutiny (reasons: anonymous, postal survey comprising closed questions and limited opportunity to elicit qualitative information)
- n = 0

CFS AND experiences, with filters applied (age related i.e. adults not children and English language papers only)

- n = 290
- n = 203 after exact duplicates removed
- n = 203 abstracts read/scanned
- **n = 19 of use**
 1. Anderson *et al.* (2012)
 2. Anderson, Jason and Hlavaty, (2014)
 3. Arroll and Howard (2013)
 4. Arroll and Senior (2008)
 5. Clarke (1999)
 6. Clarke (2000)
 7. Clarke and James (2003)
 8. Cooper (1997)
 9. Dickson *et al.* (2007)
 10. Dickson *et al.* (2008)
 11. Gilje *et al.* (2008)
 12. Guise *et al.* (2010)
 13. Larun and Malterud (2007)
 14. Lombard and Mouton (2005)
 15. Lovell (1999)
 16. Taylor (2005)
 17. Travers and Lawler (2008)
 18. Whitehead (2006a)
 19. Whitehead (2006b)

Refined search term using subject thesaurus:
chronic fatigue syndrome AND patients

- n = 43 abstracts read/scanned
- n = 34 rejected after further scrutiny (reasons: biomedical, just women, other conditions included)
- **n = 9 of use**
 1. Arroll and Howard (2013)
 2. Arroll and Senior (2008)
 3. Clarke (2000)
 4. Clarke and James (2003)
 5. Cooper (1997)
 6. Dickson *et al.* (2007)
 7. Dickson *et al.* (2008)
 8. Travers and Lawler (2008)
 9. Whitehead (2006a)

EBSCO remove duplicates n = 14

Total number of papers of use n = 20

Source:

Web of Science

20/04/14

All Data Bases

Time span 1990-2014

chronic AND fatigue AND syndrome AND qualitative AND research

- n = 66
- n = 64 after exact duplicates removed abstracts read/scanned
- n = 53 rejected after further scrutiny (reasons: children, professionals experiences, treatment evaluations)
- **n = 11 of use**
 1. Anderson *et al.* (2012)
 2. Anderson, Jason and Hlavaty (2014)
 3. Arroll and Howard (2013)
 4. Clarke (1999)
 5. Clements *et al.* (1997)
 6. Gilje *et al.* (2008)
 7. Guise *et al.* (2007)
 8. Larun and Malterud (2007)
 9. de Carvalho Leite *et al.* (2011)
 10. Taylor (2005)
 11. Whitehead (2006b)

myalgic AND encephalo* AND qualitative AND research

- n = 22 abstracts read/scanned
- n = 11 of use all duplicates and included in the previous search above

Web of Science **Total number of papers of use n = 11** but n = 10 appear in EBSCO search and n = 1 appears in PROQUEST search so effectively duplicates.

Identified papers of use:

PROQUEST (4) + EBSCO (20) + Web of Science (0 new) n = papers 26

PROQUEST n = 4 original papers (rest in EBSCO)

1. Clements *et al.* (1997)
2. Cornes (2013)
3. Tuck and Human (2006)
4. Ware (1992)

Cornes (2013) rejected as not a research paper but an opinion piece.

So PROQUEST total = 3

EBSCO n = 5 original papers

1. Dickson *et al.* (2007)
2. Dickson *et al.* (2008)
3. de Carvalho Leite *et al.* (2011)
4. Lombard and Mouton (2005)
5. Lovell (1999)

Web of Science n = 11 but all papers are duplicated in EBSCO or PROQUEST

Final number of papers selected: n = 23

1. Anderson *et al.* (2012) meta-synthesis
2. Anderson, Jason and Hlavaty (2014)
3. Arroll and Howard (2013)
4. Arroll and Senior (2008)
5. Clarke (1999)
6. Clarke (2000)
7. Clarke and James (2003)
8. Clements *et al.* (1997)
9. Cooper (1997)
10. Dickson *et al.* (2007)
11. Dickson *et al.* (2008)
12. Gilje *et al.* (2008)
13. Guise *et al.* (2010)
14. Larun and Malterud (2007) meta-synthesis
15. de Carvalho Leite *et al.* (2011)
16. Lombard and Mouton (2005)
17. Lovell (1999)
18. Taylor (2005)
19. Travers and Lawler (2008)
20. Tuck and Human (2006)
21. Ware (1992)
22. Whitehead (2006a)
23. Whitehead (2006b)

Included in the literature search were two qualitative reviews/meta-syntheses both of which include a significant number of the papers listed above and some newly identified papers which are indicated in brackets. The two reviews were as follows:

Note:

- Papers highlighted in blue above appear in Larun and Malterud (2007).
- Papers highlighted in yellow appear in Anderson *et al.* (2012).
- Papers highlighted with both blue and yellow appear in both reviews.

1. Larun and Malterud (2007)

Include the following papers of relevance to this study:

- Anderson and Ferrans (1997) (new snowballed and obtained)
- Clarke (2000)
- Clements *et al.* (1997)
- Denz-Penhey and Mardoch (1993) (new: snowballed and obtained)
- Gray and Fossey (2003) (new: snowballed and obtained)
- Horton-Salway (2004) (new: snowballed and obtained)
- Lovell (1999)
- Soderlund *et al.* (2000) (new: snowballed and obtained)
- Taylor (2005)
- Ware (1998) (new: snowballed and obtained)
- Woodward *et al.* (1995) (new: snowballed and obtained)

2. Anderson *et al.* (2012)

Include the following papers of relevance to this study:

- Anderson and Ferrans (1997)
- Clarke (1999)
- Clarke and James (2003)
- Clements *et al.* (1997)
- Denz-Penhey and Mardoch (1993)
- Donalek (2009)
- Gilje *et al.* (2008)
- Guise *et al.* (2010)
- Gray and Fossey (2003)
- Horton-Salway (2004)
- Larun and Malterud (2007) (previous meta-synthesis)
- Lombard and Mouton (2005)
- Lovell (1999)
- Soderlund *et al.* (2000)
- Taylor (2005)
- Travers and Lawler (2008)
- Ware (1998)
- Whitehead (2006a)
- Whitehead (2006b)
- Woodward *et al.* (1995)

In Conclusion

The following 11 papers were finally selected for the critical review of the literature for this study and appear below in chronological order:

1. Ware (1992)
2. Cooper (1997)
3. Tuck and Human (1998)
4. Dickson *et al.* (2007)
5. Larun and Malterud (2007) meta-synthesis (includes 4 papers above highlighted in blue)
6. Arroll and Senior (2008)
7. Dickson *et al.* (2008)
8. de Carvalho Leite *et al.* (2011)
9. Anderson *et al.* (2012) meta-synthesis (includes 10 papers above highlighted in yellow)
10. Arroll and Howard (2013)
11. Anderson, Jason and Hlavaty (2014)

Appendix B

Study invitation letter



Adult Fatigue Management Service,
RNHRD NHS FT,
Upper Borough Walls,
Bath,
BA1 1RL.

Telephone: 01225 473456

Date:

Dear Mr

We are contacting you as you agreed to be included in our CFS/ME data base at the Trust and we would like to invite you to consider taking part in some research we are conducting. The research is about men's experiences of living with CFS/ME and/or Post Viral Fatigue Syndrome (PVFS). Little is known about men who live with these conditions and we want to try and better understand their experiences and needs in order to possibly improve health care.

If you are interested in finding out more about the study please take time to read the enclosed information and complete the tear off contact slip, which can then be returned to us in the reply paid envelope enclosed. Once returned, the researcher will get in touch with you.

We want to reassure you that you are under no obligation to take part in this study and are free to disregard this information if you prefer not to be involved.

Yours sincerely,

Adult Fatigue Management Service Administrator.

Letter of invitation version number: 1 January 2013

Appendix B continued

Consent form



Study Number:

Participant Identification Number:

CONSENT FORM

Title of Project: Men and Chronic Fatigue Syndrome (CFS)/ME

Name of Researcher: Anne Johnson

Interview Number:

Please initial all boxes

1. I confirm I have read and understand the information sheet dated January 2013 (Version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
4. I agree to my research interviews being audio recorded.
5. I agree to take part in this study and consent to the findings being published and presented at conferences and understand that quotes from the data may be used
but will not identify the participant who provided them.

Name of Participant

Date

Signature

Name of Person
taking consent.

Date

Signature

1 copy to be completed for medical notes and photocopied by the researcher to provide a copy for the participant to keep.

Appendix B continued

Patient information sheet Version 4



Study Number: 13/SW/0105

Participant Information Sheet

Title of the Research Study:

Men and Chronic Fatigue Syndrome (CFS)/Myalgic Encephalomyelitis (ME)

I would like to invite you to take part in this research study which is a student project being conducted by myself as part of my doctoral studies. Before you decide whether or not to be involved I would like to tell you about the purpose of the study and what will happen if you do decide take part. Talk to others about the study if you wish before deciding.

Purpose of the Study:

In this study I aim to explore the experiences of men who have experience of living with Chronic Fatigue Syndrome (CFS), formerly known as ME (Myalgic Encephalomyelitis) which is sometimes diagnosed as Post Viral Fatigue Syndrome (PVFS). The completion of this study may provide a better understanding of how the lives of men with these conditions are affected and may help us to improve healthcare services provided.

Why have I been approached?

You have been invited to participate in this study as you have or have had CFS/ME and/or PVFS and agreed to be included in our patient data base when you first came to see us.

Do I have to take part?

Participation is entirely voluntary and it is up to you if you wish to take part. If you do take part however, you are free to withdraw at any time, without giving a reason and this would not affect the standard of care you may be receiving or may need in the future from the Service/Team.

What will I have to do?

If you are interested in taking part you will need to complete the tear off contact details slip at the end of this document and return it to me in the reply paid envelope enclosed. Once returned I will then contact you by telephone to discuss your involvement in the study and provide you with the opportunity to ask questions about anything that is not clear.

What will happen to me if I take part?

Once you are satisfied that you understand the study information, I will make an appointment with you by telephone for a face to face research interview to take place at a convenient time and date. This can be either at your home where you may feel more comfortable or at the Royal National Hospital for Rheumatic Diseases in Bath.

On the day of the interview you will be asked to read and sign a consent form to ensure you are in agreement with being included in the study. The master copy will be filed in your confidential medical records at the hospital and I will provide you with a photocopy for your records. The interview will be audio recorded to ensure accuracy.

