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Major Research Project

**Narratives of partners of individuals affected by  
Chronic Fatigue Syndrome/  
Myalgic Encephalomyelitis**

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# CONTENTS

<b>1. <u>Introduction</u></b> .....	8
<b>1.1. My theoretical position</b> .....	8
<b>1.1.1. Social construction of illness</b> .....	9
<b>1.2. My use of language</b> .....	10
<b>1.3. 'A Worthy Topic'</b> .....	12
<b>1.3.1 Personal significance of the research</b> .....	12
<b>1.3.2 Social significance of the research</b> .....	13
<b>2. <u>Literature Review</u></b> .....	14
<b>2.1 Introducing CFS/ME</b> .....	14
<b>2.1.1 Definitions and Epidemiology</b> .....	14
<b>2.1.2 Diagnosis and Aetiology</b> .....	17
<b>2.1.3 Management and Outcome</b> .....	18
<b>2.1.4 Individuals' constructions of living with CFS/ME</b> .....	19
<b>2.1.5 Summary</b> .....	22
<b>2.2 Partners' constructions of chronic illness</b> .....	24
<b>2.2.1 Historical and prevailing views of partners and chronic illness</b> ..	24
<b>2.2.2 Quantitative literature on partners' constructions around MUS and CFS/ME</b> .....	26
<b>2.2.2.1 MUS</b> .....	26
<b>2.2.2.2 CFS/ME</b> .....	27
<b>2.2.2.3 Limitations</b> .....	28
<b>2.2.3 Qualitative literature on partners' constructions around MUS and CFS/ME</b> .....	29
<b>2.2.3.1 MUS</b> .....	29

2.2.3.2	<i>CFS/ME</i> .....	31
2.2.3.3	<i>Limitations</i> .....	32
2.2.4	Summary.....	33
<b>2.3</b>	<b>Narrative approaches to understanding chronic illness</b> .....	<b>34</b>
2.3.1	Narratives of individuals affected by chronic illness.....	34
2.3.2	Narratives of individuals affected by CFS/ME.....	37
2.3.3	Narratives of partners of individuals affected by chronic illness.....	40
2.3.4	Summary.....	42
<b>2.4</b>	<b>Gaps in the literature</b> .....	<b>43</b>
<b>2.5</b>	<b>Research aims and questions</b> .....	<b>44</b>
<b>3.</b>	<b><u>Methodology</u></b> .....	<b>45</b>
<b>3.1</b>	<b>Qualitative methodology</b> .....	<b>45</b>
<b>3.2</b>	<b>Narrative Inquiry</b> .....	<b>46</b>
<b>3.3</b>	<b>'Quality' of the study</b> .....	<b>47</b>
<b>3.4</b>	<b>Ethical considerations</b> .....	<b>48</b>
<b>3.4.1</b>	Informed consent.....	48
<b>3.4.2</b>	Confidentiality.....	49
<b>3.4.3</b>	Participant well-being.....	49
<b>3.5</b>	<b>Sampling and recruitment of participants</b> .....	<b>50</b>
<b>3.5.1</b>	Sample.....	50
<b>3.5.2</b>	Recruitment.....	52
<b>3.6</b>	<b>Creating field texts and moving to research texts</b> .....	<b>54</b>

3.6.1	Constructing field texts.....	54
3.6.1.1	<i>Interview structure</i> .....	54
3.6.1.2	<i>Interview process</i> .....	55
3.6.1.3	<i>Creating written field texts</i> .....	56
3.6.2	From field texts to research texts.....	57
3.6.2.1	<i>Guiding framework</i> .....	57
3.6.2.2	<i>The tasks of analysis</i> .....	60
3.6.2.3	<i>Seeking member reflections</i> .....	61
3.7	<b>Composing research texts</b> .....	62
3.7.1	Re-presentation of narratives.....	62
4.	<b><u>Analysis</u></b> .....	64
4.1	<b>Introduction to participants and individual ‘narrative impressions’</b> .....	65
4.1.1	Oliver.....	65
4.1.2	Tom.....	67
4.1.3	Michael.....	69
4.1.4	Stewart.....	70
4.1.5	Sue.....	72
4.1.6	Louise.....	73
4.2	<b>Similarities and differences</b> .....	76
4.2.1	‘Stories from then’.....	79
4.2.1.1	<i>Life before</i> .....	79
4.2.1.2	<i>Early encounters with CFS/ME</i> .....	82
4.2.1.2.1	<i>‘A really big transformation’</i> .....	82
4.2.1.2.2	<i>‘This kind of came as complete news to me’</i> .....	84
4.2.1.3	<i>Seeking help</i> .....	85
4.2.1.3.1	<i>‘There’s nothing we can do’</i> .....	85
4.2.1.3.2	<i>The response of ‘me’</i> .....	85

4.2.2	'Stories from now' .....	87
4.2.2.1	<i>The battle day to day</i> .....	87
4.2.2.2	<i>Battling unhelpful discourses</i> .....	88
4.2.2.3	<i>Battling unhelpful professionals</i> .....	89
4.2.2.4	<i>'Battle worn': the toll in the here-and-now</i> .....	91
4.2.3	Never ending battle?.....	94
5.	<b><u>Conclusions</u></b> .....	96
5.1	<b>Summary of key findings</b> .....	96
5.2	<b>Recommendations for practice</b> .....	98
5.3	<b>Strengths and limitations of the study</b> .....	100
5.4	<b>Suggestions for further research</b> .....	101
6.	<b><u>References</u></b> .....	103
7.	<b><u>Appendices</u></b> .....	119
	▪ APPENDIX A: Literature Review Strategy	
	▪ APPENDIX B: University of Hertfordshire Ethical Approval	
	▪ APPENDIX C: Project Information Sheet	
	▪ APPENDIX D: Participant Consent form	
	▪ APPENDIX E: Participant Debrief sheet	
	▪ APPENDIX F: E-mail to point of contact at CFS/ME support groups	
	▪ APPENDIX G: Interview guide	
	▪ APPENDIX H: Transcription service confidentiality agreement	
	▪ APPENDIX I: Narrative analysis framework	
	▪ APPENDIX J: Example analysis for Sue	
	○ i) Analytical Process	
	○ ii) Excerpts from Sue's narrative account	

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## **ABSTRACT**

### **Background and Aims:**

Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) remains a poorly understood condition, shrouded in uncertainty and dispute. Research suggests this context to have a profound bearing on those touched by the condition, impacting significantly on their experience and the narratives constructed thereof. However, no studies examining the narratives of partners of individuals affected by CFS/ME appear to have been carried out to date. Based upon this gap in the literature, this study sought to hear the narratives of partners of adults living with CFS/ME, giving particular consideration to the ways in which these narratives were told to an outsider, and how the outsider may have influenced the narrative.

### **Methodology:**

This study drew on a qualitative approach. A purposive sample of six partners of adults affected by CFS/ME (4 men and 2 women) was recruited. Individual interviews were conducted that were audio-recorded and transcribed. Narrative analysis was used to analyse the transcripts, focusing principally on how participants narrated their accounts, as well as on the content of narratives and the narrative and discursive features that shaped the telling of the accounts.

### **Analysis and Findings:**

Multiple readings of the narratives identified two areas of collective focus within participants' accounts – '*stories from then*' and '*stories from now*'. Some similarities in how '*stories from now*' were told were seen to emerge down gender lines. Notably participants' storytelling could be seen to represent a form of response to wider narratives that purvey around CFS/ME, with participants' being observed to construct particular meanings around CFS/ME, as well as particular 'identities' of themselves, their partner, their relationship and 'others' who had played a key role in their story of living with the condition. The findings are discussed in terms of their potential bearing for clinical practice and future research endeavours. In addition, the strengths and the limitations of the research are considered.

## **1. INTRODUCTION**

'Man is always a storyteller! He lives surrounded by his and others' myths.

With them he sees everything in his life, no matter what befalls him'

(Sartre, as cited by Gergen and Gergen, 1997, p254)

In line with Sartre's assertion that we make sense of our experiences through the 'stories' we hold around ourselves and others, I wish to begin this thesis by presenting relevant aspects of my 'story', and the impact this has had on my research endeavours; namely my theoretical position, use of language, and the personal and social significance of my research. Subsequent chapters will then present a review of relevant literature, details on methodology and findings from my study.

### **1.1 My theoretical position**

This research is influenced by both a post-modernist and social constructionist position. This perspective is highly 'sceptical of the universal knowledge claims characteristic of direct realists (Harper and Thompson, 2012, p90), positing there to be no such thing as 'a "big story" which can give an overarching explanation of the world as we know it' (Hulse, n.d., p2). Instead it is argued we each construct our own versions of 'reality', and that our individual constructions are 'developed in a social world where...different constructions have different social power' (Harper and Thompson, 2012, p91). As such, our constructions are inherently language-bound (Gergen, 1985), and culturally and historically specific (Polkinghorne, 1991). These ideas have led me to attend to the 'local' stories of my research participants within this thesis, rather than attempt to establish any 'grand truths' (Barker, Pistrang and Elliott, 2008), while remaining mindful as to how social, cultural and historical context may be impacting on the stories told (Riessman, 2003). Furthermore, they have drawn me to consider how my interpretation of what is contained within my participants' stories may be regarded as one of 'multiple views, multiple possibilities, multiple lives' (Dickerson, 2010, p354).



In addition, the post-modernist/social constructionist perspective suggests our sense of 'self' or 'identity' not to be a fixed, stable entity, but instead decentred or 'dialogical'; co-constructed through interaction with others and 'actively incorporat[ing], reproduc[ing] and evol[ing] the contexts in which it participates' (Kogan and Gale, 1997, p2). My position on 'self' or 'identity' may be described as more 'moderate', influenced particularly by the work of Ricoeur (1984), who posits two fundamental aspects to 'self' or 'identity'. The first - 'idem' - speaks to an ongoing conceptualisation of oneself, which gives the individual 'a sense of him- or herself as an intentional agent with continuity through time' (Elliott, 2005, p126). The second - 'ipse' - refers to a constructed, dynamic 'narrative identity', which is not fixed but instead 'becomes meaningful through different ways in different contexts' (Rachman, as cited in Faircloth, 1998, p604). The latter concept in particular has influenced my approach to the narrative accounts given by my research participants.

### **1.1.1 Social Construction of Illness**

In addition, my research endeavours have been influenced by the notion of the *social construction of illness*; 'a major research perspective within medical sociology' (Conrad & Barker, 2010, S67) that attends to ways in which 'illness' is not simply a reflection of biological pathology (usually distinguished as "disease"), but a broader social phenomenon, imbued with meanings elicited from the social and cultural systems in which an individual lives (Brown, 1995). Not all 'illnesses' are the same (Conrad & Barker, 2010) - not simply because they reflect different disease processes, but because they are historically associated with different meanings. Some become stigmatised (e.g., mental illness, epilepsy, STDs); some develop a 'contested' status (discussed further below); while others develop certain metaphorical connotations (Conrad & Barker, 2010); for example, within Western societies cancer is often referred to as 'evil' or 'repressive' (Sontag, 1978), while obesity is frequently regarded as 'sinful', a product of 'gluttony' (Barry et al., 2009).

Research examining the social construction of illness has emphasised three key findings. Firstly, that medical knowledge is itself 'conditioned by the social context in which it is developed' (Conrad & Barker, 2010, S73), leaving it susceptible to the interests of certain interested parties or groups with 'power' (Conrad & Barker, 2010). Secondly, that the meanings that become attached to an illness will by default shape how society responds to it, and thereby have specific consequences for those affected and the care they receive (Conrad & Barker, 2010). Thirdly, that individuals will endow their illness experience with meanings taken from their interactions with their social and cultural context (Conrad and Barker, 2010). These ideas may therefore be considered as one of the key 'lenses' through which this research has been conducted.

## **1.2 My use of language**

Narrative analysis aims to understand how individuals make meaning of their lives through the stories they tell (Clandinin and Connelly, 2000). Thus, 'there is a stated emphasis on language and discourse' (De Fina and Georgakopoulou, 2012, p18) since language is regarded as the essential 'vehicle for [conveying] meaning' (Taylor, 2003, p6). However, language is also considered to be 'influenced by our social and personal histories and contexts' (Henderson, 2001, p153). Given this, it feels important for me to outline certain choices I have made around language throughout this thesis.

Firstly, I have chosen to narrate this research using both the first and third person; a decision informed by two of Tracy's (2010) eight criteria for 'quality' in qualitative research. My decision to write at times in the first person is influenced by Tracy's (2010) 'sincerity' criterion, which postulates that qualitative research should strive for 'honesty and transparency about the researcher's biases, goals and foibles' (p841). The decision to write in the third person can be seen to relate to Tracy's (2010) 'meaningful coherence' criterion, which argues qualitative researchers should aim at all times to

‘meaningfully [represent and] interconnect literature, research questions, findings and interpretations’ (p840).

Secondly, in line with Taylor’s (2003) assertion that ‘the contexts in which words are used may alter their meanings’, I have decided to present certain words within this thesis within inverted commas, thereby signalling to the reader an awareness of the multiple meanings that may be ascribed to these terms. In line with this idea, I have chosen to refer to the participants in this study as ‘partners’ (defined within the Oxford English Dictionary as ‘a person who is linked by marriage to another [or] a member of a couple who live together or are habitual companions’ (“OED - Oxford English Dictionary”, 2014, para. 7) as I believe this reflects a key aspect of the ‘status’ of all participants at the time they took part in the research. However, in line with my earlier point, given the multiple meanings that can be attached to this term, I am aware that some participants may not have chosen to identify themselves in this way.

Finally, Bell et al. (1991, as cited in Ax et al., 2001) once called Chronic Fatigue Syndrome the ‘disease of a thousand names’ (p162). It has previously been referred to as ‘Post-Infectious Fatigue Syndrome’, ‘Post-Viral Fatigue Syndrome’, ‘Myalgic Encephalomyelitis’ (‘ME’), ‘Royal Free Disease’, ‘Chronic Mononucleosis’, ‘Chronic Epstein-Barr virus’ and ‘Chronic Fatigue Immune Dysfunction’ (Anderson et al., 2012) among other things. In early 2015, a specialist committee working for the American Institute of Medicine recommended the name of the condition to be changed once more to ‘Systemic Exertion Intolerance Disease’ (SEID). They argued this to be appropriate as this term ‘encapsulated’ in their opinion the condition’s central characteristic, ‘the fact that exertion of any sort – physical, cognitive or emotional – can adversely affect patients in many organ systems and in many aspects of their lives’ (Institute of Medicine, 2015, p250). However, at present many within clinical and research communities within the United Kingdom refer to the condition as ‘Chronic Fatigue Syndrome/Myalgic Encephalomyelitis’ (CFS/ME) (NICE, 2007). As such, this is how I will refer to

the condition within this thesis.

### **1.3 'A Worthy Topic'**

Tracy (2010) posits another key criterion for 'quality' in qualitative research as selection of a topic that is 'relevant, timely, significant, interesting or evocative' (p840). Tracy (2010) goes on to suggest that 'worthy topics [may] grow from... societal or personal events' (p840); an assertion that particularly resonates with why I decided to carry out research in the area of CFS/ME. As such, I will outline for the reader in brief the personal and social significance of my study.

#### **1.3.1 Personal significance of the research**

My interest in carrying out research within this area is particularly informed by my own personal story, in which I was privy to my younger cousin living with, and eventually being diagnosed with, CFS/ME at the age of 11 (approximately 20 years ago). I witnessed the impact this condition had on her at the time, but also the struggle she had to be taken seriously by medical professionals that something was 'wrong'. As years passed, I learned more of the difficulties CFS/ME has 'fitting' with traditional Western bio-medical explanations of illness (Ware, 1992) and the resultant 'arguments... debat[ing] the relative significance of psychological vs. physical factors as causes of the [condition]' (Horton-Salway, 2001, p149). I also became aware of the 'delegitimation' experienced by many of those affected by CFS/ME as a result of this debate (Ware, 1992). This emphasised to me the significance of cultural and social systems for shaping one's meanings and experiences around illness (Conrad and Barker, 2010). This sparked my interest in considering the experience of illness from a systems perspective, and in particular how members of a domestic system, especially partners, may make meaning of living with a chronic illness that holds such a 'contested' status (Swoboda, 2008).

I am aware however that my personal relationship with this area of research will almost certainly have impacted on my interactions with the topic in

general, and my participants. I have tried to remain mindful of this throughout my research process, and will reflect on this where appropriate throughout the thesis.

### **1.3.2 Social significance of the research**

Growing attention has been paid in recent years at a socio-political level with respect to the impact of chronic illness on partners (Rees et al., 2001). It has become increasingly recognised that partners tend to assume a lead 'care-giving' role in cases of chronic illness (Rees et al., 2001), and as such government policy and legislation has begun to focus more on the well-being of these non-professional 'carers'. Numerous policy documents have been produced in this regard, including 'Caring about Carers: A National Strategy for Carers' (Department of Health (DoH), 1999); 'Recognised, valued and supported: Next steps for the Carers Strategy' (DoH, 2010); and 'Carers Strategy: Second National Action Plan 2014-2016' (DoH, 2014). These documents acknowledge the significant physical, financial and emotional impact that 'caring' can have, and suggest there to be 'an overriding need to personalise [carer] support to fit with individual and family preferences' (DoH, 2010, p3). Yet despite this, the stories of partners supporting adults affected by CFS/ME remain almost totally absent from the research literature. As such, there may be quite specific demands associated with living with/caring for a partner affected by CFS/ME, which remain poorly understood at this time. It therefore seems appropriate for the stories of partners of adults living with CFS/ME to be given 'voice' within the research domain, with the hope this may facilitate better understanding on the part of service providers and professionals of the particular needs of this client group.

## **2. LITERATURE REVIEW**

Appendix A contains details of the literature review strategy and a list of databases searched for the purposes of this research.

The literature review begins by orientating the reader to the topic of CFS/ME, before moving to exploration of literature around partner experiences in the wider context of chronic illness. Particular consideration is given to research examining partner experiences in the context of 'medically unexplained symptoms' (MUS), as well as the limited research considering partner experiences in the context of CFS/ME. The gaps that currently exist within the literature, and my research aims and questions, are then summarised. However, in line with the theoretical position underpinning this research, I invite the reader to consider the ideas/perspectives outlined within this review as but one 'version' of multiple possibilities (Gilbert & Mulkay, 1984)

### **2.1 Introducing CFS/ME**

#### **2.1.1 Definitions and Epidemiology**

The current National Institute of Health and Clinical Excellence (NICE, 2007) guidelines for assessment, diagnosis and management of CFS/ME in the United Kingdom are informed by a case definition posited by Fukuda et al. (1994) - a panel of medical experts working for the American Centre for Disease Control and Prevention (CDC). This definition positions debilitating fatigue of six months duration or more, and of new and definite onset, as the core defining feature of the condition, alongside the presence of at least four of the following eight symptoms; impaired memory/concentration, headaches, sore throat, lymph node pain, muscle pain, joint pain, unrefreshing sleep and post-exertional malaise (Fukuda et al., 1994, as cited in Anderson et al. 2012). Whilst critics have been drawn to highlight the ambiguity of this definition (Reeves et al., 2003), as well as emphasise how its derivation by consensus rather than empirical testing may serve to threaten its ecological validity (Christley et al., 2012), the 1994-CDC

definition is now considered the most influential of all definitions produced at this time (Brurberg et al., 2014).