The length of the interview will be determined by you and will take into account your energy levels at the time. You will have the opportunity to be interviewed up to four times in order to ensure your experiences are gathered in detail. The interviews can be spread across a period of up to 12 months in order to pace your involvement and also to provide time for you to reflect on our discussions and consider any additional information you may want to add.

Once the final interview has taken place, your active involvement will end and you will not be required to do anything more.

What are the possible risks of taking part?

You may feel that participation might cause you some upset or discomfort or may be inconvenient and for these reasons you may decide not to take part. If your involvement in the study causes you to become distressed you will be given the option to stop the interview. Additionally if you feel you need some help to deal with any distress linked to the study, you are encouraged to contact Nikie Catchpool for support and advice. Nikie's contact details appear at the end of this document. Alternatively you may wish to contact your own GP or your local Samaritans organisation for support.

What are the possible benefits of taking part?

I cannot promise the study will help you directly, but sharing your experiences may help me to better understand how fatigue affects men's lives and therefore possibly contribute to improving healthcare services.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you may suffer will be addressed. The Research and Development

Manager at the hospital Jane Carter should be contacted with any concerns. Jane's details appear at the end of this document. As the researcher I also have the ability to withdraw you from the study at any point if I have any concerns.

Will my taking part in the study be kept confidential?

Yes I will follow ethical and legal practice and all information about you will be handled in confidence. You will not be identified in typed transcripts of your interviews, which will be typed either by me or a member of the UWE Research Administration Team, who has signed a research confidentiality agreement and all summaries and the findings will be anonymised. I will however, send a courtesy letter to your GP to let them know you have agreed to be included in this study. If during the course of the study bad practice is identified, it may be necessary for me to break confidentiality and report this to Jane Carter for advice on the best course of action.

What will happen to the results of the research study?

Once the study is completed the research findings may be published. Any publications and presentations will be anonymised and you will not be identified through any of the study outputs. I will try and contact you to offer you a summary of the findings of the study if you would like to have one.

Who is organising and funding the research?

The research is being sponsored by the University of the West of England in Bristol.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by the South West – Exeter, Research Ethics Committee.

Further information and contact details:

Specific information about this study (the researcher):

Ms Anne Johnson, Joint Clinical Lead/Consultant Occupational Therapist
Adult Fatigue Management Service
Royal National Hospital for Rheumatic Diseases NHS Foundation Trust
Upper Borough Walls Bath BA1 1RL Tel: 01225 465941
Anne.Johnson@rnhrd.nhs.uk

Details of who to contact if you should become distressed

Mrs Nikie Catchpool, Joint Clinical Lead/ Consultant Occupational Therapist Adult
Fatigue Management Service
Royal National Hospital for Rheumatic Diseases NHS Foundation Trust
Upper Borough Walls Bath BA1 1RL Tel: 01225 465941
Nikie.Catchpool@rnhrd.nhs.uk

General information about the study or if you are unhappy about the study:

Ms Jane Carter, Research and Development Manager
Royal National Hospital for Rheumatic Diseases NHS Foundation Trust
Upper Borough Walls Bath BA1 1RL Tel: 01225 465941 Jane.Carter@nhrd.nhs.uk

-----*Reply slip below tear here*-----

Potential Participant's Contact Details

Name: _____

I am interested in finding out more about the study:

Men and Chronic Fatigue Syndrome (CFS)/Myalgic Encephalomyelitis (ME)

I am happy for you to contact me to discuss this information further.

Telephone numbers:

Mobile: _____

Landline: _____

Additional information (for example the best times to call you)



Can I leave a message on your mobile number to say I have called you? _____



Can I leave a message on the landline number you have provided to say I have called you? _____

Once completed please detach and return to the hospital in the reply paid envelope provided. Thank you for your interest I will contact you in the near future.

Appendix C

Thank you letter



Title of the Study:

Men and CFS/ME

Name of Researcher: Anne Johnson

Date: _____

Dear _____

Thank you for expressing an interest in being included in the above Study. This Study aimed to recruit 10 men. I have however, received a greater number of positive replies for inclusion than needed and therefore do not require your assistance this time. I would therefore like to take this opportunity to thank you for your interest.

Yours Sincerely,

Anne Johnson

Joint Clinical Lead/Consultant Occupational Therapist,
Adult Fatigue Management Unit,
Royal National Hospital for Rheumatic Diseases NHS Foundation Trust,
Upper Borough Walls,
Bath, BA1 1RL.

Thank You Letter, Version 1, Jan 2013

Appendix D

Permission for transcribing letter



**Room 2G09
Glenside Campus
Blackberry Hill
Bristol
BS16 1DD**

Date:

Study Number: 13/SW/0105

Title of Project: Men and Chronic Fatigue Syndrome (CFS)/ME

Name of Researcher: Anne Johnson

Dear

Thank you very much for being interviewed as part of the above research study. The numerous interviews I have conducted have generated large amounts of data and I have therefore, recently applied for and been granted, ethical approval from the Exeter Research Ethics Committee to use the UWE Research Administration Team for assistance with transcribing the interview data. The Committee Chair has asked me to contact you to check whether it would be acceptable to you for a member of this Team to transcribe your interviews. To reassure you, the Team have signed confidentiality agreements for the purposes of assisting researchers with this task. However, if you would prefer for your data not to be transcribed by a member of the UWE Research Administration Team, I can reassure you that I will transcribe your data myself. I will follow up from this letter with a telephone call to you to discuss and confirm your decision, before the transcribing of your interviews commences.

Yours sincerely,

**Anne Johnson
Senior Lecturer, UWE Bristol.
Joint Clinical Lead/Consultant Occupational Therapist,
RNHRD NHS FT, Bath,
Upper Borough Walls,
Bath, BA1 6HA.
01225 473456**

Men and CFS/ME Version 1 Transcribing Letter Oct 2014

Appendix E

GP information letter

**Room 1K18
Glenside Campus
Blackberry Hill
Bristol
BS16 1DD**

Date:

Study Number: 13/SW/0105

Title of Project: Men and Chronic Fatigue Syndrome (CFS)/ME

Name of Researcher: Anne Johnson

Dear Dr

Re:

NHS Number:

I would like to inform you that the above named patient has consented to be interviewed as part of this study sponsored by the University of the West of England conducted at the RNHRD NHS Foundation Trust, Bath. If you require any information about the study please do not hesitate to contact me:

Anne2.Johnson@uwe.ac.uk

Yours sincerely,

Anne Johnson

Joint Clinical Lead/Consultant Occupational Therapist RNHRD NHS FT, Bath,
Senior Lecturer, UWE Bristol.

Appendix F

Researcher Risk Assessment 4 pages

GENERAL RISK ASSESSMENT FORM

Ref: AJ Feb 2014

<p>Describe the activity being assessed: Interviewing participants for a research study off campus – e.g. in quiet community setting or in their own home by PhD student with potential for others to be present in these settings</p>	<p>Assessed by: Anne Johnson</p> <p>Endorsed by: Marc Griffith's</p>
<p>Who might be harmed: Researcher Anne Johnson</p>	<p>Date of Assessment: 10/02/14</p> <p>Review date(s): February 2015</p>
<p>How many exposed to risk:</p> <p style="text-align: center; border: 1px solid black; width: 30px; margin: 0 auto;">1</p>	

Hazards Identified <i>(state the potential harm)</i>	Existing Control Measures		Additional Control Measures		Risk Level		By whom and by when	Date completed
	S	L	S	L	S	L		
<p>Physical threat to interviewer during visits to private residences</p>	<p>Interviewer will follow personal safety guidelines such as those provided by RNHRD NHS Foundation Trust in their Conflict Resolution Training.</p> <p>Prior to the off site visit the interviewer will familiarise herself with a map of the location and let her buddies know of her location without compromising participant confidentiality.</p> <p>A list of participants and their addresses will be kept in a locked drawer within the interviewer's office. The buddy at the RNHRD NHS FT will be made aware of how to access the list in case of emergency or serious concerns regarding interviewer safety.</p> <p>The interviewer will make arrangements with the buddies to make contact once she has arrived at the arranged location and will ensure the buddies are aware of her general location and contact details via mobile telephone.</p>	3	1	3	1	3		

Appendix F continued 2/4

<p>Emotional distress for the interviewer due to sensitive topics being discussed in interviews.</p>	<p>Where possible interviews will be arranged during daylight hours.</p> <p>Buddies will be:</p> <ol style="list-style-type: none"> 1. Director of Studies: Dr Theresa Mitchell will be informed of all visits as above 2. During office hours: Nikie Catchpool Consultant OT or Ute Elwell PA/Administrator Fatigue Service 3. Out of Hours: Amanda Pacey Head of Clinical Practice or Rayna McDonald Director of Operations and Clinical Practice/Line Manager. <p>The interviewer will inform the buddies of the completion of the interview once she has safely left the interviewee's premises or other off site interview location. If the interviewer fails to inform buddies N. Catchpool, U. Elwell, A. Pacey or R. McDonald will access participant's contact details and inform police of missing interviewer.</p> <p>If interviewer telephones designated buddy/buddies and uses code words 'Café Rouge' a buddy is to access participant's contact details and inform police of interviewer location as this is the agreed code for imminent danger.</p> <p>A personal alarm will be carried by the researcher during the off site interview period.</p> <p>The interviewer will ensure she has access to support from colleagues and will discuss any concerns with her Director of Studies.</p>	<p>1 2 2</p>				
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Appendix F continued 3/4

Threat to interviewer from hazardous physical environment of interview location.	Interviewer to perform dynamic risk assessment of environment on entering the premises and take appropriate steps to minimise any perceived risk.	1	3	3				
Threat to interviewer from accidents during travel to off-site interview locations.	Care taken – e.g. attention to driving conditions, ensuring proper maintenance of private vehicle or use of public transport.	1	3	3				

RISK MATRIX: (To generate the risk level).

Very likely 5	5	10	15	20	25
Likely 4	4	8	12	16	20
Possible 3	3	6	9	12	15
Unlikely 2	2	4	6	8	10
Extremely unlikely 1	1	2	3	4	5
Likelihood (L) ↑	Minor injury – No first aid treatment required 1	Minor injury – Requires First Aid Treatment 2	Injury - requires GP treatment or Hospital attendance 3	Major injury 4	Fatality 5
Severity (S) →					

Appendix F continued 4/4

ACTION LEVEL: (To identify what action needs to be taken).

POINTS:	RISK LEVEL:	ACTION:
1 - 2	NEGLECTIBLE	No further action is necessary.
3 - 5	TOLERABLE	Where possible, reduce the risk further
6 - 12	MODERATE	Additional control measures are required
15 - 16	HIGH	Immediate action is necessary
20 - 25	INTOLERABLE	Stop the activity/ do not start the activity

Appendix G

Transcript of Interview 1 with Participant 1

- 1 P1/1 Transcript May 2014 P = Participant, R = Researcher, [] = researcher's comments
- 2 Length of interview 28 minutes
- 3 R Thank you for meeting with me I might make some notes in here ((my note book)) as we
4 go along if that's Ok alright cos I won't remember everything either ... and um so that
5 could be quite helpful
- 6 Alright well um thanks again um for meeting with me and I really want to get to know you a
7 little bit better so maybe you can just tell me a little bit about perhaps how long you have
8 been ill and when it started and take it from there really xxxx [participant's name] and take it
9 from there really however you would like to explain it
- 10 P I've had chronic fatigue syndrome since April 2008
- 11 [I realised that P1's voice is croaky and weak and it may not be being picked up adequately
12 on recorder situated on small table between us I therefore decided I needed to move
13 microphone closer to P1]
- 14 R I'll move that a little bit closer cos you've got quite a quiet voice is that alrighterr... I could
15 clip that on your top actually would you mind that would that be OK or Ok
- 16 [P1 nods in agreement microphone clipped onto P1's fleece]
- 17 R is that OK it's not too in your face there....
- 18 P it's Ok
- 19 R a bit weird?
- 20 P is that quite well connected
- 21 [P is worried connector for recorder might fall apart]
- 22 R it is well connected tell you what I'll do I'll put it there shall I [I resituate the microphone
23 closer to P]
- 24 R so you've had chronic fatigue syndrome since 2008
- 25 P um yeah April the 12th
- 26 R wow you remember it that well..
- 27 P um yeah I do
- 28 R why do you remember it that well
- 29 P well I, a lot of people have just told me that I've got quite a good memory and that's, that's
30 something that hasn't really been affected by chronic fatigue syndrome
- 31 R gosh but you know that [for] some people, it's really bad isn't it memory

P1/1 May 2014

1

32 P When I was first diagnosed with chronic fatigue syndrome I thought I was going to
33 experience a lot of problems with my memory but I was quite fortunate really

34 R yeah, brilliant Ok, so that good memory allows you to remember that April 12th 2008...

35 P yes

36 R and sort of ...that was the day you were diagnosed ... or?

37 P er no that was the day when my health changed and I then I was diagnosed um officially in
38 October of the same year

39 R Ok so you say xxxx [P's name] that your health changed I wonder if you could explain
40 what it was that you noticed made you think your health changed

41 P well in April of 2008 I felt like I'd sort of gone down with the flu or something but then after
42 weeks it didn't really improve so I had um a lot of blood tests and visited various doctors and
43 um then eventually they decided that it was chronic fatigue syndrome

44 R OK, when you say you visited various doctors was that specialist or GPs

45 P er yes just normal GPs

46 R just normal GPs ..OK so why do you think you had to see a lot of them

47 P er well I'd have liked to have stuck to seeing one particular doctor but because I was so
48 keen on getting to the bottom of it it was quicker just to see whatever doctor I could

49 R OK ...alright ...so did you have a good doctor the one you would like to have stuck with or

50 P er.....

51 R what's the benefit of that?

52 P um er well seeing one doctor it saves going over details again

53 R yeah

54 P yeah ..and I think some of the doctors I saw seemed more knowledgeable about it so

55 R yeah...yeah...and so you, you saw several in the same GP practice sort of thing?

56 R um yes I did just in xxxx [geographical location]

57 R OK, why, was that, did they have different opinions about it those doctors in the same
58 surgery? Or?

59 P um yeah I tend to think they all felt the same way about what might be the cause of it or
60 anything but um yeah I can't remember any particular em theories that they had there...um
61I think a couple said it could be sinusitis but then others said that sort of health was too
62 serious for it just to be something like that

2

P1/1 May 2014

63 R Ok so. So you, you felt that there were serious things happening to you...so could you
64 explain to me a little why you think it was so serious xxxx [P's name] what that was at the
65 time

66 P well it was just that my energy levels were so low and the aches and the just...the sort of
67 tiredness was just too, sort of too hard going really

68 R Ok so too hard going to do the things you needed to do?

69 P um yes because I was doing my GCSEs at the time

70 R Oo that's tough

71 P um yeah I went into college to complete one and I felt I felt terrible during that and um I
72 completed a few here at home with this invigilator and.. but then there was the head teacher
73 decided that it wasn't fair on me to just... she realised that I was really struggling with it

74 R um ok that was quite that sounds quite supportive of her actually?

75 P yeah I think it took quite a while to get her to come round to my side but er eventually she
76 did realise that I wasn't just trying to get out of doing them [GCSE's]

77 R is that what you felt she was sort of implying at first

78 P yeah to begin with I did feel that she wasn't taking it seriously

79 R what made you think that xxxx [P's name] at first?

80 P um well I think she was just quite casual really and she, she'd say things like "oh as long
81 as you write down something during the exams that's better than nothing" and to me she
82 didn't seem very really and she didn't seem too concerned about my health

83 R and how did you feel about just writing down something anyway, I mean presumably that
84 might not have felt very comfortable for you to do

85 P No, no I didn't think it was very fair really

86 R no, no and... and you wanted to do your best of course..

87 P yeah yes I did yes

88 R yes

89 P she said that she had made allowances for me and she'd sort of give me like extra marks
90 really but I, I didn't, that wouldn't have made any difference to my health really

91 R so you did one in the college with the group then you knew by then that you were ill,

92 P um yeah...

93 R she knew did she that you were ill?

94 P yeah I'd been feeling unwell for about 4 weeks

95 R ok so this is about May time is it in 2008

96 P er yes that's right, yes I had spoken to her about it I'd said that I'd seen a few doctors and
97 er trying to get to the bottom of it um but yeah I don't think she really fully understood, well,
98 even, obviously well I didn't either didn't know what I was going to be diagnosed with but she
99 ..I don't think she really appreciated it as much as I'd have liked

100 R yes Ok and er so that time you were trying to sort of, explain to her that you know, at the
101 college about where you were at, you didn't really know where you were at yourself by the
102 sounds of things?

103 P um no I didn't

104 R I mean, how did that feel to you, what did that mean to you at the time

105 P it was quite worrying really cos I thought I could be diagnosed with something, I could be
106 diagnosed with something more serious, I was very worried about it as I thought it might be
107 life threatening or something

108 R yeah, because it was impacting on your life so much?

109 P er yes that's right because I felt so unwell for so long

110 R and you hadn't had something like this prior to 2008

111 P er not I hadn't no

112 R so.. you said about your energy levels being low and that was one of the things that
113 worried you..

114 P um yes it was yes..

115 R yes and so but presumably though in the past you had had colds and things like that..

116 P Um yes I had yes..

117 R but this was different..

118 P um yes it was yes

119 R yeah and what you said xxxx [P's name], was that because it when on for longer or was it
120 the severity of the symptoms..or..

121 P erm it was a bit of both really it was the severity and the length of time really

122 R yeah, Ok, ok so ..so you got her on board you did the one [exam] but it was all ..sounds a
123 little bit unsatisfactory for you and you weren't terribly happy with that...

124 P originally she'd, the head teacher or assist head teacher she might have been, um she
125 said I that could have my own little room on my own, with the invigilator, but just before I was

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126 due to do the exam I was rushed into this other room with a whole class of other students I
127 was er quite disappointed really because I think I would have at least felt a bit more
128 comfortable in a smaller room

129 R and you were expecting that as well weren't you so and then suddenly that didn't
130 happen..erm and presumably struggling a bit to cope anyway with that situation and what
131 had been promised didn't quite come to fruition..no ..ok So you soldiered on with that exam..

132 P yes I did yes

133 R yes.. and then tell me a little bit about sort of what happened then in the course of events
134 after that

135 P well I failed the exam

136 R aww I'm sorry...

137 P which didn't really surprise me because of how I felt during it... and then I think that same
138 day I went up to the college again in the afternoon because, cos I was due to have another
139 exam but when I arrived I just, I just felt that I wouldn't have been able to do it at all. So erm
140 my mother told the head teacher and, she said, I think at that point then, she seemed to
141 change a bit really, and then she said, then she decided that she'd sort of try and change the
142 situation really and see if I could at least do a few at home

143 R right ok..

144 P and I did three I think three exams I think at home during the next couple of weeks ..erm
145 and the invigilator that came.. to keep an eye on me during that, said that she was going to
146 tell the head teacher that I LOOKED and seemed too unwell and she didn't feel that it was
147 right for me to just go through all, all of the exams

148 R that's interesting isn't it that the invigilator thought you looked too unwell, were too unwell,
149 but you had to convince that head teacher or assistant head teacher that day that, that you
150 were poorly you know ...yeah... so quite good, quite a good ...were you quite pleased that
151 the invigilator seemed to understand or...

152 P erm yes I was quite pleased and SURPRISED really, because I, I just had visions of just
153 having to sort of wade through all of the exams at home and I wasn't expecting the invigilator
154 to sort of speak up for me in that way...

155 R yeah so to give you some support by the sounds of it...that was quite helpful..

156 P erm yes it was yes

157 R yeah... did you... on the day you that you went in and they didn't follow through and give
158 you the room that you needed and stuff in the afternoon did you and your mum mention that
159 that it hadn't been very helpful or did you not quite get that far

160 P I think my mum mentioned it to the head teacher because I didn't feel up to telling her and
161 erm, I think the head teacher, erm ... I don't think she really apologised or said very much

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162 about it but...I think...yeah but... over the next couple of weeks she did sort of change and
163 had more sympathy really for me I think

164 R good and you think that changed that day when your mum came in

165 P yeah I think that did make a difference

166 R so you got through some exams at home

167 P erm yes I did yes

168 R well done you...and ok so...what... looking sort of back on that xxxx [P's name] what did
169 all that mean all that time for you... it sounds like it was totally different perhaps to how you
170 had been when you were at school or at college before, what, how do you remember that
171 time if you like..

172 P erm well I try like, I try not to really remember that time because that was when chronic
173 fatigue syndrome was at its worst really

174 R yeah..

175 P ...so I don't, I don't often really think about it but...

176 R so you've got a good memory...try and put that to one side...and because it was a painful,
177 difficult time, not pleasant?

178 P yeah it wasn't nice really it.... So I got three C's

179 R gosh

180 P...for my erm, I think that was mostly because I'd done quite well with the course work
181 and I got A's so that sort of made up for the fact that I didn't do the exams..