Of note, numerous definitions have historically been offered for the illness termed CFS/ME. A key difficulty for definition development has been a lack of biological markers able to be consistently associated with the condition, leading to an absence of uncontroversial bio-medical tests that can confirm the condition's presence in the individual affected (Christley et al., 2012). This has led some definition developers to promote case definitions in which non-pathological symptoms are central (Christley et al., 2012). Indeed, in some case definitions, the key signs and symptoms postulated are comparable to those seen in psychological difficulties such as depression (Christley et al., 2012). Critics however have argued this to leave the condition susceptible to being considered more as a psychological condition, rather than a physical illness (Christley et al., 2012). Thus other definitions have made it a requirement that individuals whose symptoms may be understood as indicative of underlying mental health issues should be excluded from consideration of a diagnosis of CFS/ME (Lloyd et al., 1990). However, other researchers and clinicians have argued this to be equally problematic; either because symptoms associated with CFS/ME show significant overlap with those associated with mental health issues such as depression (for example, individuals affected by CFS/ME frequently report difficulties with 'cognitive slowing' or impaired concentration, symptoms identified within the World Health Organisation's International Classification of Disease (ICD-10) as associated with depression), or given the high rates of co-morbid psychological difficulties within those affected by chronic physical health conditions (Naylor et al., 2012), it is feasible that those living with CFS/ME may also be experiencing psychological difficulty (Christley et al., 2012). As such, more recent case definitions have laid focus on certain pathophysiological processes – processes for which some definition developers argue increasing research evidence is being gathered (Carruthers et al., 2011).

Alongside the controversy surrounding criteria for case definition, debate has raged regarding the most appropriate term for the condition itself. The term 'Myalgic Encephalomyelitis' or 'ME' first became associated with the condition in 1955 (Wojcik et al, 2011), as many within the medical community at the time believed its symptoms to originate from an underlying disorder of the central nervous system (Wojcik et al, 2011). Subsequently, Holmes et al. (1988) argued it to be more appropriate to change the condition's name to 'chronic fatigue syndrome' or 'CFS', since despite significant medical testing 'encephalomyelitis, a specific and often lethal neuropathological process' (Wojcik et al, 2011, p501) could not be identified at any stage of the illness trajectory. In 2003, Carruthers et al. suggested it appropriate to re-introduce the term 'ME' into the name for the condition, as they proposed increasing research evidence was being gathered for 'widespread inflammation and multisystemic neuropathology' (Carruthers et al., 2011, p327) within individuals affected by the illness. Subsequently in 2011, an international consensus panel suggested there to be evidence that 'CFS' and 'ME' may in fact represent two separate disease entities (Carruthers et al., 2011). However, as Brurberg et al. (2014) note, this assertion remains highly disputed, with some researchers now suggesting it more helpful to conceptualise CFS/ME as an illness 'multi-faceted and heterogeneous in nature' (Castell et al., 2011, p312). As such, use of the compromise term 'CFS/ME' has been recommended in recent years (NICE, 2007).

In terms of epidemiology, as Johnston et al. (2013) note, information historically originated mainly from studies completed in the United States and Europe. However, 'increasing estimates are [now] emerging from Asia and developing countries, such as Nigeria' (Johnston et al., 2013, p105). Estimates of prevalence have been observed to vary significantly internationally, from as low as 0.2% in Hong Kong (Yiu & Qiu, 2005), to as high as 6.41% in three regions of England (Nacul et al., 2011a). However, it has been suggested that such differences may relate to the lack of consensus



on how to define the condition, resulting in variation in the case definitions used by researchers (Johnston et al., 2013). Based on the 1994-CDC definition (Fukuda et al., 1994), it has been estimated that approximately 250,000 people are currently living with CFS/ME in the UK (“Chronic Fatigue Syndrome”, 2013). It is more commonly diagnosed in women than men by a ratio of 2:1 (Brooks et al., 2014), with the commonest age of onset between early 20s and mid 40s (“Chronic Fatigue Syndrome”, 2013). Studies have also found it to affect health care workers more than any other occupational group (Bagnall et al., 2002, as cited in Christley et al., 2012).

### 2.1.2 Diagnosis and Aetiology

Numerous aetiologies have been proposed for CFS/ME, citing neurological, endocrine, immunological, genetic, psychological and infectious factors (NICE, 2007). However, ‘despite many years of research, no specific factor has been consistently associated with CFS/ME’ (Holgate et al., 2011, p539). Thus within the Western medical diagnostic system, a ‘diagnosis’ is often made once all other possible causes for the individual’s symptoms have been excluded (Bansal et al., 2012).

As highlighted earlier, the inability to ascribe a definitive physical cause to CFS/ME has led the condition to develop a ‘contested’ status within Western cultures (Swoboda, 2008), with intense debate as to whether it may be considered ‘a physical disease, a psychological illness or [something] that has both of these components’ (Hossenbaccus & White, 2013, p2). This debate has been traced to the international dominance of the bio-medical model, as well as the ongoing centrality of mind-body dualism within Western cultures (Pinching, 2003). It has been suggested that the latter’s conceptualisation of mental and physical phenomena as entirely discrete and unrelated (Crane & Patterson, 2012) alongside the former’s definition of illness as something intrinsically located in an underlying physical cause (Wade & Halligan, 2004), has resulted in the emergence within the West of a dominant cultural discourse, whereby ‘conditions’ for which no discernible physical cause can be found must therefore represent some form of underlying psychological

difficulty (Wade & Halligan, 2004). As Ware (1992) observes, this leads many living with CFS/ME to have their illness experience brought into question, resulting in many feeling pressed to ‘make the case that [their condition] is a real (i.e. physical) illness, or [to] present evidence to prove that they [are] not psychologically disturbed’ (p356).

More recently however, some within Western cultures have begun to conceptualise CFS/ME within a ‘biopsychosocial’ framework; enabling an alternative narrative of the condition to emerge as a ‘syndrome [that] has an external environmental or microbiological trigger... but [in which] psychological and social factors [may be] important [for] perpetuating the illness’ (Holgate et al., 2011, p541). Notably this is more in line with how the condition is conceptualised within other cultures (Karasz & McKinley, 2007). For example, in China symptoms associated with CFS/ME are ‘linked to traditional Chinese medical concepts centering on the depletion of vital energy (qi) as a result of physical strain and social stress’ (Kleinman, 1986, as cited in Karasz & McKinley, 2007). Notably however, this move towards a more ‘biopsychosocial’ approach within Western cultures has been met with some resistance by those affected by the condition. Many perceive it to have the potential to shift focus away from research into biological ‘triggering factors and how these then translate into chronic disease and disability’ (Holgate et al., 2011, p541); thereby reducing the potential for CFS/ME to eventually meet the ‘requirements’ associated with the dominant cultural discourse around illness.

### 2.1.3 Management and Outcome

Given the bio-medical uncertainty surrounding CFS/ME, no form of physical intervention (pharmacological or otherwise) has yet been identified that can help ‘cure’ the condition (“Chronic Fatigue Syndrome”, 2013). Instead, Western bio-medical treatments currently aim to reduce the severity of the symptoms being experienced by the individual affected.

Within the UK context, NICE (2007) guidelines 'emphasise the importance of early symptom management... ensuring [any] significant clinical features are investigated, and working in partnership with people with CFS/ME to manage the condition' (p5). In terms of treatment options, NICE (2007) recommends the use of cognitive-behavioural therapy (CBT), structured exercise programmes and medication to help control any pain, nausea or sleeping difficulties with which the individual affected may present ("Chronic Fatigue Syndrome", 2013). However, as White et al (2013) observe, 'several meta-analyses of these therapies indicate [those affected to report only] moderate benefit from these treatments (Edmonds et al., 2004; Malouff et al., 2008; Castell et al, 2011)'. In several studies, in spite of undertaking such treatments, individuals continue to report poor functioning across multiple life domains (White et al., 2013, Cairns & Hotopf, 2005); in some cases for anything between 20 and 30 years (Ax et al., 2001).

#### 2.1.4 Individuals' constructions of living with CFS/ME

Qualitative studies have sought to understand further the experiences of individuals affected by CFS/ME.

Despite the uncertainty surrounding the condition's underlying aetiology, individuals affected by CFS/ME have been found to relate their development of the illness to an infectious cause (Whitehead, 2006; Donalek, 2009; Ray et al., 1995), predominantly the acquisition of a 'virus' (Denz-Penhey & Murdoch, 1993). In some studies, those affected are seen to relate the perpetuation of their 'symptoms' to external psychological and/or social stressors (Horton-Salway, 2002; Asbring & Narvanen, 2004), while others are noted to question the role of environmental factors, for example working with/living near chemical agents (Clarke, 1999). Notably though, while individuals affected are observed to consider varying factors in relation to their CFS/ME, they are also consistently drawn across studies to 'emphasise... their condition [as] definitely not a psychosomatic disorder' (Larun and Malterud, 2007, p24)

Individuals affected also frequently cite specific physical, social and economic consequences of living with the condition (Anderson et al, 2012; Larun and Malterud, 2007). Individuals are often observed to describe a sense of feeling controlled and betrayed by their bodies (Larun and Malterud, 2007). There is consistent emphasis across studies on the profound physical and mental 'deficits' associated with the condition, and the detrimental impact these have on the individual's ability to maintain satisfying social roles/relationships or access the workplace (Ware, 1998; Tuck & Wallace, 2000; Schoofs et al, 2004; Clarke & James, 2003). Notably, those affected are also seen to relate their lack of occupational or social satisfaction to the negative response of others (Anderson et al., 2012). Across studies, individuals living with the condition regularly report feeling blamed, mistrusted, dismissed and/or morally judged by those around them, due to a lack of understanding of their illness (Soderlund et al., 2000; Asbring & Narvanen, 2002; Woodward et al, 1995). Individuals are also regularly seen to highlight significant economic pressures they now face as a result of living with the condition, either due to a desire to try new treatments available only on a private basis, or their newfound need to rely on welfare payments from the state for a source of income (De Carvalho Leite et al., 2011).

Perhaps unsurprisingly, individuals affected by CFS/ME are often seen to report difficulties in their interactions with health professionals particularly wedded to the bio-medical approach (Larun & Malterud, 2007). In several studies, individuals describe experiencing hostility from their doctors in the absence of any bio-medical markers of illness (eg, Denz-Penhey & Murdoch, 1993; Horton-Salway, 2001). Individuals are observed to report feeling pressed to negotiate the 'nature' of their disorder during their encounters with health professionals (Denz-Penhey & Murdoch, 1993), and feelings of guilt, blame or shame when confronted by doctors who ascribe their symptoms to a psychiatric condition (Horton-Salway, 2001, 2004).

In many studies, individuals living with CFS/ME describe the significance of receiving a medical 'diagnosis' as particularly great (Clarke, 1999; Asbring &

Narvanen, 2002; Woodward et al., 1995). However, while in some studies receiving a diagnosis is reported as the single most helpful event of the illness experience (Woodward et al., 1995), in other studies it is described more as something of a 'burden' (Lovell, 1999; Asbring & Narvanen, 2002), eliciting certain assumptions in others regarding the individual's personality and character (Denz-Penhey & Murdoch, 1993).

While it is suggested that these are the main themes permeating qualitative studies exploring individuals' perspectives on CFS/ME, it is also important to consider the context in which such reports were obtained, along with key limitations to the literature at this time.

Firstly, the sample sizes of the studies discussed in this section vary significantly, ranging from single case study up to 66 participants. Accordingly, the studies discussed here utilise a variety of data collection methods; some draw on 1:1 face-to-face semi-structured interviews, some on semi-structured telephone interviews, while others utilise focus groups and/or group interviews. One might argue there could be potential ramifications for the reports obtained depending on the data collection method used – for example, the perspectives reported by participants within a group situation may be quite different from those offered on a 1:1 basis with just a researcher present. However, it appears minimal consideration is given by the vast majority of researchers to such issues.

In addition, studies have recruited participants from a variety of sources, including outpatient specialist CFS/ME clinics, CFS/ME support groups and GP surgeries. Given that individuals who receive input from specialist CFS/ME clinics may be privy to quite different treatment experiences from those who do not, questions may again be raised regarding the potential impact of this on the reports obtained. Again however, there appears minimal consideration of such issues in the studies described above.

Furthermore, a significant majority of the participants within the studies discussed here are female. While this may be representative of the greater ratio of females to males affected by the condition, one is drawn to question the bearing of gender on the reports obtained – a further issue to which it appears minimal attention has been paid at this time.

Notably, there appears a significant lack of longitudinal qualitative research, leading to a paucity of exploration of how individuals' perspectives may evolve over time (Anderson et al., 2012). Moreover, most of the studies discussed here have been carried out in developed countries, leading to a lack of understanding of cross-cultural issues in each of these domains.

Finally, the majority of qualitative studies discussed here are observed to utilise phenomenological approaches when analysing participants' 'talk'. It is argued that such analytic approaches hold that it is possible 'to faithfully conceptualise the processes and structures of [an individual's] mental life' (Wertz, 2011, p124), assuming 'a "chain" of connection between people's talk and their thinking or emotional state' (Smith & Osborn, 2007, p54). However, as Wertz et al. (2011) observe, such approaches are drawn far less to 'take the narrational context into account' (p318) and to consider what participants may be 'accomplishing' through the perspectives they offer (Bamberg, 2009). One might suggest that alternative perspectives/understandings remain relatively under-explored at this time due to the prominence of this particular methodological approach.

#### 2.1.5 Summary

This section has aimed to introduce the reader to the historical and current contexts around the illness now termed CFS/ME. By introducing the controversy that has surrounded case definition for the condition, it is hoped the reader may have gained a sense of the uncertainty and dispute that exists around the condition; 'uncertainty' and 'dispute' that appear to stem principally from the difficulties CFS/ME has fitting with the dominant bio-medical model of illness, as well as the on-going centrality of mind-body

dualism within Western cultures (Pinching, 2003). By introducing the perspectives of individuals affected by CFS/ME, one may see how such a context appears to impact on the meaning-making processes of those touched by the condition, and hence why this study may be interested in how partners of adults living with CFS/ME narrate their experiences. However, since my literature search has revealed a paucity of previous research examining partners' meaning-making and experiences specifically in relation to CFS/ME, I will proceed next to an examination of the wider literature around partner experiences in the context of chronic illness, and in particular partner experiences in the context of 'medically unexplained symptoms' (MUS). This would appear appropriate since CFS/ME is frequently a condition of significant chronicity (Ax et al., 2001), and one of those most frequently observed under the cluster of conditions currently labelled as "MUS" (Swoboda, 2008).

## 2.2 Partners' constructions of chronic illness

As Baanders and Heijman (2007) note, 'it is increasingly recognised that a chronic somatic disease not only has various consequences for the patient's life but also has implications for those who live with the chronically ill, particularly the partner' (p306). Within the last four decades, a significant amount of research has therefore sought to examine the relationship between partners and chronic illness.

### 2.2.1 Historical and prevailing views of partners and chronic illness

In the 1960s and 1970s, a prominent strand of research emerged suggesting that 'significant others', and in particular partners, may play a crucial role in the *development* of certain conditions, particularly chronic mental health conditions or 'psycho-somatic' presentations (Stern et al., 1999). This appears to have been a product of early Systems Theory (Minuchin, 1974, Bowen, 1978), which suggested that such conditions often develop as a result of 'unresolved family conflict.... allowing individuals to express emotional needs that would normally disrupt the family system in an acceptable manner' (Thoburn et al., 2009, p7). Subsequently, research began to look at how partners may be implicated in the *maintenance* of such conditions (Stern et al., 1999). In particular, several studies identified a link between 'solicitous responses' on the part of partners and higher symptom levels (Block et al., 1980; Flor et al., 1987) decreased social/occupational functioning (Romano et al., 1995) and decreased overall activity (Flor et al, 1987) within the individual affected.

Questions have since been raised about the role of this type of research in constructing a narrative of 'blame' around partners for such conditions. Notably, some researchers have argued that while family dynamics may be implicated in the development and maintenance of a condition, this does not necessarily imply members of the system are to 'blame' – i.e. that 'responsibility' and 'blame' do not necessarily equate (Jacobs, 1992). More recent research has taken a different approach, focusing more on how a chronic mental health condition or 'psycho-somatic' presentation may impact



on those close to the individual affected (Stern et al., 1999). However, the legacy of earlier research, and interpretation thereof, may still be felt.

By contrast, in the context of illness considered to be purely 'physical', researchers have focused on the impact for those close to the individual affected, and in particular partners, for quite some time (Rees et al., 2001). Notably however, much of the research carried out within this area appears to have examined the perspectives of partners living with, and caring for, older individuals (Rees et al., 2001). One is therefore drawn to question whether this may have impacted on the types of difficulties reported within studies.

While early studies around partners and physical illness focused mainly on the 'burden' of caring (Zarit et al., 1980; Vitaliano et al., 1991; Glozman et al., 1998), later studies sought to examine the factors that may impact on carers' 'quality of life' (McMillan, 1996; Cliff & MacDonagh, 2000; Sells et al., 2000). Findings from such research have identified four key areas of impact for partners; namely physical well-being, emotional well-being, social functioning and financial status (Rees et al., 2001). Notably, partners have frequently been observed to report lower quality of life than the individual affected (Kornblith et al., 1994; Cliff & MacDonagh, 2000; Weitzenkamp et al., 1997). A substantial body of research has gone on to identify a strong inverse relationship between partners' quality of life, and the level of demand placed on partners as a result of their spouse's condition (Rees et al., 2001). However, partners have also been observed to report positive consequences to their caregiving status (Rees et al., 2001). For example, Knight et al. (1997) found partners of individuals living with Multiple Sclerosis (MS) to report many positive aspects to their informal caregiving role, commenting in particular how 'being a carer had made them more caring towards others' (Rees et al., 2001, p565).

It appears therefore that living with chronic illness has the potential to impact on partners across multiple life domains (Rees et al., 2001). In some cases, rates of adaptation have been observed to vary considerably between the individual affected and their partner, leading to 'a divergence in quality of life

between them' (Rees et al., 2001, p565). With these ideas in mind, it feels appropriate to proceed next to a more comprehensive examination of the research examining partners' constructions in the context of MUS, and in particular CFS/ME.

## 2.2.2 Quantitative literature on partners' constructions around MUS and CFS/ME

### 2.2.2.1 MUS

In the context of MUS, partners similarly frequently report a detrimental impact on their functioning within several key life domains. In several studies, partners report having to take on new roles and responsibilities (Bigatti & Cronan, 2002), leaving them with less time to engage in personally meaningful activities (Baanders & Heijman, 2007) and less able to build social relationships outside of the domestic setting (Bigatti & Cronan, 1998). Partners also report being unable to sustain full-time employment as a result of their partner's health status, resulting in pronounced changes in their financial situation (Baanders & Heijman, 2007).