182 R yeah..

183 P...so then I realised how good it was that I'd tried so hard during the course work

184 R yeah, yeah well done... you've got a smile on your face there ((I laugh))... so you were
185 quite pleased really

186 P erm yes I was yes

187 R so it was a really difficult time obviously

188 P erm yes but it did make me feel a bit better in some ways

189 R yeah, yeah.. and all this time you know how, how about your mates and people around
190 you do you think they understood what was going on for you...

191 P well I lost contact with a lot of my friends and cos I wasn't on Facebook then and erm and
192 yeah I just wasn't able to see my friends or get in touch with them really because I didn't feel
193 up to it or I, there wasn't really many ways of doing it so..

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194 R and so do you think they understood what you were going through or...

195 P er I think some of them might not even have known about it because of, they, I think that
196 they themselves would have been so wrapped up in their exams that...

197 R ...ah good point... ..so distracted by that, sort of thing

198 P yeah

199 R and I suppose... would that fit in with ...I guess when you are doing your GCSEs like that
200 you are perhaps not at school all the time anyway um so do you think that added to them not
201 missing you sort of being there as it were

202 P cos a lot of the time during.. .in the May June 2008 students were just expected to turn up
203 for their exams ...

204 R I've got you

205 P so...

206 R so they could have missed the fact that there was something wrong that you were
207 struggling a bit, cos you only needed to be there at a certain time

208 P about a year later I just bumped into one of my old friends and he was, he hadn't heard
209 anything about my illness or the exams so I filled him in then, so...

210 R did he understand, did he...

211 P yeah, yes he seemed to understand, but I think that would have been a similar case with
212 most of my others friends they wouldn't have been aware

213 R ok, ok, how do you feel about that, do think you would wish they knew or were you happy
214 that they didn't or did it not make a difference

215 P erm well I wish they had known really and I sort of, wish I could have been able to see
216 them again during that time, so I wouldn't have lost touch with them for a few years

217 R...and... so, what do your friends mean to you what did your friends mean to you then

218 P erm, well I don't really have too many friends, cos I prefer to just have a few close friends
219 really

220 R ok

221 P but erm, during the last couple of years I've got in touch with a few of them on Facebook
222 to, to sort of make up for not seeing them during that time.

223 R so Facebook in 2008 I suppose wasn't that popular was it

224 P no

225 R so has that been quite helpful actually that social media

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226 [I notice – my prejudgement comes into play, that speech has slowed down and P's volume
227 has reduced a little and he seems to have a dry mouth about which I am concerned]

228 R Ok, ok ... and so.... are you ok I just want to check in with you that you are not getting too
229 tired

230 P erm I'm ok at the moment

231 R yeah, ok well you just say ok cos we can stop whenever you wanna stop because I think
232 in the information you probably noticed that I can come back and see you again we can pick
233 up some of the stuff if you would like me to and you'd be up for that but we can decide at the
234 end so you just say if you are getting too tired

235 P how long are you expecting this session to last

236 R no that's... it's not about me it's about you, if you wanna go on for another five minutes
237 that's lovely if you want to go for half an hour that's fine but we can do either or somewhere
238 in between

239 P ok

240 R you tell me cos it's about you and I can tell you are getting a little bit tired now aren't you

241 P a little bit yes

242 R shall we go on for another five minutes

243 P erm yeah we could do yes

244 R yeah, alright well you just say xxxx [P's name] if you want to stop alright

245 P ok

246 R erm so we've got through your GCSE's

247 P erm yes

248 R and that was at college and we are now into about September October time 2008 or have
249 we gone into 2009

250 P erm well, in, I, in October 2008 I went to xxxx [name of NHS Paediatric CFS Service] and
251 then I saw xxxx [specialist paediatrician] and she told me about this sort of ... erm... scheme
252 thing where you could get back and help where you sort of help your health recover and that
253 was about sort of about managing your energy levels and pacing yourself reallyand
254 erm..... so from November until around March of 2009 I didn't really go out during that time I
255 was sort of building up, I was slowly trying to do more each day and then in March 2009, I
256 started erm.. slowly going out more often and I suppose just once every 2 weeks and then
257 once a week and so onand then around April of 2009 I started this course that was
258 linked to the adult learning and leisure centre that was the equivalent of A levels ..and to
259 begin with I was just about for about 3 or 4 hours a week and thenaround September

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260 time I started going up to the adult learning and leisure centre and then gradually I sort of
261 built up the to the amount of time I'd work on the assignments

262 R brilliant gosh that's quite an achievement actually isn't it

263 P erm yes it was yes

264 R yeah Ok

265 P it was quite a slow... slow thing but I

266 R yeah

267 P ... eventually I caught up with it

268 R yeah and as a young person you know a year 's a long time it can seem like a long time in
269 your life cant it

270 P yeah, yes erm 2008 and 2009 went quite slowly

271 R yeah, yeah, yeah you must have been wondering what was going on next, and where you
272 were going, you said about wondering about the seriousness of it.....

273 P erm yes

274 R So the last thing I would like to ask you this morning so we can stop and give you a break
275 erm is how important or what did it mean to you to get a diagnosis (name) ((sensing he is
276 becoming fatigued now))

277 P erm well I was quite pleased in some ways when I was told that I had chronic fatigue
278 syndrome cos that meant that I stopped worrying about the possible other reasons why I
279 was feeling unwell ..er sort of obviously gave me a few ideas about how to cope with it more
280 and...

281 R yeah Ok.... who gave you a diagnosis do you remember

282 P erm...

283 R was it one of your GPs that you mentioned earlier

284 P well around the beginning of June ((2008)) I saw one doctor ... erm I think mum knows
285 what her name is but I can't remember

286 R that's Ok

287 P and she said that because I had it about around 2 months then she said that it sounded
288 very much like I could have chronic fatigue syndrome

289 R Oh that was a good pick up wasn't it really from a GP

290 P and then about a month later I saw another doctor who I think was more experienced and
291 um she sorted of backed it up as well

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292 R in the same practice

293 P erm... I think it might have been yes

294 R yeah, well that's, that's really good actually isn't it

295 P er yes it was yes

296 R cos I know some, some people in that position can spend a long time trying to get any sort
297 of light shed on what's going on don't they

298 P yes

299 R yes good ok. Would you like to stop there

300 P well if there's a couple of quick questions

301 R ok what were you worried about, what did you think you had?

302 P umwell I, I didn't really have any particular thoughts or any specific ideas but I, I know
303 at one point.... in around the middle of June I had a CT scan cos there were, I thought I
304 might, well one doctor thought I might have a brain tumour or such

305 R gosh that is very worrying isn't it

306 P erm yeah but the results for that were fine I can't think of any other problems that I thought
307 I might have

308 R so your mind was working overtime a little bit really on what it might be ...

309 P yeah, yeah

310 R so that doctor thought you might have that because ...

311 P erm...

312 R what was it do you think that made them think it might be a brain tumour

313 P I think the doctor just thought it might be a possibility and then hearing my dad's brother
314 had one as well I think she thought that was something else to go on really

315 R ok, ok so they sent you off for some tests good but all was well

316 P erm yes

317 R which is good fantastic

318 P erm yes

319 R Ok well we will stop there so that you can have a break and a rest thank you

320 End

Appendix H

Example of the coding system employed

B+C(2006) familiarising
self & the data
Phase 1&2 Interview 1

1 P8/1 Transcript *Potential codes n = 42*

2 Length of interview – 4 hours 30

3 R Lovely all right just to note down the name of that folder, Folder A, lovely ok
4 thanks for coming in to the hospital yeah I am not going to go into interview
5 mode I will try and relax into this conversation with you so you know that this
6 study I am doing is about there are no pre-destined questions its not about the
7 programme its not about our service or anything its about your experiences as
8 a guy of living with Chronic Fatigue Syndrome.

9 P Ok.

10 R Um so wherever you want to start that is fine by me and you know go for it. *8/1/11*

11 P Maybe I should start from where I got my diagnosis and work back. *Point of*

12 R Absolutely fine yeah. *start*

13 P I got my diagnosis in I would guess it was mid 2008 and I had been off ill I had

14 a couple of planned returns since November 2007 which I had got up on the *8/1/2*

15 27th of November at 6 o'clock and my body just packed in and just couldn't *Did 2*

16 cope with anymore... anymore charges basically I was asking of it you know my *planned*

17 brain was asking my bodies to cash cheques and it couldn't and I just collapsed *RTUs*

18 I had been struggling on with a virus that I had picked up from a student for

19 about 18 months I was driving to a University *8/1/3*

20 doing that every day then I was covering for a colleague who was completely *Reason*

21 and utterly inept and had made big problems with the programme and fielding *for*

22 a lot of that as well as studying a PhD and re-writing two course and I was *being*

23 doing over 75 hours a week as well as struggling with this virus that I couldn't *off*

24 shake off and my body just said can't do it anymore. I think having had *work*

25 knowledge of CFS/ME from a young friend in the 80's and 90's I didn't really

26 want to come to terms with the psychological aspects of it I thought it was *8/1/4*

27 purely physiological I thought it was a purely viral thing and in hindsight *Thought*

28 looking back to it I was putting a lot of demands on my mental capability you *it*

29 know studying the PhD, re-writing courses and things so I was under a lot of *was*

30 pressure and I wasn't allowing my body to recover. So when I first *purely*

31 encountered CFS/ME I went to my GP and said you know I think I have got ME *physiolo*

32 the ME didn't... the first GP I actually saw just shrugged her shoulders and said *8/1/5*

Participant 8 Interview 1

Page 1

**(a significant distance away)*

*1st
discussion
e.g.
repossibility
of ME*

Appendix I

Example of initial codes generated from Edmond's data across interviews

**Phase 2 Generating Initial Codes for each interview:
(after Phase 1 familiarisation with the data via transcripts)
Interviews 1 - 2**

Interview 1

1. Start of the illness and his attitudes towards it
2. Fitness, keen sportsman, intense exercise, frustration as can't exercise, return to exercise too early, cycle of exercise getting ill and then exercise again, exercised and headaches, didn't see running as strenuous
3. Physical build
4. Physically sick, weakness and nausea
5. Like being hung over
6. Pain behind the eyes and pulse headache
7. Very severe virus
8. Became ill over night
9. Ill for 2 weeks
10. Pushing through symptoms and ignoring them
11. Lack of illness experience to know when he was unwell
12. Had really good week so ran
13. Overwhelming discomfort throughout whole body after run (one day phenomenon)
14. Pain when exercising moves on to include pain being constant in all he does
15. Body realising something wrong
16. Not comfortable leaving home to walk for more than 5 minutes unpredictable demands of physical activity
17. Always a 24 hour delay then pain
18. Anticipated delay makes it worse for the next day
19. Holistic illness mind + body a nexus between the 2
20. CFS difficult to pin down
21. Not worrying at all but still getting the physical symptoms
22. Can be provoked by the mind and treated by the mind

23. Attention to it makes it worse
24. Distraction = you feel a lot better
25. A really awkward beast to deal with
26. Realised it want going away and going on for too long
27. GP useless and GP visits 3 -4 to get diagnosis
28. Advice to rest unclear
29. Not being understood by GP
30. Hypochondriac minded
31. Blamed self for not resting enough
32. Profile of someone who gets CFS = worries
33. Comparing CFS and PVFS to anorexia = control
34. Brought up in a certain environment and reaction between personality and environment, academic pressured environment, expectations of school and self and university
35. Transition from school to uni
36. Living alone
37. Importance of uni accommodation
38. Taking up a sport to make friends, team sports culture
39. Lots of boys bigger than him he was skinny
40. Don't think about activity demands when completely well
41. Liking the effects of exercise on physique control over how he looks and feels, obsession and addiction
42. Academic discipline exercise discipline using this to pace
43. Housebound
44. Disabled otherness
45. Depression
46. Accepting limitations
47. Not knowing if it will go and uncertainty, fear of magnitude and permanence
48. Mum and dad's support
49. Retreating into distracting enjoyable activities he had one before and could manage, mental escape 'other world' (an alternative to the real experience/world), achieving something

50. Doing nothing/total rest awful in every way 2 – 3 weeks doing nothing he decides something has to be done and doesn't care if it makes it worse (we are essentially occupational beings)
51. Staying the same
52. Trying to get over it
53. Not trying to work it out and resignation to decrease worries = forgetting about it to get better (same as attention making it worse)
54. When he wakes and how he feels
55. Not wanting to read anything
56. Solitary by choice is needed and feeling selfish about protecting himself
57. Isolation and introspection
58. No one else can relate to it
59. Doesn't blame others for not understanding
60. Not the sort of thing to respond to Western medicine and puzzling to deal with
61. Unseen and unknown force
62. Anticipating frustration of others
63. Visit to specialist medic and usefulness of this
64. Help sooner would have been useful
65. No such thing as mental illness or physical illness just illness – materialism
66. Being referred to our service
67. One sentence cured him
68. Implementing advice, gradual increase paced for 3 years and measuring progress and getting back to where he wanted to be
69. Not constrained in any way now
70. Can do things most people can't
71. Exercise and withdrawal as a drug (link with addiction)
72. Male anorexia
73. Invincibility and masculinity – self confidence and body shape potent combination
74. Girlfriends and their impact
75. Doing something fun again
76. Death of social life
77. Doing normal things
78. Close friends being required to understand

79. Being equipped with the knowledge to deal with setbacks and having a direction of travel
80. Setbacks defined as illness
81. Suicidal thoughts but prevented by favourable support, emotional and 24 hour care
82. Having something to look forward to
83. Being prey to this illness
84. Using the illness for positive gain
85. Being up front = respect from others for his condition
86. Normal life back in reach
87. Normal growing up
88. Middle ground between childhood and adulthood and first real pressures
89. Something harrowing most people from 19 – 21 haven't been through
90. Settling on aversion of yourself a bit at sea with yourself
91. Trying to extract good things from bad experiences
92. It's always at the back of my mind
93. Looking back illness feels a bit alien
94. Still can get headaches but not like type when he was ill normalises and takes tablets which he wouldn't have done before and waits until it's gone before exercise
95. Now behaves normally c/f extreme exercise or doing nothing to reach optimal goal
96. Previous addiction took him away from becoming fit
97. Pushing through pain doesn't always get you there (was in a culture where discourse was opposite)
98. Learning when to push and not to push
99. Not met anyone else with CFS
100. Advice to others don't exercise if you are ill
101. On graduating thought he had come a long way since housebound days
102. Took job which was well paid as didn't think he could achieve his preferred career of being in the forces in hindsight he would have been fine too late now (regret)
103. Diagnosis messed up his career opportunities in the services

104. Not happy with current career but hasn't thought about being ill while working
105. Exercising now without consequences = wonderful feeling
106. Continues to be sensible though
107. Misses the illness and saw it as a gap year away from pressures and time spent with family
108. Needs gap year now to process the experiences he went through he feels and not sure what he want to do with his life
109. Fumbled the original transition from childhood to early adulthood
110. Could return home but some stigma attached to this he feels

Potential codes = 110

P2 Interview 2 initial code generation

1. Defining masculinity and where the problem came from
2. Body as a reliable machine
3. Engrained mentality of elite sports culture if you are going to win
4. Profile of someone with this illness academic over achiever
5. It's about control self-disciplined academic and routine
6. Psychological bonus of reaching targets
7. Difficulties with setting targets
8. Being the best at sport and things amongst his own friends (Alpha male theory)
9. The role of his needs and those of others
10. Worries about having an attractive girlfriend and his attractiveness provoking feelings of insecurity and reminded him of what he used to be like
11. Worried she would get fed up
12. Breaking up with girlfriend felt immediately better and a fresh start to recalibrate life to clear the slate (it's all about measuring: targets, %, recalibrate)
13. Recover quickly if not in a relationship unless very committed and long-term
14. Need to be selfish to recover
15. No idea what it is but people believe you if you are in pain
16. Definition of cured
17. Trust in what you are doing to cope
18. You have to cure yourself
19. You need info right assistance, encouragement and family support

20. The horizon of just a day is scary
21. Targets provide a future so horizon is changed and future rolls out before you
22. The importance of being given information and hope at the first encounter with health professionals a positive message
23. Placebos or lying would be useful even if you know its lies
24. Telling people you are able to get better
25. Don't care about managing it and wanting to get over it
26. Until we understand the easiest way to treat it is through the mind
27. If you say the only certainty is uncertainty this is guaranteed to make it worse this should be banned from the care cycle
28. Sufferance of individuals for the greater good (positivist view)
29. Suggests input needs to be massively tailored (we do this)
30. Psychological support for firm targets rather than CBT
31. CBT calibrated towards the female experience

Potential codes = 31

Appendix I continued

Number	Potential Code Name	Participant, Interview and Line Number/s of Data
1	Probably best to start from how I got the illness	2/1/2, 2/1/7 – 2/1/13, 2/1/31, 2/1/34, 2/1/239, 2/1/297
2	It was very much a compulsion for me exercise an addiction	2/1/14, 2/1/82, 2/1/83, 2/1/86, 2/1/31
3	Went back to exercise too quickly	2/1/15
4	Cycle of bit better, exercise then getting ill again	2/1/16 – 2/1/18
5	Frustrating so eager to push through symptoms	2/1/13, 2/1/19, 2/1/20
6	Not having the experience of being seriously ill before so ignored it	2/1/21, 2/1/22
7	Feeling like it was a hangover	2/1/23 - 2/1/27, 2/1/30
8	Didn't see running as very strenuous	2/1/28 – 2/1/29
9	Pain not just when exercising but in everyday activities	2/1/32
10	That feeling of the body realising something was wrong very difficult to describe	2/1/35
11	I couldn't do anything other than be in the house	2/1/37 – 2/1/39
12	It was always a 24 hour delay	2/1/40, 2/1/41
13	It involves the mind and the body at the nexus between the 2	2/1/43, 2/1/44, 2/1/45, 2/1/46, 2/1/47, 2/1/48
14	Paying attention to it makes it worse whereas if you are distracted you feel a lot better	2/1/48 – 2/1/50
15	A really awkward beast to deal with	2/1/51
16	Making appointments to see a GP as illness going on for too long	2/1/52 – 2/1/55
17	GP giving advice but advice not completely understood by Edmond	2/1/56, 2/1/56.1 – 2/1/58
18	GPs not understanding	2/1/59 – 2/1/60
19	Part of the profile of someone who gets CFS	2/1/63 – 2/1/71
20	It springs from the person and the environment and some bad luck	2/1/65, 2/1/77
21	A university problem unbelievable workloads and expectations	2/1/77
22	First time living alone at university and being unhappy	2/1/79 – 2/1/81
23	To deal with unhappiness gets into rowing	2/1/82
24	Feeling skinny compared to bigger boys	2/1/83 – 2/1/85
25	Addicted to changing your body shape and not being able to stop	2/1/86, 2/1/88 - 89

26	Academic performance and exercise as disciplines	2/1/88, 1/2/12
27	Couldn't access who he wanted to be or belong to team because of CFS	2/1/90
28	Housebound and disabled	2/1/91, 2/1/240
29	I had just done my end of year exams before I got it so I took a year out	2/1/93, 2/1/94, 2/1/95
30	I was very depressed at not being able to exercise and not accepting limitations	2/1/96, 2/1/97
31	Getting diagnosis after 3 – 4 visits to GP	2/1/98
32	The difficulty with GPs telling him the time he will have it is unknown	2/1/98, 2/1/99, 2/1/100
33	Without mum I think I would still be ill now	2/1/101 - 2/1/105, 2/1/183, 2/1/19, 2/1/256, 257, 1/2/45, 46, 49
34	I couldn't deal with it so I retreated into other things	2/1/106 – 2/1/111
35	Cognitively I was affected as well	2/1/112 – 2/1/115
36	I got a lot of satisfaction with painting	2/1/116
37	I was getting worse because we didn't know what to do to treat it	2/1/116 – 2/1/119
38	Sitting at home doing nothing all day but still not recovering so something had to be done	2/1/119 – 2/1/122, 2/1/180, 2/1/187, 2/1/188, 189, 190
39	The feeling of complete powerlessness	2/1/123
40	You shut off from it	2/1/124, 2/1/125
41	It's a feeling of being disabled	2/1/125
42	I wasn't thinking about the future or the past just the chunks of time of the day	2/1/126, 2/1/127
43	The worst months when he gave up hope of recovery	2/1/128 – 2/1/134
44	No one's giving you the way out	2/1/135
45	What I'd do all day	2/1/136 – 2/1/143
46	What I'd think when I opened my eyes each day	2/1/145 – 2/1/149
47	Mum constantly asking me how is it today	2/1/150 – 2/1/151
48	All-encompassing pain it wasn't tiredness	2/1/152, 1/2/38
49	The only escape was to do something to take you into a different world because nobody can relate to it	2/1/53
50	People don't understand there are no physical outward symptoms	2/1/153 – 2/1/155, 1/2/37
51	It's not something you've ever had experience of	2/1/156
52	Not treatable with Western medicine	2/1/157 – 2/1/158, 2/1/162
53	It's something that I found puzzling to deal with	2/1/159 – 2/1/160, 2/1/170,, 1/2/106