In line with the wider literature around partners and chronic illness, these alterations in functioning are also commonly found to correlate with decreased physical and mental well-being. Across many studies, partners of adults with MUS are seen to report more physical health difficulties than partners of 'healthy' individuals (Bigatti & Cronan, 2002; Rowat & Knafl, 1985), and to score higher on assessments for mental health difficulties such as depression and anxiety (Bigatti & Cronan, 2002). In addition, partners of adults with MUS frequently report lower levels of relationship satisfaction (Steiner et al., 2010; Flor et al., 1987), which some have linked to the 'strain' living with MUS places on traditional domestic 'roles', as well as the ability to access social support and maintain sexual activity (Steiner et al., 2010). Notably though, it remains unclear as to whether such issues represent a direct consequence of their partner's health condition.

Notably, female partners are consistently found across studies to report greater impact than male partners (Baanders & Heijman, 2007; Northouse & Swain, 1987). This also appears in line with the wider literature around partners and chronic illness. Several hypotheses have been offered by quantitative researchers as to why this might be the case, including women being perhaps more 'sensitive' to the well-being of those around them (Hagedoorn et al. 2008); or men finding it harder to connect to, and express, the emotional and psychological distress elicited for them by their partner's illness (Lutzky & Knight, 1994; Buskila & Neumann, 1997). However, many quantitative researchers acknowledge such hypotheses to be based merely on 'supposition' rather than empirical evidence, due to the difficulties quantitative research methodologies have providing contextual information to help interpret their findings (Lutzky & Knight, 1994).

#### 2.2.2.2      CFS/ME

There appears significant overlap between the findings of quantitative research around partners' experiences in the context of MUS, and the findings of studies focusing specifically on those living with CFS/ME. For example, partners of individuals affected by CFS/ME have been observed to score lower than 'age-matched' population norms on measures of physical and mental well-being (Nacul et al., 2011b; Davidhizar, 1994), while female partners have likewise been found to report greater negative impact on measures of mental well-being than male partners (Nacul et al., 2011b). Furthermore, some studies have similarly identified a correlation between increased physical debilitation within the individual affected and decreased emotional well-being and 'marital satisfaction' in partners (Goodwin, 2000).

Strikingly, in the context of CFS/ME, several studies are observed to examine how the responses of 'significant others' may impact upon the individual affected, and their illness outcome (Brooks et al., 2012). One might suggest such endeavours to be reminiscent of the historical research activities described earlier in relation to partners and chronic mental health conditions or 'psycho-somatic' presentations. For example, White et al (2006) sought to

examine the causal attributions of partners in relation to the onset of their spouse's CFS/ME. They subsequently identified a relationship between partners linking the onset of CFS/ME to factors internal to their spouse, and higher levels of anxiety and depression within the individual affected. Similarly, Brooks et al (2012) sought to examine how the causal attributions made by 'significant others' for their spouse's ongoing symptoms of CFS/ME may relate to their spouse's levels of distress. Brooks et al (2012) later identified a positive correlation between partners attributing an exacerbation in their spouse's symptoms to factors idiosyncratic to their spouse, and increased reports of distress and negative outcome in those affected. A fundamental criticism of these findings however is that both studies discussed here employed structured assessment tools as part of their study design. Again, one might suggest this limits the ability of the authors to examine the context surrounding the responses given by participants. It appears difficult to state with certainty whether the levels of distress observed within those affected may relate solely to their partners' illness attributions, or to other factors unable to be captured by such assessment tools; for example historical events or wider dysfunctional patterns of relating within the relationship.

#### 2.2.2.3      Limitations

This leads one to consider additional limitations to the quantitative literature at this time. Many of the studies discussed here are observed to employ cross-sectional designs, meaning the results obtained provide relatively little insight into partner experiences over the long-term. Furthermore, all are observed to rely principally on the use of self-report questionnaires, which many suggest are prone to response bias (Furnham, 1986), and which have been criticised for their inability to fully capture and explore the complex and fluid issues faced by partners (Ayres, 2000). In addition, across studies there appear significantly more responses from male partners than female partners (Bigatti & Cronan, 2002; Dogan et al., 2010). One is drawn to question whether there may be quite specific issues elicited for female partners that remain 'unearthed' by quantitative methods at this time. Qualitative research may go some way to addressing these limitations, by providing a richer, more detailed

picture of the meanings ascribed by partners to living with chronic MUS, and in particular CFS/ME.

### 2.2.3 Qualitative literature on partners' constructions around MUS and CFS/ME

#### 2.2.3.1 MUS

Exploration of the qualitative literature enables additional insights to emerge around partners' constructions in the wider context of MUS. Notably, the sample sizes of the studies discussed here are comparatively small, ranging from 5 to 16 participants, with all studies being observed to utilise 1:1 face-to-face semi-structured interviews as their principal data collection method. Importantly however, the researchers in question again appear to pay minimal attention to the relevance of the data collection method to the reports obtained. Furthermore, phenomenological analytic approaches are once again seen to prevail, leading questions to be raised regarding whether alternative perspectives/understandings may remain relatively under-explored at this time.

A key theme to emerge across studies is a sense of partners living in the shadow of their spouse's condition (Paulson et al., 2003; Soderburg et al., 2003). Partners comment on the increased levels of work and responsibility they are required to take on as a result of their spouse's illness (Soderburg et al., 2003), and how this leads to significant disruption to their own pattern of life (Paulson et al., 2003). Accordingly, partners report experiencing a wide variety of emotional responses to their spouse's condition, including resentment, anger and anxiety, which are prone to varying across time and situations (Fernandez et al., 2006; Soderburg et al., 2003; Paulson et al., 2003).

However, in some studies, partners suggest their emotional responses are exacerbated by the response of others to their spouse's illness (Paulson et al., 2003; Soderburg et al., 2003). This appears to differ somewhat from some of the reports observed within the wider literature around partners' and illness

viewed as more purely 'physical'. Partners regularly describe feeling there to be a lack of understanding of MUS (Paulson et al., 2003), which manifests in them experiencing simultaneous sympathy and suspiciousness from others (Paulson et al., 2003), and at times non-acceptance of their partner as really 'ill' (Soderburg et al., 2003, Paulson et al., 2003).

In several studies, partners describe their experiences of health professionals, commonly being seen to comment on a lack of holistic approach taken by professionals involved in the care of their spouse (Paulson et al., 2003). In some studies, partners are observed to report feeling pressed to seek out additional information or knowledge around their partner's condition as a result (Soderburg et al., 2003). This appears particularly characteristic of the literature examining partners' perspectives in the context of MUS. Notably, while some partners comment on how such experiences serve to strengthen their relationship with their spouse (Soderburg et al., 2003; Arestedt et al., 2014), some also describe experiencing a strong sense of 'isolation' in their relationship as a result (Soderburg et al., 2003).

The majority of qualitative studies examining partners' perspectives in the context of MUS appear to have been carried out with male participants. Importantly, none of the studies discussed here include mixed-gender samples – all consider either the perspectives of just male partners or just female partners. Significantly, exploration of the research suggests several notable differences between male and female partner perspectives. For example, male and female partners are frequently seen to highlight quite different factors when discussing the impact MUS has on their relationship with their spouse. Female partners have been shown to emphasise their spouse's condition as a forceful 3<sup>rd</sup> member of the relationship (Paulson et al., 2003), 'obliging' them to show constant consideration and to endeavour to give their partner courage (Paulson et al., 2003). In addition, females have commented on the reluctance of their male partner to talk about the feelings their condition elicits for them, and how this serves to have a detrimental impact on their own emotional state (Paulson et al., 2003). By contrast, male partners have emphasised their

spouse's condition as an opportunity for personal growth (Soderburg et al, 2003) requiring them to act as an 'advocate' on their spouse's behalf and to increase their sensitivity to their partners' changing needs (Soderburg et al., 2003). Accordingly, male and female partners frequently emphasise quite different emotional responses to their spouse's condition within the qualitative literature; for example, females describing a sense of hovering between hope and fear (Paulson et al., 2003), with males emphasising feelings of anger and powerlessness (Soderburg et al., 2003). Significantly however, it appears the majority of those *interviewing* participants within the studies discussed here have been female. Questions may therefore be raised regarding the significance of this for the reports obtained, yet once again minimal consideration appears to have been paid to this factor by researchers at this time.

#### 2.2.3.2      CFS/ME

Notably, a detailed search for qualitative research examining partner perspectives in the more specific context of CFS/ME has been able to unearth only one study of pertinence. Citing its aim as being 'to examine in-depth the beliefs and experiences of both CFS/ME patients and their 'significant others'' (Brooks et al., 2014, p1), the authors of this study selected to interview two males chronically affected by CFS/ME, and their long-term female partners. All four participants were interviewed separately. Interview transcripts were then analysed using Interpretative Phenomenological Analysis (IPA). Experiences of social interactions in relation to CFS/ME, particularly interactions with health care professionals and the 'general public', were identified as key issues for all participants 'when reflecting on their experiences of living with the condition' (Brooks et al., 2014, p1). Brooks et al (2014) suggested these findings to illustrate the importance of 'the wider social world and interactions with outside others [for] dyadic coping [with CFS/ME]' (p9). Yet each dyad was also observed to position quite different views and expectations of healthcare professionals and the 'general public'. Given 'access to networks of social support may be particularly disrupted [for individuals affected by] CFS/ME' (Brooks et al., 2014, p2), the authors proposed this to illustrate the importance of 'significant others' to the meaning-making processes of those affected by the

condition. Brooks et al. (2014) concluded 'future research and treatment interventions could usefully look to include a 'significant other' perspective' (p1).

While this study can be seen to offer valuable new perspectives on a much under-researched area, questions can nevertheless be raised over certain methodological and data analysis choices made by its authors. For example, the authors stated they wished to capture a dyadic account of living with CFS/ME, but chose to interview the individual affected and their partner separately. Interview transcripts were subsequently analysed at an individual level, before each couples' two individual transcripts were brought together and analysed as a dyadic 'unit'. One might therefore question whether these contextual factors surrounding the research encounter, and the somewhat 'artificial' dyadic accounts of living with CFS/ME constructed by the authors, may have impacted on the results obtained.

### 2.2.3.3      Limitations

It is evident that there are several notable limitations to the qualitative literature on partners' constructions around MUS and CFS/ME at this time. With respect to the qualitative literature around partners and MUS, notably no research appears to have been carried out exploring partners' perspectives outside of the heterosexual context, leading to a significant absence of voices of partners from lesbian, gay, bisexual and transgender communities. Furthermore, while qualitative studies have offered greater understanding of the differences in male and female partner responses to living with MUS, there remains minimal work completed in this area at this time. Perhaps the most striking limitation however is the near-absence of qualitative studies examining partner perspectives in the more specific context of CFS/ME. Existing qualitative research suggests particular challenges to arise for the partners of those living with CFS/ME or other MUS; challenges that may be somewhat different to those faced by partners/carers of individuals affected by other chronic health issues due to the context of 'contestation' that surrounds



such conditions. It is argued that more in-depth understanding is warranted in this regard, as it may have potential implications for both partners and individuals affected, as well as those around them (e.g. professionals, welfare providers, friends).

#### 2.2.4 Summary

This section has aimed to provide the reader with an overview of historical and prevailing views around partners and chronic illness, as well as introduce key themes from the literature on partner perspectives in the context of MUS and CFS/ME. Quantitative studies examining partners' experiences in relation to MUS and CFS/ME have elicited broad understanding of the key areas of impact for partners, and have identified significant differences between male and female partners' responses. Qualitative studies examining partners' experiences in the context of MUS have elicited richer understanding of the key areas of impact for partners, and have provided more information on what may underpin the differences in impact reported by different genders. However, there appears a striking paucity of qualitative research examining partners' experiences in the context of CFS/ME. Of particular note, much of the qualitative research completed in this area appears to have relied principally on phenomenological approaches; focusing primarily on what partners have said, while paying minimal consideration to how partners speak of their experiences and the contextual factors that may have impacted on the research encounter. It is suggested that this is an important area of neglect, and one that may well be addressed through the utilisation of more narrative approaches in the field.

Indeed, in recent years increasing attention has been paid within social scientific studies of medicine and illness to the narratives of individuals affected by chronic health conditions, including CFS/ME (Hyden, 1997). Attention has also been paid to the narratives of those caring for individuals affected by a long-term physical or mental illness. In the following section, I will briefly outline some significant ideas of relevance to emerge from these areas of research.

### **2.3 Narrative approaches to understanding chronic illness**

As Lawton (2003) observes, over the past 30 years narrative medical sociological research has made a significant contribution towards 'our understandings of lay experiences of health and illness' (p23), emphasising 'the importance of looking at timing, setting and individual biographies [in order] to understand the complex and often variable ways in which people ... 'live with' illness' (p27). Notably, researchers examining illness narratives are frequently observed 'to make inferences about how... illness... affect[s] the identity of the sufferer' (Horton-Salway, 2001, p162), but treat 'self' and 'identity' as residing within the individual concerned; a concept in line with Ricoeur's (1984) construct of 'idem', described earlier within the 'Introduction' chapter of this thesis. Minimal research examining illness narratives appears to have considered identity as 'a [form of narrative] process...something [to] emerge in interaction... and... achieved through discursive and communicative work' (De Fina & Georgakopoulou, 2012, p158); a notion more in line with Ricoeur's (1984) construct of 'ipse'. One key study founded on this latter perspective however will be considered further in section 4.3.2.

#### 2.3.1 Narratives of individuals affected by chronic illness

Bury's (1982) conceptualisation of chronic illness as a form of 'biographical disruption' is frequently cited as a seminal 'turning point in our understanding of.... lay experiences of... illness' (Lawton, 2003, p25). Through interviews carried out with individuals recently diagnosed with Rheumatoid Arthritis, Bury (1982) observed those affected to emphasise their condition as a major disruptive experience, 'leading to a fundamental re-thinking of the person's biography and self-concept' (p169). Bury (1982) theorised there to be three aspects to the disruption associated with chronic illness (p169); namely disruption in 'taken-for-granted assumptions and behaviours' (p169), disruption in the 'explanatory systems' normally used in relation to the self (p169), and action in 'response to disruption involving the mobilisation of resources' (p169). For Bury (1982), the experience of chronic illness was therefore best represented as a marked 'biographical shift from a perceived

normal trajectory.... to one fundamentally abnormal and inwardly damaging' (p171).

However, this premise was subsequently greatly criticised. For example, while G. Williams (1984) similarly identified illness as 'an assault on an individual's sense of identity' (p175), he also observed many individuals affected by chronic health conditions to attempt 'to reconstruct a sense of order from the fragmentation produced by chronic illness' through 'linking-up and interpreting different aspects of biography' (p177); an endeavour he termed 'narrative reconstruction'. As such, G. Williams (1984) suggested the experience of living with chronic illness to be better conceptualised as an evolving process of understanding, in which the individual affected attempts to 'create a sense of coherence, stability and order in the aftermath of the "biographically disruptive" event of illness onset' (Lawton, 2003, p26/7).

However, several researchers have since observed how the age and life-stage at which an individual first becomes unwell, as well as the social context in which they live, may have a significant bearing on how the illness experience is conceptualised. For example, in Pound et al's (1998) study, in which elderly working-class people in the East End of London were interviewed regarding their experiences living with a stroke, participants were observed to characterise their illness as a relatively 'normal crisis', 'one which made sense in the context of age, patterns of co-morbidity and the... lives these elderly East-Enders had experienced' (S. Williams, 2000, p50). Such findings led to the emergence of an alternative conceptualisation of chronic illness as at times 'biographically anticipated'; an expected 'part of the normal chaos of everyday life and existence' (S.Williams, 2000, p51) and an experience in which total 'biographical disruption' could not always be assumed (S.Williams, 2000).

Indeed, further challenges to Bury's (1982) original perspective of illness as 'biographical disruption' have since emerged. For example, in their interview study of asymptomatic haemophilic HIV positive men, Carricabaru and Pierret (1995) observed many participants to perceive the experience of living with

HIV as a form of 'biographical reinforcement', as 'long before HIV infection [many] had organised their lives... around an illness trajectory' (Lawton, 2003, p28). Thus for many there appeared a degree of conjecture between the identity they associated with the illness and their previous identity (Kehoe, 2009). Similarly, Faircloth et al (2004) observed individuals living in the aftermath of sudden illness onset to have found ways to incorporate their illness 'into their personal trajectory with other life events' (Roger et al., 2014, p2); in other words to have found ways to integrate their illness and its meanings into existing self-narratives; an endeavour they termed 'biographical flow'. Notably, Faircloth et al (2004) went on to emphasise how paying attention to an individual's conceptualisation of their illness experience may have clinical relevance, suggesting that failing to do so may result in professionals treating the experience of illness as 'universal', 'resulting in poorly designed interventions, and in turn, low outcomes for particular people' (p242).

In conjunction with these ideas, other researchers have observed notable differences in the structure of individuals' stories of illness. Many have suggested that by attending to this aspect of illness narratives, one is able to elicit additional valuable insights into 'the meanings the ill... construct around their [condition]' (Frank, 1998, p199). Perhaps the most well-known ideas in this regard are those offered by Frank (1998). While urging caution against 'classifying' stories in an attempt to 'pre-judge' the teller (Weingarten, 2001), Frank (1998) suggested three distinct narrative 'types' to frequently emerge out of the stories of those living with illness - 'restitution', 'chaos' and 'quest'.

The 'restitution' narrative is conceived as 'perhaps the most preferred illness story form in Western cultures, and... perhaps the easiest... to listen to well, if not deeply' (Weingarten, 2001, para. 26). Frank (1998) characterises such a narrative as one preoccupied with restoration to health, in which the individual 'repeats everything that treatment has already done, is doing, and will be able to do if the present efforts fail' (p200) in a bid to return them to former functioning; a narrative type that tends to 'predominate in the talk of

the recently diagnosed' (p201) and to recede in the stories of those living with chronic illness. Notably, the teller themselves may remain largely absent in such a narrative, giving way to the actions and possibilities offered by health professionals and treatments (Weingarten, 2001).

In stark contrast is the 'chaos' narrative; a narrative type frequently associated with 'deepest illness; [in which] disability can only increase, pain will never remit [and] physicians are either unable to understand what is wrong or unable to treat it successfully' (Frank, 1998, p201). Frank (1998) observes the chaos narrative to be peppered with a certain verbal 'style'; frequently trailing off, devoid of effective action and dominated by a 'passive' voice in which "it" – the illness - dominates the teller. Frank (1998) highlights how chaos narratives frequently have a pronounced impact on the listener - described as a sense of 'claustrophobia' – due to their pronounced 'lack of distance from immediate events' (Frank, 1998, p202).

Finally, there appears the 'quest' narrative – a narrative type to frequently emerge 'when restitution can no longer be imagined' (Frank, 1998, p203), and when illness has instead begun to be conceived as 'a condition from which something can be learned' (p203). Quest narratives frequently emphasise new qualities of self to have emerged as a direct result of illness, thereby placing some meaning and value on the suffering endured (Frank, 1998). It is argued that within Western cultures, there may even be an inherent expectation on those living with chronic illness to 'rhetorically deploy' such a narrative after a certain period of time (Frank, 1998). However, it is suggested that such narratives can also elicit a strong sense of resistance within the listener, because of our need 'to believe in a restitution that the teller has had to work to give up' (Frank, 1998, p205).

### 2.3.2 Narratives of individuals affected by CFS/ME

The limited studies examining the narrative accounts of individuals affected by CFS/ME primarily examine the stories of individuals who have been living with the condition for substantial periods of time. Strikingly, a typical illness

trajectory can be seen to emerge across studies, linked by many researchers to a process of core 'identity transformation and reconstruction' (Whitehead, 2006, p1027).

In line with Bury (1982), in some studies individuals are observed to describe the initial onset of their condition as linked to a period of acute 'biographical disruption', due to the profound consequences their illness has for 'the usual markers on which they had previously formed their self-identities' (Bell, 2013, para. 1). For example, in Bell's (2013) study, participants are observed to characterise the onset of CFS/ME as threatening 'their understanding of their bodies, their position within their family and community, and their interactions with their doctors' (para. 1). However, in other studies, the onset of CFS/ME is characterised as involving more 'partial' disruption. For example, in Asbring's (2001) study, many participants are observed to link their condition's onset to particular disruption in work and social life, but to less disruption in other life domains. While Asbring (2001) suggested this 'partial' disruption to perhaps represent a more 'partial transformation of identity' (p313), participants' narratives nevertheless emphasised a profound response to this imposed 'identity-transformation', depicting a strong sense of 'longing for the life lived earlier' (Asbring, 2001, p315).

Notably however, across studies participants are typically seen to progress to descriptions of attempts to integrate the condition into their lives – an endeavour perhaps more akin to G. Williams's (1984) concept of 'narrative reconstruction'. In some studies, attempts to integrate the condition are seen to bring unforeseen 'gains' – for example in Asbring's (2001) study, participants can be seen to highlight their illness as having afforded them opportunity to reflect on their relationships and priorities, and to bring about 'change in attitudes, strategies and habits' (p317). Such stories would appear to resonate with Frank's (1998) 'quest' narrative type, due to their positioning of 'a new self that draws on the experience of having suffered' (Whitehead, 2006, p1024). In other studies however, attempts to integrate the condition are characterised more as endeavouring to reconnect and return to activities

associated with life prior to symptom onset. For example, in Whitehead's (2006) study, many participants are observed to describe multiple attempts to return to work and to take up previous social and personal roles, in spite of the impact these behaviours have on their condition. By contrast, these stories would appear more characteristic of Frank's (1998) 'restitution' narrative type, seemingly underpinned by 'a belief in restorable health [and functioning]' (Kilty, 2000, para. 9) and a desire 'to return to the former self' (Whitehead, 2006, p1024).

However, it is also important to comment on a particular limitation to this literature; namely that the majority of studies discussed here have explored the narratives of individuals who have been, and remain, under the care of specialist CFS/ME clinics. As Whitehead (2006) observes, the experiences of these individuals may have therefore been somewhat different from those without access to such forms of support, which may in turn have had a pronounced impact on the narratives told.

As highlighted earlier however, very little research has been identified at this time that has explored the accounts of individuals affected by CFS/ME from the perspective of the 'narrative identity' being constructed therein. One such study of particular relevance to the current study, completed by Horton-Salway (2001), examined the illness narrative of one female affected by CFS/ME for a number of years. Horton-Salway (2001) argues her approach towards this individual's narrative to have been informed by a 'discursive psychology' perspective (Edwards & Potter, 1992), in which 'memories, attitudes, attributions and identities are respecified as situated discursive accomplishments', rather than reflections of 'an inner world of cognitions and core identities' (p248). Horton-Salway (2001) observed her participant to have employed certain 'discursive devices' as a means of accomplishing a particular 'narrative identity' in her narration of her illness experience; namely that of a woman who prior to her illness had engaged frenetically in activity, and who therefore could not be accused of malingering, or being someone vulnerable to

psycho-somatic difficulties. Horton-Salway (2001) went on to comment how the identity constructed by her participant during their research encounter enabled 'concerns about the cause of ME, its management and the status of sufferers' (p256) to be managed; in other words that the 'narrative identity' constructed in situ had been done so in response to wider contextual issues surrounding CFS/ME. Horton-Salway (2001) concluded that considering the content of illness narratives 'as relating to participants' interactional concerns' (p256) rather than a reflection of their 'inner life', may serve to enhance research examining the narratives of those affected by chronic illness.

### 2.3.3 Narratives of partners of individuals affected by chronic illness

It appears that no studies have considered the relevance of biographical concepts of chronic illness to the narrative accounts of partners of individuals affected by CFS/ME. However, several studies have considered the relevance of such concepts when examining the narrative accounts of carers for individuals affected by other conditions. Many researchers have suggested such an endeavour to be appropriate, since the advent of caring frequently represents 'a [significant] turning point in the [individual's] biography' (Denzin, 1989, p23), often having profound ramifications for the carer's life, which in turn may elicit an ongoing 'quest for meaning' (Pierret, 2003, p8). Notably, participants within such studies frequently consist of a mixture of relative-types, meaning the findings that emerge often include the perspectives of parental, offspring and spousal caregivers. Given the focus for this research however, emphasis will be laid on the findings to have emerged from spousal accounts.

In some studies, spousal carers' accounts present the caregiving role as having been readily assimilated 'into an existing life course' (Chamberlayne & King, 1997, p606). For example, in Chamberlayne and King's (1997) study of the caregiving accounts of two parental carers and two female spousal carers aged 60 and 64, one spousal carer is observed to comment how the demands placed on her by her husband's chronic physical health condition seemed part of 'what the marriage contract entailed' (p612) As Chamberlayne and King (1997) note,



in such cases the caregiving experience is presented as having laid no particular threat to the carer's pre-existing sense of 'self' or 'identity', instead being conceptualised as a form of 'biographical continuity' (S.Williams, 2000); becoming integrated into some pre-existing biographical form.

By contrast, in other studies, spousal carers' have been observed to speak of the experience of caregiving more in terms of profound 'biographical disruption', emphasising how the encounter with caring has resulted in the loss of former plans, significant changes in relationships with the individual affected and others, and an unknown future outlook (Adamson & Donovan, 2005; Chamberlayne & King, 1997; Ramsay, 2010).

However, several studies have observed how the age at which the individual assumes a caregiving role may significantly impact on how the caregiving experience is conceptualised. For example, in Adamson and Donovan's (2005) study, individuals who had assumed carer responsibilities at a younger age were observed to characterise the caregiving experience as more profoundly disruptive. As Bury and Holme (1991) note, these findings would suggest that 'most of us... operate within a definite "social clock" which guides our expectations of events within the biographical context' (as cited in Pound et al, 1998, p503).

Other studies however have highlighted the importance of other aspects of the wider cultural context for how the caregiving experience may be narrativised. For example, in Ramsay's (2010) study of the narrative accounts of mainland Chinese carers for individuals affected by serious mental health issues, the experience of caregiving was observed to be perceived by all as one of stark biographical disruption. Ramsay (2010) argued this to potentially relate to the intense stigma surrounding mental illness within Chinese culture, which may have heightened for the carers the perceived level of burden. Thus as Adamson and Donovan (2005) suggest, 'it appears that time and context, [alongside] norms and expectations.... [may be] crucial [for how] the experience of caring [is conceptualised]' (p44).

In line with the accounts of those affected by illness, significant differences have also been identified in the narrative structure of the stories of carers. For example, in Stern et al's (1999) study examining carers' accounts of supporting a loved one affected by psychosis, two distinct narrative types were identified. The first, termed stories of 'restitution or reparation' (Stern et al., 1999, p5), were identified as those in which the caregiver had managed to 'locate the illness and... its consequences into their map of the world' (p5); in other words, those in which some form of meaning had been attached to the illness experience of their loved one – a narrative type not dissimilar from Frank's (1998) 'quest' narrative. The second, termed 'chaotic or frozen' stories (p5), were characterised as those in which 'carers seemed unable to break loose from a roundabout, repetitive way of telling their story' (p5); stories in which 'the occurrence of illness [still appeared] a series of random events by which one had been afflicted' (p7) – a narrative type perhaps reminiscent of Frank's (1999) 'chaos' narrative, due to its similar lack of distance from 'the "abyss" of illness' (Stern et al., 1999, p5). Stern et al. (1999) went on to observe how the 'perspectives taken by carers seemed to... impact on how each managed their situation in terms of coping, and the solutions they were able to generate' (p12). While acknowledging the limited generalisability of their findings due to the study's small sample size, Stern et al. (1999) suggested their findings pointed to the importance of attending to how carers speak of their experiences. They argued that by doing so, one may gain valuable insights into the caregiver's resources in relation to their loved one's illness; insights which may subsequently form the basis for therapeutic support and intervention.

#### 2.3.4 Summary

Narrative medical sociological research is considered to have made a significant contribution towards our understanding of lay experiences of health and illness (Lawton, 2003). Such research has highlighted significant variation in how the illness experience may be conceptualised and 'storied' by the individual affected; variation that appears dependent on factors such as the individual's biography, age and social/cultural context. Significant variation

has also been observed in how individuals conceptualise and 'story' their experience of caregiving, variation that again appears dependent on factors relating to the caregiver's personal and social context. Notably, some researchers have argued how paying attention to the way in which an individual 'stories' their caregiving experience may be of potential clinical relevance (Stern et al, 1999). Yet in spite of this, no attention appears to have been paid to how partners caring for adults affected by CFS/ME narrate their experiences of living with the condition. Analysis of the narratives of partners of those living with CFS/ME may help deepen understanding of the challenges they face in telling their stories, and eliciting the help and understanding they need.

Notably, while the majority of studies appear to have considered how the personal, social and cultural context in which the participant lives may have bearing on the narratives they tell, minimal research appears to have considered how factors specifically relating to the research encounter, including the nature of the interaction between narrator and listener, may also be of significance. Certain schools of narrative research would argue this to be a notable omission (Goffman, 1969; Riessman, 2003); suggesting attendance to such factors to have potential to elicit additional valuable perspectives.

#### **2.4 Gaps in the literature**

CFS/ME remains a poorly understood condition at this time, shrouded in uncertainty and dispute. This context appears to stem from the international dominance of the bio-medical model, as well as the ongoing centrality of mind-body dualism within Western cultures. Research suggests such a context to have a profound bearing on those touched by the condition, impacting significantly on their experience and the narratives constructed thereof. However, minimal research consideration appears to have been given to partners supporting individuals affected by CFS/ME at this time. A small body of quantitative research has identified particular areas of impact for the partners of individuals affected by this condition. However, there appears a near-absence of qualitative literature seeking to gain more in-depth

understanding of partners' perspectives at this time.

Notably, narrative medical sociological research has been shown to make a significant contribution towards our understanding of lay experiences of living with illness. However, no studies examining the illness narratives of partners of individuals affected by CFS/ME appear to have been carried out to date. It is hoped that by attending to the narratives of partners of individuals affected by CFS/ME - giving particular consideration to the ways in which these narratives are constructed and told to an outsider, and how the outsider may influence the narrative - better understanding may emerge of the key areas of concern for partners, which may in turn help health professionals and others to provide better understanding and support.

## **2.5 Research aims and questions**

The aim for this study is to attempt to address some of the gaps identified in the existing research literature, by exploring the stories told by partners of individuals diagnosed with CFS/ME about their experiences. Furthermore, to consider the situational, societal and cultural factors that may be impacting on how partners tell their stories about their experiences.

Thus the proposed research questions are as follows: -

1) How do the partners of individuals affected by CFS/ME narrate their experiences of living with and caring for their partners?

Within this, attention will be paid to:

- a) the content of narratives
- b) the narrative and discursive features shaping the telling of these accounts.

### **3. Methodology**

This chapter begins by offering the reader a rationale for the research methodology<sup>1</sup>, including the use of a qualitative approach and more specifically narrative inquiry. Consideration is then given to factors relating to the 'quality' of the research, as well as ethical issues. The chapter then moves on to discussion of the research sample and participant recruitment, before a thorough explanation is provided for the research process; moving from the composition of field texts through to the creation of research texts. It is hoped the level of detail and transparency offered should enable the reader to consider the appropriateness of the research design, as well as decisions made in relation to representation of the analysis; an endeavour in line with one of the markers of 'quality' in qualitative research postulated by Tracy (2010) - 'sincerity' – discussed earlier within the 'Introduction' chapter of this thesis.

#### **3.1 Qualitative methodology**

A qualitative approach was selected for this study since to date, the vast majority of research examining partners' perspectives on CFS/ME has drawn on quantitative approaches. While the value of quantitative research is not denied, one might suggest its principal focus to lie on precise measurement of aspects of an individual's experience (Barker et al., 2008). By contrast, qualitative approaches can enable researchers to hear partners' experiences as they tell them, enabling 'rich[er], deep[er] and [more] complex information [to emerge]' (Barker et al., 2008, p72). Such information may significantly enhance understanding of the issues faced by partners of those living with CFS/ME; understanding which may be of particular value to both professionals and other partners of those affected by the condition. Furthermore, it may also indicate directions for future research endeavours.

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<sup>1</sup> The reader is also referred back to the 'Introduction' section of this thesis, in which the epistemological position of the researcher is discussed, as well as the personal significance of the research.

### **3.2 Narrative inquiry**

Narrative inquiry was selected as the most appropriate methodological choice for this study for a number of reasons.

Firstly, a key objective for the study was to examine the meanings attached by partners of individuals affected by CFS/ME to their experiences of living with the condition over time. Narrative has been argued to be the principal way in which humans make meaning of their experiences (Murray, 2003; Polkinghorne, 1988). Riessman (2008) defines narrative as 'a bounded segment of talk that is temporally ordered and recapitulates a sequence of events' (p116). However, as Wertz et al. (2011) state, narratives are always played out 'in the context of other stories that may include societies, cultures, families or other intersecting plotlines in a person's life' (p224). Given the vast array of 'stories' surrounding CFS/ME outlined earlier in the literature review, it was felt narrative inquiry may help to illuminate the wider context being drawn upon by participants when narrating their experiences.

However, it has also been suggested that narratives represent a construction of events 'composed jointly [between narrator and audience], crafted in collaborative conversational interaction' (Riessman, 2008, p31). As such, they may be regarded as 'encouraged and shaped by [the]... context [in which they are told]' (Murray, 2003, p116). It was therefore felt that narrative inquiry could enable attention to be paid as to how the situational context of the research encounter may have had bearing on the stories co-constructed therein (Plummer, 2001); an endeavour one might argue of particular interest given my status as a trainee clinical psychologist, and the longstanding debate surrounding whether CFS/ME may represent 'a physical disease, a psychological illness or [something] that has both of these components' (Hossenbaccus & White, 2013, p2),

Furthermore, narrative inquiry is able to facilitate examination of the identities performed and claimed by individuals in their encounter with another (Riessman, 2008). It is suggested such an endeavour may be of

particular value, since in the context of research examining partners' constructions of chronic illness, it appears little consideration has been given to the examination of 'identity' in this way.

### **3.3 'Quality' of the study**

Historically, qualitative researchers such as Lincoln and Guba (1985) argued 'quality' in qualitative research to relate to issues of 'trustworthiness'; whether the research may 'be accepted into the pantheon of knowledge and be received as suitable for use in various ways' (Loh, 2013, p4). However, a number of competing claims as to what constitutes good 'quality' work in qualitative research have subsequently emerged (Seale, 1999). Notably, several qualitative researchers have argued against the 'development of permanent unvarying ['quality'] standards... suggesting universal criteria [to be] problematic' (Tracy, 2010, p838). However, others have contended the development and consideration of criteria of 'quality' within qualitative research to be of crucial importance, particularly if qualitative approaches hope to gain wider recognition and acceptability (Elliott et al., 1999, as cited in Loh, 2013).

Thus informed by the latter perspective, the 'quality' of this study has been considered in relation to Tracy's (2010) 'Eight Big-Tent Criteria for Excellent Qualitative Research'. These criteria appear to fit well with the pluralistic perspective associated with the post-modernist/social constructionist position underpinning this research, due to their focus on delineating 'common markers of goodness [for qualitative research] without tying these markers to specific paradigmatic practices or crafts' (Tracy, 2010, p839).

Tracy (2010) recommends attendance to the following aspects when examining the 'quality' of a piece of qualitative research; 'worthy topic', 'sincerity', 'meaningful coherence', 'significant contribution', 'rich rigor', 'credibility', 'resonance' and 'ethical considerations'. The reader is oriented to the 'Introduction' chapter of this thesis for discussion of the first three of these criteria. With regards to the remainder, it is my intention to discuss

these where appropriate throughout the rest of this chapter, and my summary of findings.

### **3.4 Ethical considerations**

As highlighted above, ethical considerations are identified by Tracy (2010) as a particularly key criterion for 'quality' in qualitative research. As such, prior to embarking on my research process, I consulted the British Psychological Society Code of Ethical Practice (BPS, 2009) to ensure ethical principles formed the basis of my study, particularly in relation to informed consent, confidentiality and participant well-being.

Prior to starting my research, ethical approval was sought and obtained from the University of Hertfordshire Advisory Committee on Ethics (Appendix B). Confirmation was also obtained from the National Research Ethics Service (NRES) that this research did not require their approval, since participants were not to be recruited through the NHS.

#### **3.4.1 Informed consent**

At point of expressing interest in the study, potential participants were provided with a copy of a Project Information Sheet (PIS) (Appendix C). This outlined the key aims of the research, as well as what participation in the project would involve. The voluntary nature of participation, issues surrounding confidentiality, and the fact the research formed part of a doctoral qualification in Clinical Psychology were particularly highlighted. It was hoped that by providing each potential participant with this information, along with an extended period of time to consider any questions they may have about the research process, each individual was offered sufficient information and time to make an informed decision about participation.

Prior to each interview taking place, the PIS was reviewed with the participant and further opportunity for questions was provided. If the participant reported that they were happy to proceed, they were then presented with a consent form, which reiterated issues of consent and



confidentiality (Appendix D). If the participant expressed their agreement, both researcher and participant subsequently signed the consent form.

### 3.4.2 Confidentiality

Throughout the research process, participants were assured that any personal information they provided would remain confidential; stored securely on a password-protected computer, accessible only to the researcher. It was explained that extracts from their interview could be used in the write up of the study but that any personally identifying features would be removed, with participants (and any individuals to whom they referred) being allocated pseudonyms in an attempt to maintain anonymity and confidentiality. However, participants were informed that despite such endeavours, there remained a possibility their story could be recognisable to those familiar with their experiences, due to the use of direct quotations and the individual nature of the analysis. Again, this information was provided to support participants to make a fully informed decision about participation.

Issues of confidentiality were also considered in relation to the actual interview process. If participants were interviewed in their own home, the researcher sought to carry out the interview in a location in the house that afforded maximum confidentiality, while remaining mindful of their own personal safety. If participants were interviewed in public places, e.g. a local park, the researcher again sought to carry out the interview in a location that helped to maintain confidentiality as far as possible. If an unexpected event occurred during an interview that had the potential to compromise the participant's confidentiality – for example, another individual entering the location where the interview was taking place - the researcher stopped the interview process until a confidential environment was re-established.

### 3.4.3 Participant well-being

The personal, and potentially sensitive, nature of the topics to be discussed during research interviews was held in mind throughout every stage of the research process. Thus every effort was made to protect the well-being of

participants. Prior to signing the consent form, it was discussed with participants that the research interview might have the potential to elicit unexpected distress. Participants were reminded that they could take a break at any time, choose not to answer certain questions if they felt they didn't want to, or even stop the interview and withdraw from the study without needing to provide an explanation. If any participant became distressed during interview, the researcher checked that they remained happy to proceed, and drew on their clinical skills to support them. All participants were provided with an opportunity to debrief at the end of their interview, and to ask any questions they had. A debrief sheet (Appendix E) was also provided, offering information on organisations that could provide ongoing support, as well as the contact details for both the researcher and principal supervisor for the study should the participant wish to discuss any issues raised by the research encounter.