54	All mental energy going into focus on pain and how you can deal with it introspectively nothing left for other tasks	2/1/163
55	Its your entire life	2/1/165
56	Changing the way you live entirely for the worse	2/1/168
57	An unseen and unknown force	2/1/168
58	There is nothing more important to you day to day than understanding what it is	2/1/169, 2/1/170
59	How mum felt	2/1/171
60	You feel a bit pathetic and anticipate peoples frustration	2/1/172, 173, 174,, 2/1/227
61	The feeling that only you know what's going on	2/1/175
62	Being a burden	2/1/175
63	Feelings of 'otherness' when interacting with normal people and the desire to protect and isolate yourself	2/1/176
64	Fear about the true magnitude of what's going on	2/1/177 – 2/1/179
65	Dad around as well but not sure if he was worried	2/1/181, 182, 185, 186
66	Deciding to do something and organising to see a specialist privately as GP useless	2/1/53, 2/1/188 - 2/1/190, 2/1/195
67	What the specialist did and said	2/1/191 – 2/1/194, 2/1/196 – 2/1/199
68	It was one sentence he heard from a specialist fatigue team which cured him	2/1/199 – 2/1/203, 2/1/206, 2/1/245, 2/2/76
69	Feeling 100% again and exercise not constrained	2/1/204
70	Following what he heard	2/1/203, 2/1/206 -207
71	Living a relatively normal quality of life and his motivation to achieve this	2/1/209, 210, 211
72	The metaphor of exercise as a drug addiction and control and intoxicating	2/1/212, 2/2/6, 2/2/7,2/2/8, 2/2/11
73	Friend calls it the male anorexia	2/1/213
74	It's all about being as fit and muscular as you can be	2/1/213
75	I'm naturally skinny and know what body shape I like	2/1/214, 217, 218, 219
76	A certain feeling of ease in your physical self, invincibility and masculinity as well	2/1/215, 216, 1/2/4
77	Being careful about exercise at first	2/1/220, 2/2/81, 2/2/82
78	I needed to focus on myself rather than the needy girlfriend	2/1/221 – 2/1/229, 2/2/31, 2/2/32, 33
79	Seeing a former girlfriend and doing something fun again	2/1/230, 231, 233

80	Your social life almost completely dies	2/1/233
81	Having to think about the unpredictable demands of physical activity and micromanaging	2/1/234 – 2/1/237
82	Being clear with close friends even when getting better	2/1/235 – 2/1/238
83	Making small but noticeable progress	2/1/243
84	I get to the stage when I can go back to university	2/1/244
85	I had a set back before I went back to university but knew what to do	2/1/246 - 249
86	Thinking about suicide crops up quite a lot but he always had something to look forwards to	2/1/250 – 2/1/253
87	Making a fuss about his university accommodation on his return	2/1/259 - 265
88	Materialism is the answer and there is no such things as mental illness	2/1/266 -67, 2/2/103
89	Normal life again was in my reach	2/1/268 – 271, 2/2/85
90	Illness changes you it was harrowing and I learned a lot about myself	2/1/272, 2/1/277, 2/1/278, 279
91	You don't really know who you are as you're changing all the time anyway	2/1/273 - 276
92	You have to try and extract good things from the experience	2/1/280
93	I am 100% better now I feel like I used to	2/1/281, 282, 284, 2/2/50, 2/2/51
94	The pain I get now is not the same	2/1/285 – 2/1/290
95	I don't do gratuitous things now I have normalized my behaviour	2/1/291 – 2/1/296
96	Advice to others about exercising when feeling ill	2/1/298, 299
97	I was scared of reading about it I let mum do that	2/1/300 - 303
98	I got the degree I wanted I've come a long way	2/1/304 , 305, 308
99	The upset of trying to join the services but being rejected because of his CFS diagnosis	2/1/310 - 311
100	Back to square one with work but knowing he will get through it	2/1/313, 2/1/334, 2/1/339
102	Being unhappy in work but still being well	2/1/314
103	Using the gym as a release mechanism for unhappiness without any negative consequences	2/1/315 - 317
104	Worried about applying for services because of his CFS but in hindsight feels he would have managed	2/1/318 - 322

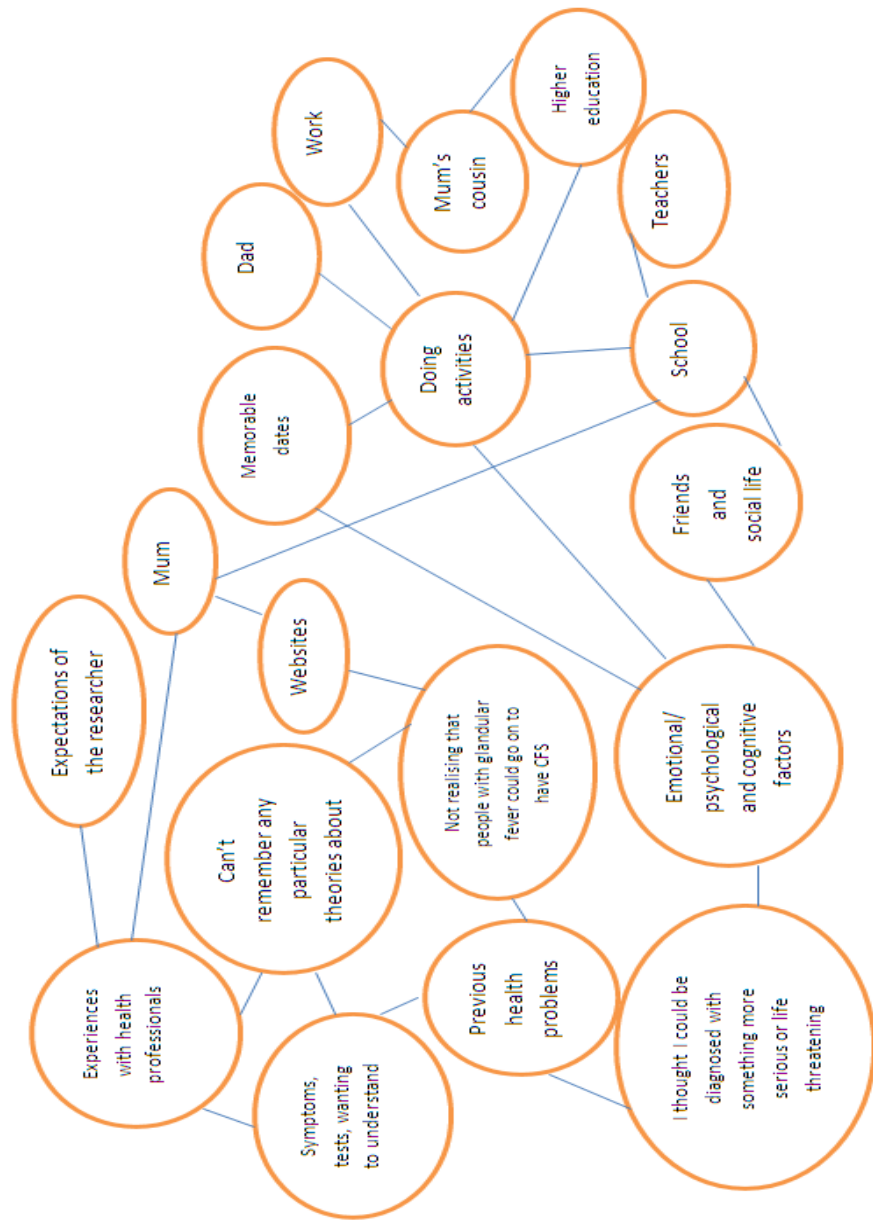
105	Looking back I almost miss it and long for it	2/1/324 - 330
106	Would like to resign from job he hates but needs to earn a living	2/1/332
107	Could leave job and live back at home but might be stigma around that	2/1/332, 333
108	(Masculinity) for me there's a large physical aspect to it and competitiveness which is where the problem came from	2/2/1
109	Competitiveness translates into your personal life and you become competitive with yourself	2/2/3
110	When you can't compete you feel emasculated	2/2/3
111	Body feels like a machine that you can rely on that's never going to stop	2/2/5
112	Can't rely on body at all	2/2/6
113	A competitive university environment similar mentality to elite sports	2/2/9, 2/2/10
114	I know the profile of someone who gets these illnesses	2/2/13 – 2/2/15
115	I am a big fan of routine and hitting my targets	2/2/16
116	When ill missing your targets is difficult until you set new ones	2/2/17
117	Setting concrete targets is a good treatment for someone like me it gives a psychological bonus	2/2/18, 2/2/77
118	Masculinity as an attitude	2/2/20
119	Dad is masculine	2/2/21
120	Masculinity and his friends	2/2/22
121	I consider myself a bit of an Alpha male amongst my own friends	2/2/24
122	My attractive girlfriend made me feel emasculated when I was ill	2/2/25 - 30
123	Unless you are in a committed relationship you are going to recover quicker if you are not with anybody	2/2/34 - 36
124	If you tell people you are in pain they tend to believe you	2/2/39
125	Support from other family members	2/2/41
126	Distressing for mum and dad	2/2/45
127	Defining cured	2/2/50
128	I don't worry about it coming back	2/2/53
129	Defining illness as a setback that happens 24 hours after exertion	2/2/63 - 67

130	Once I had an immediate set back	2/2/67 - 70
131	Learning to trust self, tune out and not be hyper vigilant to niggles	2/2/71 - 72
132	You do have to cure yourself there's no pill you can take	2/2/73 - 75
133	Suddenly you can do things that you wouldn't previously do	2/2/80
134	What is the difference between me and someone who is better	2/2/85
135	When you can show no progress there is no future your horizons are just around the day	2/2/90, 91
136	Reaching targets gives back an horizon and your future rolls out in front of you	2/2/92
137	Everyone experiences the illness in a unique way so they will bring different complaints to their GP and need tailored input	2/2/93, 2/2/111
138	Important for whoever sees them first to give them something to avoid despair	2/2/94, 95, 2/2/99,100
139	Placebos would be extremely helpful	2/2/97
140	The foundation and start point for recovery it to relax and not worry	2/2/98
141	I don't care about managing I want to get over it	2/2/101
142	Lying to people is the best way of treating it	2/2/101
143	The mind as a physical phenomenon and talk as tablet	2/2/102, 2/2/104, 105
144	Eradicating the only certainty is uncertainty from the care cycle	2/2/106
145	Suggestions for treatment approach for men	2/2/107
146	What I was told	2/2/08, 09
147	Lying for the greater good	2/2/110
148	Advice on how to improve recovery rates	2/2/110 – 2/2/113
149	Thoughts about CBT/ACT	2/2/114 – 2/2/119