### **3.5 Sampling and recruitment of participants**

#### **3.5.1 Sample**

Participants were selected using a purposive sampling approach, a sampling technique commonly used in qualitative research (Oliver & Jupp, 2006). Six partners in total were recruited to the study – four males and two females, recruitment of whom is set out within the next section. While some might suggest this figure to represent a relatively small sample size, Wells (2011) argues this to be appropriate for narrative studies, given the detailed and rich information narrative research generates. In my definition and recruitment of partners no assumption of heterosexuality was made, but in the event all those recruited were in heterosexual relationships.

The inclusion criteria for the study were as follows: -

1. To be aged 18 or over
2. To be in a long-term relationship with an individual who has been diagnosed with CFS/ME, or whose symptoms are understood as indicative of CFS/ME.

3. To be fluent in English.

The first two criteria were selected to ensure participants were of adult age, and had spent some time living with a partner affected by CFS/ME. It was hoped this would enable them to share a narrative of the meaning they had developed over time around living with their partner's condition. The criteria of being able to speak English fluently was included as it was felt certain meanings within a participant's narrative may have been lost if the researcher had had to rely on an interpreter, or may not have been able to be communicated if the individual didn't have sufficient English to verbalise what they felt important to share. For narrative analysis, when one is considering not only the content of talk, but also the nuances of how talk is being put together – e.g. structure, use of metaphor etc. – this is particularly relevant.

The exclusion criteria for the study were therefore: -

1. Individuals whose relationship with someone affected by CFS/ME may not be viewed as long-term (i.e. less than one year).
2. Individuals who were not fluent in English.

Table 1 provides information on key demographics of the sample.

**Table 1: Key sample demographics**

<b>Pseudonym</b>	Oliver	Tom	Michael	Stewart	Sue	Louise
<b>Age</b>	58	45	70	45	63	53
<b>Marital Status</b>	Married	Married	Married	Co-habiting	Married	Married
<b>Occupational Status</b>	Retired/ Full-time carer	Employed full-time	Retired/ Full-time carer	Full-time carer	Self-employed	Employed full-time
<b>Approximate length of time known partner affected<sup>2</sup></b>	30 years	23 years	18 years	11 years	27 years	30 years
<b>Estimated onset of partner's CFS/ME<sup>3</sup></b>	29 years ago	9 years ago	17 years ago	27 years ago	15 years ago	6 years ago

### 3.5.2 Recruitment

All participants were recruited from regional CFS/ME support groups. Participants were recruited from 5 support groups in total.

The recruitment process consisted of a number of stages. Initially, a list of CFS/ME support groups operating throughout the UK was obtained from the 'ME Association' website – an online organisation which seeks to provide information, support, education and training around CFS/ME. Telephone contact was then made with the main point of contact listed for 10 support groups within the southern part of the UK. During these conversations, key details of the research study were provided, including its aims and what participation would entail. If the point of contact was in agreement, following this discussion a brief e-mail was sent to them summarising my research interest (Appendix F). A copy of the PIS was also attached to this e-mail, providing more detailed information on the study. This e-mail was subsequently distributed by the point of contact to members of their support

<sup>2</sup> Time periods calculated backwards from 2015.

<sup>3</sup> Time periods calculated backwards from 2015.

group. This resulted in seven individuals contacting the researcher via e-mail to express interest in taking part in the study. Unfortunately one individual was subsequently excluded as it emerged their partner had in fact been diagnosed with Fibromyalgia, rather than CFS/ME; a condition which is suggested by many within the bio-medical community to have significant overlap with CFS/ME, but which is still regarded as a separate disease entity at this time (Johnson, 2014). This individual was thanked for their expressed interest, but was informed that due to the study's principal focus on CFS/ME it would not be possible for them to take part in the research. A copy of the PIS was subsequently sent via e-mail to the remaining six individuals, to ensure each had access to this prior to any prospective meeting. All potential participants were informed that should this elicit any questions for them, they could contact the researcher via e-mail for clarification at any time. Interview arrangements with all six participants were subsequently made.

### **3.6 Creating field texts and moving to research texts**

As Clandinin and Huber (2002) observe, 'narrative inquiry follows a recursive, reflexive process, moving from field... to field texts (data) to... research texts' (p1). In this section, I aim to take the reader through my research process, from the composition of field texts through to the creation of research texts. Central to the research process detailed below is the perspective that we as investigators do not have direct access to another's experience (Riessman, 1993). Instead, we deal with representations of experience, representations that may be considered partial, ambiguous and co-constructed in interaction (Riessman, 1993). Furthermore, it is acknowledged that 'what becomes shared in research texts is usually only a small portion of the overall data' (Clandinin & Huber, 2002), bound by the time and context in which the research text is composed. As such, it is held that the stories to emerge out of my research endeavours may be regarded as some of potentially many (Clandinin & Connelly, 2000).

#### **3.6.1 Constructing field texts**

##### **3.6.1.1 Interview structure**

As Savin-Baden and Major (2013) observe, the interview represents the most common method used to create field texts within narrative research, and similarly represented the principal method employed within my study.

As Riessman (2008) notes, 'the goal in narrative interviewing is to generate detailed accounts rather than brief answers or general statements' (p23). Thus I was particularly keen to attempt to establish a climate within the research encounter that encouraged detailed storytelling (Riessman, 2008). Informed by Riessman (1993), I therefore initially developed a draft broad interview guide (Appendix G), based on some of the literature around partner experiences in the context of chronic illness outlined in the literature review. However, in an attempt to prevent my assumptions or preconceptions 'imposing' on the interview guide, and as a means of incorporating service user participation into the development of this study (an endeavour in line

with the National Institute for Health Research and INVOLVE's (2009) good practice guidelines), I approached a CFS/ME support group in the south of the United Kingdom to request consultation with the partner of an adult member living with the condition. Telephone contact was subsequently made with a female partner, during which key areas of her experience were discussed. Notably, this woman did not later go on to take part in the study. The final interview guide was subsequently loosely structured around several key areas of experience to emerge during the course of this telephone conversation.

Each interview opened with the broad opening question *'I wonder if you could begin by telling me about when you first became aware of CFS/ME in x's life, beginning at the place you feel is most appropriate to start?'* The purpose of this question was to encourage participants to 'tell their story'. In line with Riessman (1993), probe questions were also identified in case the participant found it difficult to get started – for example, *'Could you tell me a bit more about that?'; 'What happened next?'; 'Can you explain a bit more what you mean?'* Following this, open-ended questions were used to explore key areas of interest; for example, how the condition may have impacted on the relationship between the participant and their partner over time; the response of those around the participant and their partner to their situation over time; and how the participant viewed the future as someone supporting/caring for someone affected by CFS/ME. However, emphasis was laid on minimising directive influence. Instead the researcher sought to actively listen (Kvale, 2007) to each participant, following the participant's lead throughout the course of the interview but remaining aware of how my presence was leading to a jointly constructed narrative to emerge (Mishler, 1986).

### ***3.6.1.2 Interview process***

Each participant was interviewed once, with interviews lasting anything between 50 and 110 minutes. Given participants' status as partners of individuals affected by a chronic debilitating condition, each individual was

offered a choice to be interviewed in a location convenient to them. As such, the locations for the interviews varied significantly, and included a local park, a meeting room at one participant's place of work, and four home visits. The researcher adhered to the University of Hertfordshire Lone Worker Policy in order to minimise any potential risks to her well-being from working alone in such locations.

Once participants had signed a consent form to indicate their willingness to take part in the research, certain demographic details were obtained. These included the participant's age and occupational status. The purpose of this was to gather a context for the conversation that would take place as part of the research encounter.

All interviews were subsequently audio-recorded. Following completion, time was offered to participants to share any reflections they had on their experience and to de-brief. Once the researcher returned home from each research encounter, audio-reflections were made detailing my thoughts and reflections on the stories that had emerged, as well as my experience of the interview process.

### **3.6.1.3** *Creating written field texts*

As Riessman (1993) observes, 'taping and transcribing are absolutely essential to narrative analysis' (p56). However, as I began to transform the audio accounts of my research participants into written field texts, I became acutely aware how the act of transcription in itself represents a form of 'interpretive practice' (Riessman, 1993, p13); that in effect I was forming a re-presentation of the interview shaped by my underlying theoretical position (Etherington & Bridges, 2011). As such, all of my resulting transcripts may be considered 'incomplete, partial, and selective' (Riessman, 1993, p11).

My decision how to transcribe was guided by Riessman's (2008) notion that narratives are always co-produced in contexts. As such, all interviews were



transcribed verbatim, incorporating the researcher's involvement. Transcription also included other notable features of the conversation and expressions of emotion - for example, pauses, laughter, crying, sighing and non-lexical expressions such as 'Mm', 'Uh' and 'Um' - since these too may be regarded as key features of narrative performance.

The researcher transcribed the first and third interviews to be completed. However, given time limitations, the remaining four were transcribed by a professional transcription service. Prior to these interviews being released for transcription, the transcriber was requested to sign a confidentiality agreement (Appendix H). Once these transcripts were received back from the transcriber, they were each read while listening to the interview in question, and any necessary amendments or additions were subsequently made.

### **3.6.2 From field texts to research texts**

As Tracy (2010) suggests, 'rich rigor' in qualitative research 'is marked by transparency regarding the process of sorting, choosing and analysing the data' (p841). Thus, in the following section, I aim to offer a detailed account of the process I drew on to transform my field texts into research texts.

#### **3.6.2.1 Guiding Framework**

My process of analysis was informed by a variety of analytical perspectives; an endeavour supported by Coffey and Atkinson (1996) who suggested the more we consider our data from multiple viewpoints 'the more we may reveal - or indeed construct - their complexity' (p14).

In line with Riessman (2008), each narrative was analysed in its entirety, rather than being separated into discrete units or categories. Narrative accounts were initially analysed drawing on Gubrium and Holstein's (1997) 'analytical bracketing' procedure. Analytical bracketing is described as 'an orienting procedure for alternately focusing on the whats and then the hows of interpretive practice (or vice versa) in order to assemble both a

contextually scenic and contextually constructive picture of everyday language-in-use' (Gubrium and Holstein, 2000, p500). As Smith and Sparkes (2009) observe, such a procedure has been argued to suit the intricacy of narrative, enabling the researcher to begin to attend to the different facets of the data obtained.

In seeking to consider the primary research question '*how do the partners of individuals affected by CFS/ME narrate their experiences of living with and caring for their partners*' I drew from questions developed by several authors (Appendix I). These questions enabled the narratives co-constructed during the research encounter to be considered on multiple levels; from the local situational context to the wider societal, cultural and historical context. These questions were not attended to in turn, but rather were moved back and forth between as the analytical process proceeded.

The majority of these questions were taken from Riessman (2003), and were designed to enable consideration of how 'a socially constructed "self" came to be performed for (and with) an audience' (Riessman, 2008, p116). As Riessman (2003) observes, this analytical focus is seen to have its origins in Goffman's (1959) 'dramaturgical metaphor', which argues 'individuals negotiate how they want to be known in the stories they develop collaboratively with their audiences in interview situations' (Riessman, 2003, p8). Harper and Thompson's (2012) questions around narrative 'structure' enabled consideration to be given to the narrative 'type' developed in interaction (Frank, 1998). Burnham's (1993) 'GRRACCEESS' enabled consideration of issues of diversity, difference and power in relation to the situational context of the research encounter and the narratives co-constructed therein. Finally, Harper and Thompson's (2012) questions around 'audience', alongside Mishler's (1991) '*who might be the ghostly audiences*' question, enabled attention to be paid to what participants may have been seeking to 'achieve' through the narrative co-constructed during the research encounter, as well as the other 'audiences' that may have been borne in mind as the narrative emerged.

In seeking to attend to the content of narratives, I drew on questions developed by Taylor and Littleton (2006). Taylor and Littleton (2006) promote a 'narrative-discursive' approach, which holds that whilst a narrator constructs an identity in interaction they can be seen to draw on shared 'discursive resources', such as 'interpretative repertoires' (Edley, 2001) - 'a lexicon or register of terms and metaphors drawn upon to characterise and evaluate actions and events' (Potter & Wetherell, 1987, as cited in Edley, 2001, p198) - or 'canonical narratives' - 'understandings of current consensus about what it is acceptable to say or do in [an individual's] local and national cultures' (Phoenix, 2013, p73). From this perspective, the 'content' of narratives may therefore be understood as the ways in which participants' talk has been 'shaped and constrained by the meanings which prevail within the larger society' (Taylor & Littleton, 2006, p22). Thus to facilitate attendance to the 'content' of narratives in this way, two questions developed by Taylor and Littleton (2006) were drawn upon; *'what common elements occur across the interviews, and also at different points in the same interview?'* and *'how might these be seen to relate to the "discursive resources" which pre-exist an individual speaker's talk?'*

Finally, in seeking to attend to the narrative and discursive features shaping the telling of the accounts given by participants, I drew on questions developed by Langellier (1989; as cited in Riessman, 2008), which ask the researcher to observe uses of repetitions, pauses, reported speech, shifts in pronouns, shifts in time (now/present to past) and use of vivid detail and gesture.

This framework was utilised over several readings, enabling the researcher to become deeply immersed in multiple possible understandings (Bakhtin, 1991, as cited in Riessman, 2008).

### 3.6.2.2 *The tasks of analysis*

The analytical process involved multiple tasks, an endeavour fitting for the complexity and richness of narrative. Appendix J details each of the analytical tasks completed with respect to one transcript<sup>4</sup>.

- The first task involved reading and immersing myself in the narrative. The audio-recording of each narrative was listened to at the same time as reading the transcript, to enable details of the interaction within the research encounter to be heard which were perhaps unable to be captured within the transcript, e.g. the tone in which something was said. The researcher also listened to the audio-reflections that had been made following the research interview.
- Informed by Gubrium and Holstein (1997) the narrative was then read through several times, with the researcher focusing on what she perceived was being said, and how.
- Once the narrative had been read several times, a narrative 'impression' was written. This helped the researcher to summarise and reflect on key initial interpretations of the narrative.
- The narrative was then read with the questions outlined in the previous section held in mind. Notable 'storylines' were listened out for; 'storylines' being defined as the key topics, events or 'identities' positioned during the course of the narrative. These were identified by the intensity of their presence, or how importantly the researcher perceived their being heard to have been for the participant.
- Brief narratives were written for each storyline identified.
- This process was completed for each narrative in turn.
- Once all six transcripts had been analysed individually in this way, they were then considered collectively. Principal focus was laid on considering the key topics, events or 'identities' that had been positioned, and any areas of similarity or difference between these across narratives.

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<sup>4</sup> In the interests of maintaining confidentiality, only six pages of transcript will be included in the appendices.

### **3.6.2.3** *Seeking member reflections*

Tracy (2010) argues another key criterion for 'quality' in qualitative research to be 'credibility', suggesting this to refer to the 'trustworthiness, verisimilitude and plausibility of the research findings' (p842). Tracy (2010) goes on to suggest that one path to credibility may involve the researcher 'seeking input during the process of analysing data' (p844). Member validation – 'checking' or 'verification' by research participants of the conclusions drawn by researchers from their analysis – has become increasingly recommended in qualitative research as a way of meeting such a requirement (Cresswell, 1994). Indeed, several researchers have proposed the act of member validation to have potential to elicit the recounting of more 'defended' narratives - narratives which participants may have felt unable, or reluctant, to articulate in the original research encounter – thereby helping to enrich the data obtained (e.g. Kirkpatrick & Byrne, 2009).

However, it was felt such a practice would run counter to the social constructionist/post-modernist perspective underpinning this study, as it may also be regarded as supporting the notion of there being one interpretable 'truth' (Angen, 2000). Instead, key 'storylines' identified during the analytical process were discussed with my supervisors and within a narrative peer supervision group. Feedback was then gained as to whether the interpretations made seemed plausible in relation to the narrative accounts obtained. In this respect, issues of credibility were attended to, but in a manner more in keeping with the study's underlying epistemological position.

### **3.7 Composing research texts**

Before offering my interpretations of the co-constructed narratives of the six participants in this study, I will briefly outline my decision-making process in relation to the composition of the research texts for this thesis. Again, my aim through this endeavour is to enhance the 'rigor' of my study, by ensuring my analytical choices and motivations are transparent for the reader (Tracy, 2010).

#### **3.7.1 Re-presentation of narratives**

Once analysis had been completed, I was drawn to consider how best to 're-present' the narratives that had emerged (Etherington and Bridges, 2011). This was a challenging task, since the narratives co-constructed were both rich and complex. I was concerned to ensure 'justice' would be done to each participant's account, whilst offering the reader a coherent analysis within the limitations of the word count. Informed by my research questions, I decided to begin my re-presentation of narratives on an individual basis. My analysis therefore begins by offering the reader some relevant background information to each participant, followed by key impressions of each individual narrative, as interpreted by the researcher. In line with Saukko (2000), these are written in the third person, so the reader may appreciate them as the researcher's interpretations. Direct quotations are interspersed into these third person interpretations to highlight 'how the voices of the author [researcher] and the characters [participants] are always entangled with one another' (Saukko, 2000, p303).

Subsequently, collective narratives are shared. It is hoped this will facilitate the reader to see the researcher's interpretations of particular areas of similarity and diversity in the narratives co-constructed. Analysis and discussion are presented together to enable a coherent narrative to be elicited for the reader, contextualising the researcher's interpretations in relation to the situational, societal and cultural context, as well as the existing literature within the field.

Importantly, my decision to re-present the narratives in this way has also been influenced by Tracy's (2010) 'resonance' criterion for quality in qualitative research, which argues qualitative research should aim to 'meaningfully reverberate and affect an audience' (p847).

#### 4. Analysis

The aim of this chapter is to offer the reader the researcher's interpretation of the narratives co-constructed with six partners of individuals affected by CFS/ME. All participants, and any individuals associated with them, have been allocated pseudonyms. Any other information that could facilitate identification of those who took part in this study has either been removed or altered.

The first part of the analysis contains two aspects. In line with Riessman's (1993) assertion that narratives are always co-produced in contexts, initially brief background information is offered on the participant and the context surrounding the research encounter. It is hoped this may help the reader to situate the researcher's interpretations that follow. Subsequently a 'narrative impression' is offered of each participant's individual narrative account, containing brief quotes that aim to illustrate key storylines identified.

In the second part of the analysis, the researcher's interpretation of areas of similarity and difference across narratives is presented. These interpretations are linked to existing research, and are considered in light of the situational, societal and cultural context surrounding each research encounter. Two particular areas of collective focus within participants' accounts are discussed – '*stories from then*' and '*stories from now*' – as all participants fell easily into speaking about their story of living with the condition historically, as well as in the present. Presenting participants' narratives under these two broad areas of focus enables notable areas of commonality or diversity to be considered, and the heterogeneity of partners' constructions to be reflected.

Notably, whilst presentation of collective analysis has been set within a temporal framework, participants' narrative accounts did not sustain a clear temporal, or chronological, trajectory throughout. This may relate to the structure of the interview schedule, which sought to gain participants' stories over time in relation to specific topics, rather than obtain a



chronological detailing of 'experience' more characteristic of a 'life-history' approach (McAdams, 1993).

#### **4.1 Introduction to participants and individual 'narrative impressions'**

##### **4.1.1 Oliver**

###### *Introduction*

Oliver was 58 years old, white British, married, and had taken early retirement at the end of 2010. Oliver reported knowing his wife for approximately 30 years at the time of our meeting, and that they had been married for approximately 28 years. Oliver and his wife had no children, and he described them as being fairly distant from many family members, with the one exception of his wife's niece. Oliver traced the onset of his wife's CFS/ME to shortly after they had got married. He described how at this time his wife had been hit by a car whilst running for a bus, hitting her head '*with sufficient force that it cracked the windscreen*'. Oliver reported that his wife had failed to recover as one would expect from this accident. Oliver went on to state that his wife had previously worked as a cardiothoracic nurse, assisting a prestigious cardiothoracic surgeon in theatre, and that they now believed she had picked up a virus from such work, which later developed into CFS/ME. Oliver and I initially met at a leisure centre close to where he lived, before moving to a bench in a nearby park to complete the research interview. Early on, Oliver introduced that he had a background in social work, working with young people who had been in contact with the criminal justice system.

###### *Narrative Impression*

Oliver's narrative appeared tentative and somewhat 'disorganised' for the most part. I recall questioning at the time whether this reflected a degree of apprehension around our meeting. However, towards the end of the research encounter, Oliver informed me that the research interview represented the

first time he had ever spoken about CFS/ME and its impact. Thus, this may have had significance for the storytelling style observed.

Oliver's narrative appeared permeated with stories of 'battle' as a result of CFS/ME, particularly with health professionals. These stories appeared underpinned by a sense of injustice and frustration. Furthermore, multiple images linked to combat and even warfare can be observed throughout his narrative; for example *'it's like we have to be armed with, with the knowledge to give to [my wife's GP]'*. However, alongside such stories of 'battle' were stories that spoke of the couple's, and Oliver's, isolation and loss as a result of his wife's condition. For example, Oliver described how *'it does, it really does feel much of the time that [it's] you against the world really'*. Notably, such stories had the effect of constructing those affected by, or affiliated to somebody living with, CFS/ME, as part of an oppressed 'sub-group' within society.

For much of the narrative, Oliver was observed to use the pronoun 'we'. This had the effect of positioning Oliver alongside the CFS/ME sufferer, and of diminishing a sense of Oliver's 'identity' in his own right. However, Oliver was observed to use the pronoun 'I' on a few occasions, principally when speaking of his previous career, and how this had equipped him with *'skills to really look at [my wife's condition]'*. Indeed, Oliver can repeatedly be observed to draw on quite 'technical' terminology or vocabulary throughout the narrative; for example, introducing the researcher early on to a particular treatment option for CFS/ME, *'what you call EPD injections, Enzyme Potentiated Desensitisation, which are known, which is known to benefit ME sufferers'*. There is also a sense that Oliver held multiple 'ghostly audiences' in mind throughout the narrative, particularly those within the bio-medical community or wider society who may question the validity of CFS/ME as a 'physical' condition

#### 4.1.2 Tom

##### *Introduction*

Tom was 45 years old, white British, married, and identified himself as employed full-time, working in 'computer software'. Tom reported that he had known his wife for approximately 22 years, and traced the onset of her CFS/ME to approximately 8 years prior to our meeting. Notably, he reported his mother to have also 'experienced ME years ago'. Tom reported that he and his wife had previously planned to have children, but that due to his wife's condition this was no longer being contemplated. Tom reported that his wife had never been a 'super energy person', but that in approximately 2006/7 he had noticed that 'she was always very tired', taking most of the weekend to recover from a demanding working life. In 2007, his wife had begun to suffer from recurring sinus infections, which eventually required surgery. Tom went on to describe how following a second operation, his wife never fully recovered, and that her health subsequently deteriorated to such an extent that in early 2008 she had required hospital admission. Tom and I met at his place of work at the end of the working day, carrying out the research interview in a meeting room in a modern office.

##### *Narrative Impression*

Tom's narrative seemed particularly ordered and coherent throughout. However, Tom's early narrational style appeared somewhat emotionally 'disconnected'. For example, Tom was repeatedly observed to speak of how CFS/ME had 'changed everything', but at one stage described how 'for example, when Sarah [Tom's wife] got ill, we were planning to have children. We had to knock that on the head, right'. Later, Tom used the exact same phrase in relation to the couple's inability now to take 'exotic holidays' due to CFS/ME. I am now drawn to question whether the situational context in which the research encounter took place – a meeting room in Tom's place of work – may have had some bearing on Tom's style of delivery; a location where Tom was perhaps regularly expected to 'perform' or 'deliver' coherent narrative accounts with little or no emotional 'connection'.

Tom's narrative evoked less of a sense of acute isolation, due to its positioning of family members and friends who offered Tom and his wife support, and who 'understood' Sarah's condition. For example, Tom referred to his own mother, stating *'she's been just fabulous because she completely understands'* as well as some close friends who *'have been very good because they've seen the impact'*. Furthermore, Tom portrayed himself as a man still able at times to maintain his own interests and social network. However, as the narrative progressed, Tom repeatedly emphasised how he and his wife had been left as a *'little team against the world'* as a result of CFS/ME. Indeed at one stage, Tom was observed to employ a particularly striking metaphor to capture the change of dynamic in their relationship, stating *'I sort of orbit her now'*. Due to its planetary associations, this metaphor constructed for the researcher a sense of the relationship's magnitude for Tom. However, it perhaps also constructed both parties as being 'fixed' on similar, but different, 'paths'; existing in close proximity but never able to fully 'connect'.

Tom can be observed to portray an identity of a 'thinker' within the narrative, describing himself and his wife as *'people that have a very sort of rich inner life, if that doesn't sound ridiculous?'* Central to Tom's narrative were his reflections on CFS/ME as a condition, as well as the unhelpfulness of treatment approaches offered within the UK at present. At times, Tom can be seen to make use of a discursive strategy called 'active voicing' (Woofitt, 1992) within such reflections, characterising the individuals involved in a way that serves to bring to life, and add authenticity, to his perspectives. There is a strong sense that Tom also held multiple 'ghostly audiences' in mind throughout the narrative, particularly those within the bio-medical community researching into the underlying cause for CFS/ME, as well as those who devise, and adhere to, the current treatment guidelines for the condition within the UK.

### 4.1.3 Michael

#### *Introduction*

Michael was 70 years old, white British, married, and identified as having been retired for approximately 5 years. At our meeting, Michael reported that he had first met his wife approximately 18 years ago, and that they had been married for approximately 16 years. Michael stated that his wife had children from a previous marriage, but that he and his wife had no children together. Michael reported that his wife suffered from multiple physical health issues, but traced the onset of her CFS/ME to shortly after they had got married. Michael and I met at his home to complete the research interview. Michael's wife was not present in the house as the interview took place.

#### *Narrative Impression*

From its outset, Michael's narrative was characterised by a measured, almost sombre tone, punctuated by substantial pauses. Generally however, Michael's narrational style felt somewhat disorganised and tangential, leading the narrative to lose consistency or 'thread' at times. Michael was observed to repeatedly place himself in stories of 'tolerance' and unconditional care and regard for his wife; for example, describing at one stage *'there have been occasions when Lindsay [Michael's wife] has said "Oh I'd love to do so and so". [Clears throat] And "OK, yeah, that's fine, we'll do that"'*. Michael's narrative was also permeated by examples of 'active voicing' (Woofitt, 1992), particularly in relation to his interactions with his wife. This again added authenticity, or a sense of 'factuality', to Michael's perspectives on such interactions. On several occasions however, Michael was observed to position his status as an older man, and the consequences of this for meeting all of his wife's needs. This repeated positioning of stories relating to 'getting older' suggested this to perhaps represent an area of concern for Michael.

Notably, Michael was also observed to repeatedly position the physical consequences of his wife's condition. Michael also strongly positioned his

wife as physically disabled, and his narrative was permeated with stories of the couple 'in conflict' with wider society due to a perceived lack of regard for those living with disability. Such stories again constructed a sense of 'battle' for those affected by, or affiliated to somebody living with, CFS/ME. Again, there was a strong sense that Michael held multiple 'ghostly audiences' in mind throughout, particularly those who may question the validity of CFS/ME as a physical condition, or members of wider society who fail to consider the needs of those living with disability.

#### 4.1.4 Stewart

##### *Introduction*

Stewart was 45 years old, had been co-habiting with his partner for approximately 9 years, and identified as her full-time carer for the past 5½ to 6 years. He reported having been resident in the UK for a substantial period of time, but that he had American parents and had spent some of his early life in America. Stewart reported that his mother had also previously been diagnosed with CFS/ME, and that he had acted as her full time carer 'from age about four, right through to sort of when I left home'. Stewart stated his partner had children from a previous marriage, but they had no children together. Stewart reported that he had known his partner for approximately 11 years, and that they had been dating for approximately 9½ years. He reported that his partner believed she had first developed symptoms of CFS/ME when she was aged approximately 19. However, medical professionals had not linked these symptoms to the condition until some time after their relationship began. Stewart and I met at his home to complete the research interview. Again, Stewart's partner was not present in the house as our meeting took place.

##### *Narrative Impression*

Stewart's narrative was characterised by a coherent, logical narrational style. At the outset, Stewart's storytelling felt somewhat emotionally 'disconnected' - offering a clear history of events relating to his partner's

condition but with minimal reference to their emotional consequences. However, this was observed to shift when Stewart began to speak more of the impact of CFS/ME for him and his partner. From this point, Stewart's narrative became dominated by multiple stories of 'battle', and even 'oppression', as a result of his partner's condition; stories that involved multiple parties, including family members, friends/acquaintances, health professionals, wider society and 'Atos' – an organisation previously contracted by the government to complete work capability assessments. As a result, as Stewart's narrative progressed its tone became increasingly frustrated, and even angry. Indeed, on several occasions the strength of Stewart's emotion led him to inhale deeply, or stop mid-sentence, in an attempt to moderate his emotions: for example, *'But Sophie's [Stewart's partner] illness, which is a life-changing illness, which is a permanent illness, for which there is no cure, they have no interest in it because it doesn't impact on them (R: Mmm) (Inhales) And.... sorry'*. This suggested such stories to have remained relatively 'untold' until this time.

Stewart was also observed to repeatedly position the change in personal circumstances that had occurred for him as a result of his partner's CFS/ME, making multiple references to a profound shift in his financial and social status. However, Stewart was also seen to position a strong sense of reward from his role as full-time carer. Stewart's narrative was filled with multiple examples of detailed description, evocative imagery/language and 'active voicing' (Woofitt, 1992); all of which served to increase the emotional resonance and legitimacy of Stewart's perspective for the audience. Again, there was a strong sense of multiple 'ghostly audiences' being held in mind, particularly those who may question the validity of CFS/ME as a medical condition, or the demands associated with being a full-time carer.

#### 4.1.5 Sue

##### *Introduction*

Sue was 63 years old, white British, married, and identified as a self-employed writer/researcher. She stated that she had known her husband for approximately 26 years prior to our meeting, and that they had one son together who was now in his early 20s. Sue and I met at her home to complete the research interview, and Sue's husband was present in the house throughout this time. Sue appeared somewhat uncertain at the outset of the research interview regarding the onset of her husband's CFS/ME, stating that *'he tells me it was 2000, right, so, but I actually can't remember exactly'*. Indeed mid-way through our interview, this uncertainty led Sue to invite her husband briefly into the room where our interview was occurring, in order to gain further information on the chronology of his illness.

##### *Narrative Impression*

Sue's narrative was characterised by a somewhat disorganised, fragmentary narrational style, which led the narrative to lose its 'thread' on several occasions.

Sue was observed to repeatedly place herself in stories that spoke of a longstanding propensity for 'caring', as well as her status as a sufferer of chronic health issues herself. Notably, Sue was observed to speak of discrepancy between how her physical health issues, and her husband's CFS/ME, are viewed. Such stories served to construct a strong sense of 'burden' for Sue; burden that appeared exacerbated by a lack of support from others, as well as her husband's condition itself – *'Umm, so having James [Sue's husband] with ME throughout all of this has not been great frankly'*. As such, Sue's narrative appeared underpinned by a strong sense of frustration, and even exasperation on occasion.

Sue was also observed to portray significant tensions that had arisen in her relationship with her husband, which she appeared to link to how James had



approached his condition at times. In addition, in contrast to all other narratives co-constructed, Sue was observed to portray a strong sense of surprise at the extent of her husband's difficulties prior to being officially diagnosed.

Notably, Sue can be observed to laugh at multiple points throughout the narrative. At times however, such laughter appeared somewhat at odds with what was being described. In line with Marander-Eklund (2008), I am now drawn to question whether laughter was being drawn on by Sue in an attempt to 'reduce the burden' (p106) of the stories being told, both for herself and her audience. Sue did not appear to hold many 'ghostly audiences' in mind until the end of her narrative, when there was a strong sense of Sue 'addressing' those responsible for social care provision within the UK regarding the short-comings of the current system.

#### 4.1.6 Louise

##### *Introduction*

Louise was 53 years old, white British, married, and identified herself as employed full-time as a teacher. She stated that she had known her husband for approximately 30 years, had been married for approximately 25 years, and traced the onset of her husband's CFS/ME to approximately 6 years previously. Louise reported that her husband was Iranian, and early in the research interview described how he '*had been a prisoner of conscience in Iran, and... tortured*'. She reported she and her husband had three children, and that at times her husband's CFS/ME could elicit conflict within the family, with one such conflict having occurred on the morning our research interview took place. Halfway through the research interview Louise informed me that she suffered from Multiple Sclerosis, introducing this information when discussing a new diet she and her husband were trying in an attempt to improve both of their conditions. Louise subsequently made minimal reference to her own health issues again. We met at her home to complete the research interview. Louise's husband, Brian, introduced himself

to me prior to our interview starting, before removing himself to another area of the house.

### *Narrative Impression*

Louise's narrative was characterised by a fairly succinct and 'to the point' narrational style. She was observed to generally offer fairly limited stories of her experiences in response to questions asked by the researcher. As a result, the researcher appeared particularly 'present' within her narrative; the most present out of all narratives co-constructed during the study.

Louise was observed to place herself in multiple stories that spoke of how she and her family were 'struggling' with her husband's condition. For example, early on she described how the condition had '*really impacted on our children a lot*', positioning the couple's eldest son as perhaps most affected, and divisions between the couple and their children regarding her husband's approach to his condition. Whilst Louise was seen to characterise her relationship with her husband as close and robust, at times she also portrayed areas of disagreement or difference between them. Indeed on occasion, Louise could be observed to speak of a sense of 'failure' in relation to her husband's condition: '*I feel we're so much in the middle of it... And I don't really feel that we've achieved anything. I still feel that we're not achieving most of the time, with it*'. Louise was also seen to position the family as 'on their own' with her husband's condition, and to principally relate this to the unhelpfulness of treatments offered by health professionals. As such, many of Louise's stories appeared characterised by a sense of frustration, futility and even hopelessness.

Louise was also observed to laugh at multiple points within her narrative, and again, much of this laughter appeared at odds with what was being described. Again, questions may be raised regarding the 'social action' (Edwards & Potter, 1992) of this feature of Louise's narrative, and whether this may have again been employed as a means to 'reduce the burden' of the stories being told. In addition, Louise was seen to pose multiple rhetorical

questions throughout her narrative. This was particularly noticeable following discussion of how Louise's life had changed as a result of her husband's condition, for example: *'Yes, but the way you deal with it is that you, um, it's not really that important, is it?'* In line with Horton-Salway (2001), this discursive strategy appeared to counter any alternative 'possibility' for Louise, and her audience. Again, there appeared far less of a sense of 'ghostly audiences' in comparison to some of the other narratives co-constructed. This suggested Louise's focus to have been more on what was emerging 'in the room' between she and I, rather than using the research interview as a mouthpiece to a 'wider' audience.

#### **4.2 Similarities and differences**

Once individual analysis had been completed, participants' narrative accounts were considered collectively. Focus was on consideration of key topics, events or 'identities' portrayed, and any areas of similarity or difference between these. Following the analytical process, two areas of collective focus were observed within participants' narrative accounts - '*stories from then*' and '*stories from now*' - with particular storylines emerging within each, as displayed in Table 2. Some similarities in how '*stories from now*' were told were seen to emerge down gender lines. However, in line with Riessman's (1993) assertion that narratives are co-constructed and context-specific, participants' positions within these storylines may be regarded as dynamic, rather than fixed. Furthermore, that the interpretations now offered by the researcher of participants' positions are similarly time- and context-specific (Clandinin & Connelly, 2000).

**Table 2: Areas of collective focus and key storylines**

<p>Stories from 'then'</p>	<ul style="list-style-type: none"> <li>- 'Life before'</li> <li>- 'Early encounters with CFS/ME' <ul style="list-style-type: none"> <li>• <i>'A really big transformation'</i></li> <li>• <i>'This kind of came as complete news to me'</i></li> </ul> </li> <li>- 'Seeking help' <ul style="list-style-type: none"> <li>• <i>'There's nothing we can do'</i></li> <li>• The response of 'me'</li> </ul> </li> </ul>
<p>Stories from 'now'</p>	<ul style="list-style-type: none"> <li>- The battle day-to-day</li> <li>- Battling unhelpful discourses</li> <li>- Battling unhelpful professionals</li> <li>- 'Battle worn': the toll in the here-and-now</li> </ul>

In line with Horton-Salway (2001), participants' storytelling was observed to represent a form of 'response' to wider narratives that purvey around CFS/ME; in particular the longstanding debate regarding the condition's status as a 'physical' or 'psychological' illness (Ware, 1992). Participants could therefore be seen to construct particular meanings around CFS/ME, as well as particular 'identities' of themselves, their partner and 'others' who had played a significant role in their story of living with the condition. Participants' constructions of themselves and their partner also served to

position the couple in relation to one another. These different 'sets' of constructions did not exist in isolation within participants' narrative accounts. Instead they were observed to 'co-exist', interweaving throughout; working to make available, or counter, particular positions. The researcher will attempt to reflect these observations in the presentation of the analysis to follow.

Attention will now be paid to the two areas of collective focus observed within participants' narrative accounts, beginning with '*stories from then*'.