Appendix J

Initial Thematic Map for Participant 1: George

P1 Phase 3: Initial Thematic Map Showing Potential Main Themes & Derived Candidate Main Themes



Appendix K

Example of Thematic Analysis Phase 5: Participant 8/Arnold

Phase 5 Arnold

Data Analysis: defining and naming the themes and interpretations

Main Themes: 4 in total

1. Maybe I should start from where I got my diagnosis
2. It's a misunderstood condition
3. That was the point I died and then there was a new me
4. I would consider myself in some sort of remission

Notes and Quotes

Arnold's speaks from a horizon of having had CFS/ME on two separate occasions with a 'recovery' in the middle of approximately fifteen years. He has experienced his illness as being labelled different things including Epstein Barr Virus, YUPPIE Flu and ME. At his worst during the first episode in the 1980's when he was 26, he had difficulty with walking and had to crawl on hands and knees to try and get around the house. At his worst, during his second episode which started in his fifties, he contemplated suicide and shared this idea with a close male friend who also had personal experience of a chronic illness, then his wife and eventually his GP.

He currently still has the illness but considered himself as being in remission at the time of our meetings. Remission being described as his ability to return to activities and occupations he likes to do wants to do and has to do.

Arnold lives with his supportive wife and they have been married for approximately thirty years. His wife has now retired from her professional career and Arnold has given up

employment as a university lecturer to return to his original career and valued interest, as a fine artist.

Arnold is the only participant in this study who was known to me as a clinician prior to being recruited. He had however, been discharged from the service some years before the study commenced. When we discussed why he wanted to be involved in the study he explained that the service in which I work had saved his life by the interventions offered to him. These included listening and validating Arnold's experiences and offering practical and psychological strategies for coping. These he explained, enabled him to abandon thoughts of suicidal ideation, accept the complexities of CFS/ME and begin living again despite its presence and impact on all aspects of his life.

1. Maybe I should start from where I got my diagnosis

Definition of the theme: This theme represents how and when Arnold received a diagnosis of CFS/ME and prior to that, a diagnosis of Epstein Barr Virus some 15 years earlier.

Sub themes:

- Maybe I should start from where I got my diagnosis
- This was the 80's and they just called it Glandular Fever
- I went to my GP and said I think I have got ME

Maybe I should start from where I got my diagnosis	Interpretation
<p><i>"Maybe I should start from where I got my diagnosis and work back... I got my diagnosis in, I would guess it was mid 2008..." 8/1/11</i></p> <p><i>"...I got my diagnosis... the year after we got married. We got married in 2005 and I became ill in 2006/2007..." 8/2/18</i></p> <p><i>"I was fine and then I picked up this virus in it must have been 2006 and had it for about 18 months and so... flu like type virus... and... it's led to this condition now. I ache, I ache pretty much all the while... "... I am using my stubbornness, I mentioned my stubbornness earlier on, I am using it positively now where in the past, I would actually just push through and not think about things and just struggle on I have now got to the point where, ok you pushed through but if you don't feel very good stop and there is no shame in stopping, there is no shame in stopping and resting up um you know, my intention is to, as I've mentioned, I have gone back to the gym to get my health back, my fitness back and my intention is to go back to Karate in the New Year, so I know I have to be sensible now, I have to work with my body rather than against it..." 8/1/15, 8/1/18</i></p> <p><i>"I had been struggling on with a virus that I had picked up from a student, for about 18 months. I was driving to</i></p>	<p>Arnold is an accomplished story teller and happy to share his experiences/horizon with me whilst mindful of mine and the service I represent to him. He feels the service saved his life and is grateful for this and happy to contribute therefore to research.</p> <p>Logically he provides the time of his most recent diagnosis 2008 and works backwards filling in the story over several years.</p> <p>Interestingly although this is the second time he had experienced chronic fatigue he doesn't initially associate this episode with the first which he had in the 1980's. (Use of HC here to piece together the experiences).</p> <p>He hopes the episode will be transient and returns to work after experiencing some</p>

<p><i>a University in [country name] from [different country name] and I was doing that every day, then I was covering for a colleague... as well as studying a PhD... and I was doing over 75 hours a week as well as struggling with this virus that I couldn't shake off and my body just said can't do it anymore... It was just a flu like virus... I think I had a couple of weeks off I can remember the student who I got it from one of my favourite students... he was a great student he came in with a really nasty virus and he couldn't shake it off... and I picked it up from him and I had a few days off because I felt really awful then I came back in and it just didn't go away..." 8/1/3</i></p> <p><i>"... when I first... collapsed I got up and collapsed my wife called the paramedics because I was having a lot of chest pain so I got a paramedic out said you know check me out and said look I think you need to go and see your GP later on today... Heart was ok he said you haven't had a heart attack he said I suspect it was basically just a panic attack that you just can't face it anymore... he said you are possibly overworked, exhausted and you know your body is just saying can't cope with this anymore..." 8/1/7</i></p> <p><i>"So I went to see my GP and they sent me up to the [name of acute hospital] and I had a lot of stress tests and heart tests and things like that. I had never had any problems with anything like that, even though my parents had coronary conditions, my heart was fine..." 8/1/8</i></p> <p><i>"...I trust my GP... whole heartedly." 8/2/11</i></p> <p><i>"The pain... and the muscle pain and the tiredness the absolute just bone aching tiredness went away and... I was well enough to go and study Karate and there was obviously muscle pain with Karate but it was 'a... ok that's an exercise'... it was an exercise pain... because if I didn't train for a few days the pain went away... and I could see that I'd exercised and I pushed my body hard and I was getting muscle pain and tiredness... if I went on holiday that went away and I felt fine." 8/1/21</i></p>	<p>occupational disruption. After collapsing with acute chest pain as a significant symptom (like Christopher) his GP suggests his body can't cope anymore. He is listened to by GP rather than suggesting his need are purely psychological. It is only after being ill for about 18 months with flu like symptoms (also like Christopher) that he suggests to the GP in whom he has faith, that he may have ME and the GP agrees. This is a sign to Arnold that his GP is respectful of his opinions as a patient. Arnold has decided that there is no shame in not performing activities and occupations as completely as he may have set out to do because of his illness. Something that he didn't accept initially.</p> <p>Arnold is able to differentiate between pain and tiredness associated with exercise and different bone aching tiredness, which supports the notion of good pain and tiredness and bad. He finds resting helpful in alleviating his symptoms.</p>
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<p>This was the 80's and they just called it Glandular Fever</p> <p><i>"...I have one of those enquiring minds and I like to know the correct things and I like to research things myself so that's when I found out that a little knowledge is a dangerous thing so yeah I found out it was called Epstein-Barr but no I think in the... this was in the 80s and they just call it Glandular Fever..." 8/2/1</i></p> <p><i>"... I started doing a bit of research myself you know with some of the worry... Wikipedia is a great thing [laughs]..." 8/1/8.1</i></p> <p><i>"I'd had Epstein-Barr virus about 20 years before... it was the onset of HIV in the UK and I remember going into the [name] Hospital in London... because I had a flu like virus and I didn't have a GP and... I ended up for blood tests at [name] Hospital and in the meantime, between the first initial blood tests and going back for second blood tests, the issue of HIV appeared on the news, so the next time you go back all the nurses are double gloved, masked and all sorts of bits and pieces and that's when I got my diagnosis of Epstein-Barr virus... you know I was in and out of pubs and stuff like that I had a lot of friends and things and I you know yeah you were worried..." 8/1/11, 8/1/12</i></p> <p><i>"...I think I must have just picked up a virus on the tube or the bus or something like that yeah, very heavily populated environment... which in those days was incredibly packed... led to me getting Epstein-Barr virus and feeling awful for a month or so, six weeks, eight weeks and then just feeling just tired and achy and headachy and worn out for about seven years and that lessened as you know, over the seven years obviously and then disappeared." 8/1/17</i></p> <p><i>[The possibility of having HIV] "...scared the bloody life out of me um I have... always been heterosexual I have never been an intravenous drug user I have had a wild, wild past as most people you know I have had more than several partners and I have been known to take things in the past but I have never been the two things that we originally associated with HIV so my first thought was my god have I caught this and it actually turned out that I found... later... a friend a female friend who died of HIV</i></p>	<p>Interpretation</p> <p>Knowledge is power and useful when explaining to others and also for self-understanding.</p> <p>He is aware of existence of different labels associated with enduring fatigue.</p> <p>Troublesome fatigue some 20 years earlier led to suggestions re HIV = very scary for him as a killer at the time and the media played a role in raising his fears that it might be HIV or AIDS.</p> <p>Finding out he had had Gilbert's Syndrome just by chance due to a life insurance check was disconcerting for him. This knowledge had been available for 4 years but none of the medics he saw before the check had bothered to share this with him.</p> <p>Note: Sparky and his life threatening liver condition.</p> <p>Is able to identify with David Sheppard's horizon of experience (published CFS/ME author) and using EHC better understands symptoms and the lead up to his diagnosis.</p> <p>Experienced loss of access to occupations defined as occupational deprivation, due to fatigue and aches knows this as he is unable to do all he usually did and judges he has lost fitness.</p> <p>After tests for a variety of health conditions and nothing being discovered he</p>
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<p><i>she was one of the very first people who wasn't gay or an intravenous drug user who died of HIV... in the time between the first blood test and the second blood test it really hit the BBC news with the advertising don't die of ignorance and all this, that and the other and because it was... in vogue and scary people had never really come across it you know it was a viral thing that... had obviously been around for a long while but you know it suddenly burst through the barrier um you know all the nurses were terrified you know were double gloved and masked where upon the first time they had just been bare handed and no masks..." 8/2/2</i></p> <p><i>"I would say it was about four years afterwards ... I had to get... a hospital checkup for life insurance that I took out and this was down at Harley Street and the GP I saw there, just said 'you have had Gilberts Syndrome' which is where your liver packs up and you get jaundice and I didn't know anything about it, he said 'you have had it... it's fine you are ok now'..." 8/1/13.1, 8/1/13.2</i></p> <p><i>[The insurance report GP] "They just said 'no you have had it and there is no damage to your liver'... after I had ME... I went and read David Sheppard's book living with ME and it's very interesting... some of the issues that he had going up to developing ME and you are thinking crikey he had Epstein-Barr virus, he had liver issues, he had this neurological falling over and he said that these markers appear in quite a lot of people with ME, so I thought well maybe that's the fore runner and you could start to think oh gosh you had this, then you had this then and this, and reading the book and then going back over my history, I could see some correlation that lead up to it..." 8/1/13.3</i></p> <p><i>"I had Epstein-Barr virus it must have been for about 7 years. The impacts of it... I would crawl from my bedroom in the flat to the bathroom some mornings I couldn't walk... the fatigue and the ache and I would catch any viral issue going around, any flu like virus that people were catching that they would shake off in a couple of days it would take me two weeks... I was working in London and I was feeling just awful I just ached all the while I was tired I had headaches, flu like</i></p>	<p>is not hopeful that it would ever go away after having symptoms for 7 years. Also compares his recovery times with those around him and realises it takes him longer than average to recover from viruses.</p>
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<p>viruses I got tonsillitis more times than I can remember and I can remember one morning crawling along the landing it was one of those big old houses... that had been divided into individual bedsits and just crawling along the landing because I couldn't walk... I was 26, 25/26... [previously] I was as fit as a flea... I felt so ill I couldn't... I didn't even care about how I felt I would just sleep all day and I must have had the impacts of that for getting on for seven years and then I kept on getting balance issues where you would just fall over so I had neurological scans which came back clear... really I thought this is life." 8/1/13</p>	
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I went to my GP and said I think I have got ME	Interpretation
<p>"So when I first encountered CFS/ME I went to my GP and said you know I think I have got ME... the first GP I actually saw just shrugged her shoulders and said and what am I supposed to do with it which was an interesting response... It made me feel awful actually um it made me feel angry she was a young GP that had just got into the practice luckily she is not there anymore and... it was a case of ok so I have got to take ownership of my own condition but I was very angry... it was the first time I had seen her the first and last time I had seen her... I was confused, I was very confused that first day, I was concerned that maybe it was me you know, all in my head, that it was made up... I went away from the first GP and questioned whether I was actually ill or not or whether it was you know some issue of panic attack and not recovering from this virus..." 8/1/5</p> <p>"... I said [to first GP he saw] 'you know I think I have got CFS/ME or some post viral fatigue issue' and it was just very much this case of you know 'so what'. 8/1/8.2</p> <p>"I saw another GP... who said well I know nothing about ME CFS/ME only what the guidelines from NICE are that you know its 6 weeks or 6 months... fatigue that doesn't change improve by rest um so they kept on signing me off with chronic fatigue syndrome... he didn't know much about it so I think for him it was a learning curve." 8/1/6</p> <p>"... the second GP... because I was actually feeling very</p>	<p>The first GP Arnold sees about his fatigue did not seem to care about his opinion and had no access to usual formulaic treatment for this contended illness. Similar to Andy's experience linked to his asthma diagnosis being focused on. The need for GP to do something and respond was not present – like Christopher's experiences.</p> <p>Faith in the 2nd GP as he admits misdiagnosis and listens to what Arnold had researched and presented and agrees with his self-diagnosis. Has a willingness to be open and treat Arnold as a partner rather than a subordinate patient. An example of sharing of horizons and learning about the illness together/collectively in a genuine encounter.</p> <p>He learns that he considered CFS/ME to be just a physical</p>