#### 4.2.1 'Stories from then'

##### 4.2.1.1 Life before

All participants offered constructions of their partner prior to the onset of their condition. Notably, these constructions were frequently offered with minimal prompting from the researcher. In line with Horton-Salway (2001), this suggested participants were drawn to undertake such 'identity work' within the research encounter in response to the wider discursive environment that exists around CFS/ME, and those that suffer from it. Of particular note, all participants offered constructions that spoke of their partner's former professional standing and/or significant levels of physical activity. A particular example of this was observed very early on in Stewart's narrative, following the researcher asking him to describe the story surrounding his partner's development of CFS/ME:

*'From everything I know from prior to knowing me, Sophie was, um, an active woman. Um, I mean she's a Youth Worker by nature. She was a Child Protection Officer attached to Local Government. Um, so she did a lot of youth work. She was very active.'*

*(Stewart, 28-31)*

Notably, the two female participants were observed to offer constructions that spoke of their partner's 'character' prior to condition onset. One such example of this could be seen mid-way through Sue's narrative, arising after she had spoken at some length about her relationship with her partner in the present day:

*'I wasn't prepared to have a relationship with somebody who didn't do 50% of the housework and the child care... Umm anyway, so the thing is that he was completely brilliant.... and he always did, I mean when [son] was very tiny, from the time [son] was born, he always did do, you know, the looking after him'*

*(Sue, 591-594)*

Participants' provision of such details in the early to middle stages of the research encounter served to construct a 'normative image' (Horton-Salway, 2001, p254) of the partners affected by CFS/ME as hardworking and physically able, with the constructions offered by female participants eliciting a particular sense of their partners as men of integrity and 'moral standing'. This narrational focus could be seen to 'script' the affected partners as individuals who would not 'choose' to live a restricted existence (Horton-Salway, 2001), working to counter claims of those affected as 'potential malingerers or even... habitual complainer[s]' (Radley & Billig, 1996; as cited in Horton-Salway, 2001).

Concurrently, all participants were observed to offer constructions of 'themselves' prior to their partner's condition onset. Again, these constructions were offered with minimal active invitation from the researcher. For some male participants, these constructions were tied to their former professional status. For example, early in his narrative Oliver described:

*'I mean, cos, er, simply, I mean within my, within my career and job, wou-, I wouldn't just take an opinion. I did conduct a sort of, almost like a forensic (pause) assessment.. take that, that whole person's life and try and understand what has got them to this, to this point'*

*(Oliver, 178-180)*

This positioning of professional identity at an early stage of the research encounter served to construct Oliver as someone with significant capability within a challenging role. In line with Edwards and Potter (1992), who suggest narrative accounts 'are built up to support the credibility of claims and versions' (Horton-Salway, 2004, p356), it could be argued this narrational activity served to 'script' Oliver as astute and perceptive; constructing in turn for his audience a sense of his 'reliability' as a narrator, and by implication the 'authenticity' of his account of living with CFS/ME.



Notably, Louise was also observed to speak of her professional identity, but at a later stage in her narrative. By contrast, she positioned how she had previously lacked interest in developing a career; a preference since overtaken by her husband's condition:

*'I, I had to take on a Head of Department role at school, which I wouldn't have taken on if um (pause) Brian had been working full time. Um, because I didn't look for, I wasn't, I've never really been a career person...'*

*(Louise, 303-306)*

Such narrational activity can be seen to relate to the findings from other qualitative studies examining partners' constructions of living with MUS (Baanders & Heijman, 2007; Bigatti & Cronan, 2002), in which partners are often seen to position the additional roles and responsibilities they have had to assume as a result of their partner's condition. However, Louise's 'scripting' of herself as a woman happy within a more traditional gender role, not seeking to build a career, also appeared to work to counter any potential suggestion that her husband's condition was 'functional' for her; enabling her to do things previously unavailable to her. This could be viewed as a manifestation of the legacy of early research around partners and chronic illness, as discussed in section 2.2.1, which at times could be seen to 'implicate' partners in the development and maintenance of their spouse's condition.

Indeed, two participants could be seen to offer constructions of their relationship with their partner prior to condition onset:

*'before she got ill, we were (pause) a unit, but we would still have our own lives very much'*

*(Tom, 141-142)*

*'we'd gone through quite a lot of that, kind of (pause) building of a, of a strong relationship...'*

*(Louise, 82-83)*

Again, this information was provided by the participants in question in the initial stages of their research interviews and without any explicit form of prompting from the researcher, suggesting its presence to represent a particular 'interactional concern' (Horton-Salway, 2001). One might suggest this narrational activity worked to construct these participants' relationships prior to condition onset as functional and 'robust'; countering any potential claims that the condition represented a manifestation of interpersonal difficulty between participant and their affected partner. Again, such narrational activity appeared a response to the wider 'debate' surrounding the underlying cause for CFS/ME, working to discredit the relevance of psychosocial attributions for the onset of symptoms (Ware, 1992).

#### **4.2.1.2**     *Early encounters with CFS/ME*

##### **4.2.1.2.1**     *'A really big transformation'*

Notably, the majority of participants positioned a radical physical decline/deterioration in their partners when symptoms of CFS/ME first began to emerge. These constructions were again all offered at an early stage in the research encounter and with minimal prompting from the researcher. A particular example of this was observed in Tom's narrative, after the researcher had asked him to describe when he first became aware of CFS/ME in his partner's life:

*'...it was suddenly that transformation between being able to cope... to suddenly not being able to do anything much except for, at the weekends, sleep, to, a couple of months later not being able to go to work...'*

*(Tom, 68-72)*

Indeed, in line with the findings of multiple qualitative studies carried out with individuals affected by CFS/ME (e.g. Whitehead, 2006, Donalek, 2009, Denz-Penhey & Murdoch, 1993), some participants could be seen to speak of organic, 'viral' factors, and their potential relevance for their partner's condition:

*'we think it's possible that er, she could have picked up a virus, erm, from, from her work'*

*(Oliver, 198-199)*

*'I mean he'd had sort of flu-type colds and things like that, um, and, and then from then on he just went down hill pretty quickly'*

*(Louise, 15-16)*

Stewart was the only participant not to have known his partner prior to condition onset. However, he also positioned at an early stage in the research interview the physical limitations he had observed in his partner as their relationship developed:

*'...she was struggling a lot. She seemed to be tired an awful lot... And it would affect how we dated and stuff, because a lot of the time you simply, "I'm too tired", you know?'*

*(Stewart, 58-59)*

Notably, Stewart went on to share with his audience questions he had asked himself at this time regarding his partner's tiredness:

*'I was kind of a bit like, you know, is it something? You know, is she doing drugs or something?'*

*(Stewart, 60-61)*

In line with Edwards and Potter (1992), one might argue Stewart's positioning of his own reflexivity in this regard worked to further strengthen

the ‘factuality’ of his account of living with CFS/ME. Through demonstrating his consideration of other potential causes for his partner’s fatigue, Stewart could be seen to construct himself as ‘cognizant’, thereby increasing for the audience the ‘reliability’ of his perspectives on his partner’s condition. More generally however, this particular narrational focus by the majority of participants appeared once again to represent a response to wider narratives that exist around CFS/ME; working to construct further evidence for the ‘irrelevance’ of psychosocial factors for the condition (Ware, 1992).

4.2.1.2.2 *‘This kind of came as complete news to me’*

Notably, when asked by the researcher when she had first become aware of CFS/ME in her partner’s life, Sue was the only participant to position how the onset of her partner’s condition had gone ‘unnoticed’ by her. This represented a striking area of difference between Sue and all other participants:

*‘...they said he had ME. And, but the thing is that, I mean (sighs) it was like, actually this kind of came as complete news to me, in a funny kind of way, that he was even feeling this bad...’*

*(Sue, 11-13)*

However, as her narrative progressed, Sue was seen to offer perspectives on her partner’s condition more in line with the prevailing narrative observed in others participants’ accounts – for example, later speaking of a period in which her husband had experienced a total physical ‘collapse’:

*‘it got very bad in 2005... he basically, he became.... more or less completely bed-ridden...’*

*(Sue, 236, 244)*

Thus despite her different early narrational focus, in line with other participants Sue also appeared drawn to emphasise the physical consequences of CFS/ME for her husband.

### 4.2.1.3 *Seeking help*

#### 4.2.1.3.1 *'There's nothing we can do'*

All male participants were observed to speak of the contact they and their partner had had with health professionals during the early stages of condition onset. Again, such constructions were offered with minimal prompting from the researcher. A particular example of this could be seen in Oliver's narrative:

*'that's when we started going to the doctor... [and] you know we'd drive to hospital and she'd just sit in A and E and er, see someone, and of course they said, well, you know, nothing, "doesn't seem to be anything wrong"'*

*(Oliver, 123, 125-7)*

Of note, these early interactions with health professionals working from a bio-medical perspective were all constructed by male participants as having been 'unhelpful'; reminiscent of the findings from multiple qualitative studies carried out with individuals affected by CFS/ME (e.g. Larun & Malterud, 2007), as well as the findings from several qualitative studies completed with partners of individuals affected by MUS (e.g. Paulson et al., 2003).

#### 4.2.1.3.2 *The response of 'me'*

All male participants also positioned themselves as having played a key role in supporting their partner to access medical input. This was in direct contrast to Sue, who positioned herself as relatively 'absent' from her partner's decision to access medical input:

*'...I don't know if he had been to the doctor a few times and hadn't told me, he might have.....'*

*(Sue, 17-18)*

The significance of each participant's personal context may go some way to explaining these observed differences. However, questions can also be raised regarding the influence of wider cultural narratives around gender in this regard. For example, in several studies examining men's attitude to help-seeking in the context of illness, men have been observed to speak 'of endur[ing] pain and [remaining] "strong and silent" about trivial symptoms', suggesting that doing otherwise would challenge 'conventional notions of masculinity' (O'Brien et al., 2005, p514). Thus the lack of communication positioned by Sue between her and her husband in the early stages of his condition could be viewed as a reflection of wider discourses around expected 'masculine' behaviour in the context of illness. Furthermore, that male participants' positioning of their active role in seeking professional help for their female partners may speak to traditional cultural narratives around gender roles, and in particular males as 'protector' (Meek, 2015). Yet one might also question the significance of a female researcher for this aspect to male participants' storytelling, and whether, in line with Ickes (1993), this drew male participants to 'enact' through their storytelling particular 'traits' associated with a traditional male gender roles.

Importantly however, participants were observed to principally orientate their storytelling to the 'here and now', speaking comparatively little of historical events surrounding their partner's condition. Instead, greater emphasis was placed on there having been a 'consistency' in the story of their spouse's illness, or on offering stories of experience in the present day. In the following section, attention will therefore be paid to the researcher's interpretation of these stories.

#### 4.2.2 'Stories from now'

Participants 'stories from now' generally characterised CFS/ME as placing the couple, and even participants themselves, 'at odds' with others; 'others' including family members, friends, health professionals and wider society. This constructed for the researcher a strong sense of ongoing 'battle' across narratives – a battle which for some participants appeared to have dominated their lives for many years and which had elicited little change. This section of the analysis will therefore begin by exploring in more detail the 'battle' constructed by participants in their research encounters.

##### 4.2.2.1 *The battle day to day*

All participants were observed to position in the early stages of their research interviews the 'battle' their partners faced on a daily basis with the physical limitations CFS/ME imposed on them. A particular example of this could be seen in Louise's narrative, following the researcher asking her to describe her observations of her partner's condition over time:

*'... it's a question really of his tiredness, his weakness and pain in his body just increasing over... he tries to keep now, um, a very part-time job going, um, but (pause) the tiredness and weakness, means that that's becoming, his ability to work, becomes less and less'*

*(Louise, 34-37)*

Notably, Louise's narrational activity in this regard appeared once again to represent a form of response to the wider narratives that purvey around CFS/ME and its sufferers – working to 'script' her partner as a man keen to be active whilst highlighting the 'physicality of [his] illness experience' (Crix et al., 2012, p2).

Significantly, all participants also portrayed in the early stages of their research interviews the active role they played in their partners' battle with their physical limitations. This constructed for the researcher a strong sense of the condition as a 'joint enterprise'; an observation in line with the findings

from multiple studies carried out with partners of individuals affected by chronic illness (Rees et al., 2001). One such example of this could be seen in Tom's narrative, again emerging after the researcher had asked him to describe his observations of his partner's condition over time:

*'She's not well. (R: Mm). She's not well. I mean, she can't do much, and we have to very very carefully meter her time'*

*(Tom, 102-104)*

Again, Tom's narrational activity here appeared influenced by wider discourses surrounding CFS/ME, with his emphasis on the word 'can't' invoking a strong sense of physical 'impossibility' for his wife, working to discredit any possible accusations of her condition being 'all in the mind' (Horton-Salway, 2001)

#### **4.2.2.2** *Battling unhelpful discourses*

Notably, all male participants spoke of certain meanings attached at a wider societal level to CFS/ME. In particular, all men spoke of how there remained a pervasive view of the condition among the wider general public as 'yuppy flu' – a derogatory term that first came to be associated with CFS/ME in the mid 1980s, and which positioned the condition as a form of 'burnout' due to stress and overwork ("ME Non-Sufferer's Guide, 2012). A particular example of this could be seen relatively early on in Michael's narrative, emerging after he had spoken at some length of the endeavours his wife undertook to raise awareness of her condition, and its impact:

*'And people still think about it as, "it's yuppy flu, it's, it's nothing, it's not an illness". It is an illness'*

*(Michael, 172-173)*

This narrational activity constructed for the researcher a strong sense of continuity over time in the meanings attached to CFS/ME. Furthermore, that the wider societal meanings around CFS/ME had significant bearing for the



response of 'others' to the condition – an observation that can be seen to resonate with findings from research examining the social construction of illness (Conrad & Barker, 2010).

#### **4.2.2.3** *Battling unhelpful professionals*

Indeed the unhelpfulness of the response of others was observed to represent a key storyline across all participants' narratives. Participants were observed to lay particular emphasis in their storytelling on the unhelpfulness of treatments offered by professionals working from a bio-medical perspective at the present time – narrational activity once again strongly reminiscent of the findings from multiple qualitative studies carried out with individuals affected by CFS/ME (e.g. Larun & Malterud, 2007). A particular example of this could be seen in Sue's narrative, arising after the researcher had asked her to comment on her experiences of professionals involved in her partner's care over time:

*'...basically I have to say that the ME Unit at [hospital] has been completely useless. (Laughs) Com:pletely useless. James goes in and sees this specialist... once a year, and he goes "oh well, you still seem the same, go away, come back and see me next year", you know?'*

*(Sue, 924-928)*

Several participants highlighted how a particular difficulty in the treatments offered by medical professionals was a lack of holistic thinking – a perspective also observed by Paulson et al. (2003) in their study with female partners of men affected by MUS. One such example of this could be seen in the early stages of Louise's narrative, again after the researcher had asked her to comment on her experiences over time of professionals involved in her partner's care:

*'But nobody will see him for the ME overall, and deal with it in a holistic way, which is, um, which is the real problem....'*

*(Louise, 141-143)*

Yet strikingly, participants could also be seen to position the unhelpfulness of treatment approaches offered by psychology professionals to those affected by CFS/ME. One is now drawn to question the significance of the researcher's professional status as a trainee clinical psychologist for such narrational activity. For example, in line with the dominant cultural construct of mind-body dualism, participants may have been drawn to construct the researcher as someone liable to consider their partner's condition as being 'all in the mind' (Horton-Salway, 2001), and therefore a particular advocate of psychological approaches for its treatment. A particular example of this observed narrational focus could be seen in the mid-stages of Oliver's narrative:

*'...we tried again, another Psychologist, another waiting list, another Psychologist, more cognitive behavioural stuff, which helps a tiny bit.... [but] there's no coping with if you're prostrate on the bed thinking "why am I alive?"'*

*(Oliver, 282-5, 287-8)*

Indeed, Stewart drew on the 'corroborating voice' (Wooffitt, 1992) of a friend who held a doctoral level qualification in psychology in this regard, commenting at an early stage of the research encounter:

*'And as I say, my friend, who is a doctor in psychology, is going "well I don't see that, if it's not a psychological issue, I don't... It's like having a broken leg, but if you talk about it enough it'll get better"'*

*(Stewart, 245-247)*

Stewart's portrayal of the perspective of 'a doctor in psychology' may be viewed as particularly significant in the context of a research encounter with a trainee psychologist; working to increase Stewart's authority to speak on the unhelpfulness of psychological approaches, as well as counter possible counter-arguments.

Notably however, in these stories of the unhelpfulness of the response of professionals, participants were observed to cast themselves in quite different 'roles'. For example, in line with the findings from Soderburg et al.'s (2003) study with male partners of females affected by MUS, all male participants positioned how their partner's condition required them to assume an 'advocacy' role. A particular example of this could be seen in Stewart's narrative, emerging after the researcher had asked him to comment on the response of others over time to his partner's condition:

*'One of the reasons I always go with her [to the doctors]... is some doctors.... respond much better when there's a big strapping 6' 2" bloke comes wandering in behind the woman and sits there looking at them...'*

*(Stewart, 639-40, 642-4)*

Such displays of 'self' could again be seen to relate to wider cultural narratives around 'masculinity'; with male participants' portrayal of the endeavours they undertook on behalf of their female partners once more positioning them in line with the traditional male gender role of 'protector' (Gregor, 1985).

#### **4.2.2.4** *'Battle worn': the toll in the here-and-now*

Significantly however, storylines could also be seen to emerge that spoke far less to a sense of participants and their partners being 'unified' in their approach to living with CFS/ME. Notably, such storylines emerged particularly, but not entirely, within the narrative accounts co-constructed with the female participants. For example, in line with the findings from Soderburg et al.'s (2003) study, all participants could be seen to portray a sense of 'isolation' in their relationship with their partner at times. In some accounts, this isolation was linked by participants to wanting to protect the affected partner from worry or concern. One particular example of this could be seen in Tom's narrative – notably emerging in the very latter stages of the research encounter. One might argue the timing of this depiction to perhaps be of significance, emerging at a stage where rapport between researcher and

participant had had time to build, thus enabling Tom to feel more able to speak of more challenging aspects to the story of living with his wife's condition:

*'...we protect ourselves, and each other, by almost having areas that we don't particularly talk about, because it's just too horrific to think about, so we don't....'*

*(Tom, 1170-1172)*

Notably, Tom's storytelling in the latter stages of his research interview served to characterise the condition in far darker terms than that positioned at the outset. Yet it also constructed for the researcher a sense of there being certain things that remained 'unspoken' between the couple as a result of the condition; a storyline that in fact prevailed within the majority of participants' narratives. A further example of such could be seen in the early stages of Louise's narrative. Of note, Louise was observed to speak of how much that remained unspoken between her and her partner was related to her partner's approach to living with his condition:

*'Um (laughs) his New Year's resolution is to go to the gym and go swimming (Laughs) And I was thinking, you know, you know it's not going to work. And it's very hard to, to... it's very hard to say "no, don't do that"*

*(Louise, 105-106)*

In contrast, Sue was observed repeatedly to speak of feeling 'unheard' by her husband in relation to his approach to living with his condition, and to highlight the detrimental consequences of such for her own psychological wellbeing; one particular example occurring in the mid stages of her narrative:

*'But I have been finding it much harder to cope the longer it has gone on, and finding it very hard to kind of keep my resilience shall we say...'*

*(Sue, 268-70)*

Of note, Sue later spoke of how having an opportunity to express some of the feelings that had built up for her from living with her partner's condition had had a beneficial impact on her:

*'so I had this trip lined up for myself... I was totally ragged with fury and everything with James before I went. Fortunately I was staying with a friend of mine... so, you know, I just had an opportunity to get it off my chest. And actually, I did feel better when I came back....'*

*(Sue, 630-634)*

Such storylines worked to construct for the researcher a significant toll for participants from living with their partners' condition, and emphasised in particular the importance of emotional support for their ability to manage such.