<p>down, he said to me 'I think you have got depression, clinical depression' and then it was a case of, he revisited his diagnosis and said you know, 'I think yeah you do have ME' and I have got a lot of time for this GP now, he is very good... I had never had depression, I had never had any psychological condition. I was always... I thought I was well balanced and well adjusted, that's why I really thought in the beginning it was just purely a viral thing..." 8/1/0.1, 8/1/0</p> <p>"...I don't have the black dog as I used to I used to have the black dog quite badly... I used to have it before I have often had the black dog um but... I can't remember if I had it in childhood I suspect I did... I think it was clear my dad was a depressive and I know my sister is so I suspect I have well I know I have depression yeah... two years ago... I had a packet of Fluroxene... before I got my diagnosis of ME my GP diagnosed as clinical depression well I was depressed because my body wouldn't do what I wanted it to do... so he suggested some Fluroxene... he said how are you on taking medication and I said if I have to take it... because you know I explained to him my wild past and he said look you know these are not going to be addictive or anything like that you know they are not going to be that bad mood altering and as so as I found out that they actually do alter your mood and the amount of people who have come off anti-depressants have real nightmare try coming of them I am glad I didn't take them... I went and had CBT... and I kept them in my sock drawer for two years um and my GP I said look I am sorry to waste a prescription he said if Gordon Brown can face it and hearts can stand it he said just keep them if you want to take them take then if you don't you don't and I had them in my sock drawer for about two years over two years I suspect yeah more like about 3 years... I just flushed them down the loo I didn't need them... my GP was very good he actually went back and revisited his diagnosis and said that he possibly misdiagnosed it... it was ME..." 8/2/41</p> <p>"I actually have a very good relationship with my GP... he didn't know much about ME and he said... it's going to be a learning curve for both of us... so I think for me I went to my GP with one of those, those worried well type diagnosis I think this is what I have based upon the experience of knowing somebody who had it in the 80's</p>	<p>entity originally.</p> <p>Acknowledged has had depression but in terms of more recent illness feels depression came as a consequence of CFS/ME preventing him from not being, doing belonging and becoming who he wanted to be.</p> <p>The importance of the genuine encounter achieved through sharing of a common dialogue to fuse horizons is also acknowledged.</p>
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comparing what they said they felt like to how I felt doing a web search on how I feel and I guess being an academic at the time you can use the right terminology to cut... you know there is that kind of peer to peer type stuff rather than a GP talking down to a lay person I could actually use the right terminology to be thought of as an equal... and he said well you know he signed me off with Chronic Fatigue Syndrome CFS and he said you know the only way is if you have gone six months... is it six months?... Six months with no relief um and I want you to keep a diary record of all the bits and pieces and I came back after six months he said yeah then I am more than happy to give you a diagnosis and then we will put you in for the... he said you have to go to the [name of specialist hospital] to have some diagnosis to test for rheumatoid arthritis fibromyalgia... and Lupus?... so it being a diagnosis by admission I got my diagnosis in early 2008 and um I think with him it was a very much of a... as I said because using the right terminology, right language you kind of you know I got treated differently... yeah articulate... I think that's one of the reasons I use Epstein-Barr virus rather than glandular fever..." 8/2/42

Appendix L

Published data: 3rd European Occupational Science Conference, Bournemouth University 2015



Health and Wellbeing through Occupation
3rd International
Occupational Science Europe Conference 2015
3 – 4 September 2015
Bournemouth University, United Kingdom

FILE TWO

For Office Use
Abstract Number:
Reviewers:
Outcome:

Title

**Exploring Experiences of Men with Chronic Fatigue Syndrome:
An Interpretive Phenomenological Study.**

Abstract

Introduction

Chronic fatigue syndrome (CFS) commonly known as myalgic encephalomyelitis/encephalopathy (ME) may cause significant disruption to occupation, health and wellbeing. Current treatment interventions are based on limited available research (National Institute for Clinical Excellence (NICE), 2007). Few studies exist which capture the experiences of men living with this condition. The purpose of this doctorate is therefore, to add to the body of knowledge linked to a largely unexplored topic. Anticipated completion date for the study is 2016.

Aim of the Study: To explore how CFS/ME is experienced by men living with this condition and the impact of the illness on their being, doing, becoming and belonging.

Methodology and Method

A qualitative design informed by service user involvement. Interpretive phenomenology based on the work of Hans-Georg Gadamer adopted as the philosophical framework.

Purposive sample: eight men aged between 21 and 68 years, Up to four in-depth conversational style interviews conducted on a 1:1 basis. Interviews lasted between

40-90 minutes, dependent on participants' fatigue/risk of post exertional fatigue. Twenty three interviews have been audio recorded and transcribed verbatim. Data were analysed using thematic analysis and application of the hermeneutic circle via an occupational lens.

Appropriate ethical approvals granted. Data anonymised in all outputs.

Results

Examples of occupational marginalization, deprivation and injustice identified.

Discussion

Assists with understanding how CFS/ME affects occupations, health and well-being and may positively impact upon policy and practice.

Contribution to Knowledge

Connects Gadamerian philosophy to new ways of knowing and interpreting occupation (Whiteford and Hocking, 2012).

References:

References

National Institute for Clinical Excellence. (2007). *Chronic fatigue syndrome/ myalgic encephalomyelitis (or encephalopathy). Diagnosis and management of CFS/ME in adults and children. Quick reference guide.* London: Author.

Whiteford, G.E., & Hocking, C. (Eds.). (2012). *Occupational Science Society, Inclusion, Participation.* Chichester: Wiley-Blackwell.

Word count: 247

Choice of presentation type:

15 minute oral presentation of research, followed by 10 minutes discussion time.

Appendix M

Publications Plan

- 1. *The meaning of living with CFS/ME for eight men summarised as: $b+d+b2=sh$.***
Publication of choice: The Journal of Occupational Science.
Authors: Johnson, A., Palmer, S. and Mitchell, T.
- 2. *Serendipitous data: artworks and poetry offered as expressions of experience: Andy's life with CFS/ME.***
Publication of choice: British Journal of Occupational Therapy.
Author: Johnson, A.
- 3. *Enabling transition from 'chaotic-being' towards health, defined as 'harmonious-being' and subsequent doing, belonging and becoming: men's experiences of CFS/ME and role of the Occupational Therapist.***
Abstract submission for platform presentation to: 4th European Occupational Science Conference, HAWK University, Hildesheim, Germany, September 2017.
Authors: Johnson, A., Palmer, S. and Mitchell, T.
- 4. *The value of employing a Gadamerian philosophical framework when conducting qualitative Occupational Therapy research.***
Publication of choice: OTJR: Occupation, Participation and Health.
Authors: Johnson, A., Palmer, S. and Mitchell, T.
- 5. *Combining thematic analysis and the metaphorical concept of the hermeneutic circle to make sense of data in a Gadamerian interpretive phenomenological study.***
Publication of choice: Qualitative Health Research.
Authors: Johnson, A., Palmer, S. and Mitchell, T.

References

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