### 4.2.3 Never-ending battle?

As highlighted in section 2.3.2, in line with Frank (1998), several qualitative studies have observed how the ‘types’ of narratives told by individuals affected by CFS/ME can be seen to change over time (e.g. Bell, 2013; Whitehead, 2006), moving for many from stories of ‘chaos’ to stories of ‘quest’. Of note, the majority of narratives co-constructed with male participants in this study could be seen to relate to these findings - appearing more in line with Frank’s (1998) ‘quest’, or Stern’s (1999) ‘reparation’ narrative types, emphasising the profound impact that their partners’ condition had had for their lives, but also the insights that had emerged from such a situation now able to be ‘passed on to others’ (Frank, 1998, p203). This form of narrational activity could be seen to relate to G. Williams (1984) concept of ‘narrative reconstruction’, as well as Faircloth et al.’s (2004) concept of ‘biographical flow’:

*‘And it’s like, you know, you’re a carer. You’re doing something worthwhile.... I’m making... one person’s life a lot better.... And that’s what I like.... I’ve become fairly simple. I don’t have that many needs any more...’*

*(Stewart, 1082, 1085-7)*

Notably however, the narratives co-constructed with the female participants in this study fitted much less with such findings - seeming far more akin to Frank’s (1998) ‘chaos’, or Stern’s (1999) ‘frozen’ narrative types; appearing for the most part ‘devoid of effective action’ (Frank, 1998, p202) and offering minimal sense of either female having been able to ‘construe a significant whole out of scattered events’ (Stern, 1999, p5). In line with Bury (1982), such narrational activity worked to construct CFS/ME as an ongoing source of ‘biographical disruption’ for both women:

*'... because what I can't stand, you know, I do find it harder and harder, is this kind of you know relapse, and then it goes on for weeks and months, and you know, miseries and negativity and depression , you know, I just, that's, that's the thing I find really hard...'*

*(Sue, 542-545)*

The significance of each participant's personal context may go some way to explaining these observed differences. As France et al (2013) state, 'women and men might have different narrative "genres" available to them [simply] because their experiences of [living with] chronic illness might differ' (p1650). However, one is also drawn to question the significance of both situational, as well as wider contextual, factors for such differences - specifically the implications of a female researcher, as well as wider cultural narratives around gender.

## **5. Conclusions**

This study has sought to explore the stories told by six partners of individuals affected by CFS/ME, in response to the paucity of previous research carried out within this area. As discussed in chapter 4, some aspects of the stories told by the participants in this study can be seen to relate to findings from literature examining partners' constructions around chronic illness, and partners' constructions around MUS. However, analysis has also suggested the current study to offer new perspectives that may enhance current understandings. In this section, I aim to provide a summary of the key findings to have emerged from this study, and to consider their potential bearing for clinical practice and future research endeavours. In addition, the strengths and limitations of the research will be considered.

### **5.1 Summary of key findings**

Following analysis, two particular areas of collective focus were observed within participants' narrative accounts, identified by the researcher as '*stories from then*' and '*stories from now*'. In line with Horton-Salway (2001), participants' storytelling appeared to represent a form of response to the wider discursive environment that purveys around CFS/ME, and in particular the longstanding debate regarding the condition's status as a 'physical' or 'psychological' illness (Ware, 1992). Accordingly, participants were observed to construct particular meanings around CFS/ME, as well as particular 'identities' of themselves, their partner, their relationship, and 'others' who had played a significant role in their story of living with the condition.

Notably, in the early stages of each research interview, all participants offered constructions of their partners that served to 'script' the individual concerned as 'active' and 'hardworking' prior to condition onset. Some participants offered constructions of themselves that appeared to work to enhance the credibility of their account of living with CFS/ME (Edwards & Potter, 1992), whilst other participants could be seen to emphasise the 'robustness' of their relationship with their partner prior to condition onset. Participants provided such information with minimal prompting from the researcher, suggesting its



presentation to represent a particular 'interactional concern' (Horton-Salway, 2001).

Participants could also be seen to emphasise in their early storytelling the profound physical impact that CFS/ME had had on their partners, and the active role they played in managing their partners' physical limitations. Some participants were observed to speak of particular meanings that had become attached at a wider societal level to CFS/ME, and how these meanings had significant bearing for the response of others. Of particular note, all participants were observed to speak of the unhelpfulness of treatments offered by the medical profession, as well as psychologists, for their partners' condition.

Such narrational activity worked to construct for the researcher a strong sense of ongoing 'battle' for participants and their partners – a battle which for some appeared to have dominated their lives for many years, and which had elicited little by way of change. In the early stages of participants' accounts, this battle tended to be characterised as a form of 'joint enterprise' between participants and partners. However, storylines later emerged that appeared to challenge somewhat this prevailing narrative. Notably, these storylines emerged particularly, but not entirely, within the narrative accounts co-constructed with female participants.

Significantly, the majority of narratives co-constructed with male participants appeared characteristic of Frank's (1998) 'quest' or Stern's (1999) 'reparation' narrative types, emphasising how their partners' condition had had a profound impact on their lives but also the new insights that had emerged from such a situation. In contrast, the narratives co-constructed with female participants appeared far more akin to Frank's (1998) 'chaos' or Stern's (1999) 'frozen' narrative types, emphasising to the researcher how their partners' condition remained an ongoing source of major 'biographical disruption' (Bury, 1982).

## **5.2 Recommendations for practice**

This study has highlighted the profound emotional and lifestyle consequences for partners of those affected by CFS/ME. In line with recommendations made within the DoH Carers Strategy (2014), participants' narrative accounts suggest there to be a particular need for provision of more formal support for partners at this time. Furthermore, that such support should be available to partners at multiple and ongoing stages in their lives, given the uncertainty surrounding the trajectory of a condition like CFS/ME.

Participants' references to the endurance of certain discourses around CFS/ME suggest there to be a potential role for services and professionals in increasing understanding of the wider public around the condition. However, findings from this research also indicate a need for training programs about CFS/ME and its impact for professionals themselves; programs that in line with recommendations made within the National Service Framework for long-term conditions (2005) could look to reinforce the importance of a person-centred holistic approach for addressing the support needs of partners and individuals living with CFS/ME.

Perhaps one of the most significant recommendations for practice to emerge from this research is for professionals to consider the wider societal and cultural meanings that may pervade around conditions like CFS/ME, and the potential significance of these for their interactions with those affected. Furthermore, to consider how interactions with individuals living with conditions such as CFS/ME may also be shaped by the social identity constructed by the individual or the professional concerned. Indeed, consideration of such issues by professionals with partners or individuals affected by CFS/ME may potentially significantly enhance 'working alliance'.

A particularly striking characteristic of all narrative accounts co-constructed with participants in this study was a lack of future-oriented narratives. Notably, Olson (2015) reported a similar pattern of narrational activity within the accounts of spousal carers of individuals affected by cancer. Olson

(2015) argued this to represent a form of 'emotion work' on the part of these carers – that in order to manage the 'lack of control and loss of direction' (p63) associated with their partner's condition, carers adopted 'an alternative approach to time... either 1) re-adjust[ing] their temporal orientation to be present-oriented or 2) perform[ing] cognitive emotion work to re-interpret their perception of the cancer diagnosis and maintain a future oriented perspective' (p63). Olson (2015) went on to observe an association between carers' re-definition of time and the nature of their partner's diagnosis, with those whose partners had received a terminal prognosis being seen to orientate more to the present. Extending on such ideas, one might suggest the lack of future-oriented narratives told by participants in this study to perhaps be symptomatic of the relative permanence of a condition like CFS/ME, where minimal hope of a 'cure' exists due to the difficulties the condition has fitting with current bio-medical explanations of illness. However, given the identified significance of future orientation for psychological wellbeing (Beal, 2011), one might suggest these findings to highlight a particular need for professionals to attend to the temporal orientation of partners or individuals affected by CFS/ME. Furthermore, to support those living with the condition 'to assume [alternative] orientations to time' (Olson, 2015, p73) incorporating future perspectives where appropriate.

Importantly, participants' storytelling has suggested that for some partners, the opportunity to have a therapeutic 'space' of their own to explore the thoughts and feelings elicited for them from living with CFS/ME may be of significant benefit. However, participants' depiction of certain patterns of interaction within their relationships that had emerged in response to CFS/ME - and the profound impact in some cases of these communication patterns for participants' emotional wellbeing – also appears to indicate a need for more systemic therapeutic interventions for couples affected by the condition. Where appropriate, Narrative Therapy, with its emphasis on 'seek[ing] the neglected aspects of our stories that have been given less power and visibility' (Cotter, 2009, para. 1) may also be helpful to couples affected by CFS/ME.

### **5.3 Strengths and limitations of the study**

The adoption of a qualitative approach in this study may be conceived as a particular strength, as it enabled rich, detailed data to emerge. Furthermore, the narrative approach drawn upon by the researcher enabled detailed analysis of the stories told by participants and their storytelling, as well as consideration of how the situational, societal and cultural context surrounding each research encounter served to impact on participants' 'talk'. Whilst acknowledging narratives to represent a construction of events 'composed jointly [between narrator and audience]' (Riessman, 2008, p31), the researcher's decision to ask open questions and to minimise directive influence within each research encounter might also be considered a particular strength of the study – enabling more of the participants' stories to emerge. In addition, the sample recruited to the study was mixed-gender, enabling greater understanding to develop of the perspectives of both male and female partners in the context of CFS/ME.

However, one might also propose there to be several notable limitations to this study at this time. Firstly, the self-selection of the sample through five CFS/ME support groups needs to be acknowledged. This may have led to sample bias, as all individuals who took part in the study were already connected to a 'community' or 'network'. In addition, the sample recruited to the study was not ethnically diverse – all identifying as White British – thus there was a notable absence of voices from different ethnic backgrounds. In line with Small et al. (2005), a more diverse ethnic representation would have enabled better understanding to emerge of the stories held by partners of individuals affected by CFS/ME cross-culturally. Furthermore, all participants who took part in this study were in heterosexual relationships, meaning there was also a notable absence of voices from lesbian, gay, bisexual or transgender communities. In addition, due to the timescale available to the researcher for completion of this study, participants' stories could only be captured at one period in time. One might suggest a more longitudinal approach, involving meeting participants on several occasions, could facilitate

the sharing of more stories, and enable consideration of how the stories of partners affected by CFS/ME may alter over time.

In line with Myers (2000), it is recognised that due to this being a small qualitative study, the interpretations contained within its analysis are not generalisable, and thus may be considered limited to this particular sample of partners. Furthermore, in line with Ricoeur's (1976) assertion that there is 'more than one way to interpret a text' (p76), and Stern's (1999) perspective that 'different but equally valid interpretations are possible' (p355), it is acknowledged that the interpretations offered are both time- and context-specific, and may well differ from those of the reader. However, it is hoped that the researcher's careful attention to methodological rigor, detailed in chapter 3, may have served to enhance the credibility of the interpretations offered at this time.

#### **5.4 Suggestions for further research**

Riessman (2008) argues that the ultimate test of validity for a piece of narrative research is whether that research has potential to form the 'basis for others' work' (p193). Further to my analysis and discussions thereof, it would appear that this study holds a number of potential avenues for future research endeavours.

Firstly, it would be valuable for future research to study the narratives of partners affected by CFS/ME from a more diverse range of ethnic backgrounds. This may serve to develop a more culturally varied understanding of the meanings held around CFS/ME by partners, and the implications of such for those concerned.

Secondly, it would also be valuable to seek the 'voices' of partners from lesbian, gay, bisexual and/or transgender communities, in order to develop a less 'hetero-dominant' perspective on the meanings attached by partners to living with CFS/ME.

As highlighted above, collecting the narratives of partners at more than one time-point may enable analysis of how partners' experiences of living with the condition may be narrated differently over time.

Finally, given differences were able to be observed in how the male and female participants in this study narrated their stories of living with CFS/ME – with the majority of male participants being seen to tell stories more in line with those 'culturally expected' after a prolonged period of time living with chronic illness (Frank, 1998) – it may also be valuable to see whether these gender differences in storytelling emerge within other narrative accounts of partners living with CFS/ME.

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## **7. Appendices**

- APPENDIX A: Literature Review Strategy
- APPENDIX B: University of Hertfordshire Ethical Approval
- APPENDIX C: Project Information Sheet
- APPENDIX D: Participant Consent form
- APPENDIX E: Participant Debrief sheet
- APPENDIX F: E-mail sent to point of contact at CFS/ME support groups
- APPENDIX G: Interview guide
- APPENDIX H: Transcription service confidentiality agreement
- APPENDIX I: Narrative analysis framework
- APPENDIX J: Example analysis for Sue
  - i) Analytical Process
  - ii) Excerpts from Sue's narrative account

## **Appendix A: Literature Review Strategy**

### Stage 1: Initial Exploratory Search

Initially relevant books held at the Learning Resource Centre at the University of Hertfordshire were reviewed. Database searches were also carried out using Web of Knowledge and Google Scholar. Initial search terms used included:

'Chronic Fatigue Syndrome' OR 'CFS' OR 'Myalgic Encephalomyelitis' OR 'ME'  
AND  
'Partners', 'Significant Others', 'Systemic'.

### Stage 2: Following up references

Following consultation of relevant articles, key references and authors were identified and followed up.

Where key articles were unavailable through the University of Hertfordshire or personal NHS Athens account, inter-library loan requests were made from the British Library.

### Stage 3: Detailed review of the literature over 18 month period

Informed by searches carried out to date, a detailed review of the literature was conducted according to the search criteria detailed below:

Inclusion criteria:

- Studies exploring individual accounts of living with CFS/ME
- Studies exploring partners' accounts of living with CFS/ME
- Studies exploring individual accounts of living with MUS
- Studies exploring partners' accounts of living with MUS
- Studies exploring partners' accounts of living with chronic illness
- Papers published in English (or where translations were available)
- Peer reviewed journals
- Grey literature – unpublished doctoral dissertations



Exclusion criteria:

- Studies exploring child and adolescent accounts of living with CFS/ME

Dates of search:

The literature was searched for all relevant articles up to April 2015. Citation alerts were also set up to keep me informed of latest publications that were associated with key papers.

Search terms:

To ensure all relevant papers were retrieved, Boolean operators and truncation options were employed, along with the following search terms:

'Chronic Fatigue Syndrome'; 'CFS'; 'Myalgic Encephalomyelitis'; 'ME'; 'Chronic illness'; 'Medically Unexplained Symptoms'; 'Partner\*'; 'Partners'; 'Significant Other'; 'Family'; 'Families'; 'Experience'; 'Subjective'; 'Personal experience'; 'Relationship'; 'Impact'; 'Cause'; 'Adjustment'.

'Qualitative methodology'; 'Qualitative'; 'Narrative Analysis'; 'Phenomenology'; 'Constructionist'; 'Constructivist'.

Search Engines:

The following search engines were utilised: -

- Google Scholar
- Scopus
- PubMed

General web searches:

Other websites informed other aspects to the study. The following websites were accessed using generic search engines on the internet: -

- NICE guidance and guidelines
- Department of Health
- National Research Ethics Service
- ME Association.

## Appendix B: University of Hertfordshire Ethical Approval



UNIVERSITY OF HERTFORDSHIRE  
HEALTH & HUMAN SCIENCES

### ETHICS APPROVAL NOTIFICATION

**TO** Rebecca Ramsden  
**CC** Wendy Solomons  
**FROM** Dr Richard Southern, Health and Human Sciences ECDA Chairman  
**DATE** 30/06/14

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Protocol number: **LMS/PG/UH/00216**

Title of study: Narratives of partners of individuals affected by Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME)

Your application for ethical approval has been accepted and approved by the ECDA for your school.

This approval is valid:

From: 01/08/14

To: 01/06/15

**Please note:**

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1. Should you amend any aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit form EC2. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

## Appendix C: Project Information Sheet



### PROJECT INFORMATION SHEET

#### **Title of research project:**

Experiences of partners of individuals affected by Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME)

#### **Introduction**

You are invited to take part in a research study looking at the experiences of partners who support adults living with CFS/ME

This information sheet aims to explain how and why the research is being carried out. Before you decide whether you would like to consent to take part, please take the time to read it through.

#### **The researchers**

The study is being carried out by Rebecca Ramsden, Trainee Clinical Psychologist, as part of a Doctoral qualification in Clinical Psychology at the University of Hertfordshire. The study is supervised by Wendy Solomons, an experienced Research Supervisor and Clinical Psychologist.

#### **What is the purpose of the study?**

This research aims to explore how partners of individuals living with CFS/ME have understood, made sense of, and experienced the condition over time. CFS/ME remains a poorly understood condition, and particularly little is known about the experiences and views of partners who support individuals affected by the illness. It is hoped that this piece of research will benefit other people in similar situations, as well as psychologists and other health professionals. With increased understanding, professionals may be able to develop better support/information/interventions for partners, which may in turn impact on outcomes for those affected by CFS/ME.

#### **What is involved?**

You will be asked to participate in an interview in a location that is convenient for you. The interview will last for approximately one hour; however, the length of the interview will depend on how much information you wish to share. The interviews will be audio-recorded so that I can listen back to our discussions and write up an accurate account of your experience. When I have studied your story, the tape will be destroyed and no-one will know it was your story. Every participant will be asked similar questions, but the aim is to hear about your individual experience. Some of the questions may focus on areas such as:

- the impact CFS/ME has had on your relationship with your partner
- your understanding of CFS/ME

- the impact/consequences of living with CFS/ME for you
- the responses of health services/ professionals to your partner's condition

### **Who is eligible to take part?**

This study will include partners of adults with CFS/ME. Participants will need to be 1) 18 years of age or above; 2) to be in a long-term relationship with an individual who has been diagnosed with CFS/ME, or whose symptoms are understood as indicative of CFS/ME; and 3) to be fluent in English.

### **Do I have to take part?**

No, you do not have to take part. If you do not wish to take part, or you choose to take part but then later change your mind, you can withdraw and do not need to give a reason.

### **What are the benefits of taking part?**

This research will give you an opportunity to talk about and explore your experiences. It is possible that you may not experience any direct benefits as a result of taking part in this research. However, it is hoped that this research will provide deeper understanding of the experience of living with CFS/ME.

### **What are the potential difficulties that taking part may cause?**

Talking about experiences can sometimes cause some discomfort and distress. If this does occur you can take a break from being interviewed. You will not be required to answer any questions that make you uncomfortable. You can choose to stop the interview and withdraw at anytime, for any reason. You will be given a number of contact details for relevant support organisations following taking part in the study, should you feel you require further support.

### **Will taking part be confidential?**

Yes, your participation is strictly confidential. If you agree to take part in the study, your personal information will be stored securely and will only be accessible to the researchers. Written transcripts of recordings will be anonymised and stored securely. This information will be kept for up to five years after the research is submitted for examination (until approximately June 2020) and will be stored securely according to the University of Hertfordshire's 'Good Practice in Research' guidelines.

The only circumstance under which I may need to break confidentiality is if you disclose information that leads me to have serious concerns about your safety, or the safety of others. However, I would always seek to discuss my concerns with you first, followed by my research supervisor, in order to establish how best to support you.

### **What will happen to the results of this research study?**

The results will be reported in a thesis for the purpose of gaining a doctorate in Clinical Psychology. All identifiable information will be anonymised in the write up of the study. It is hoped that this study will also be written up and published in a psychological journal.

**Who has reviewed this study?**

This study was reviewed by the University of Hertfordshire Research Ethics Committee, and was given ethical approval on 30<sup>th</sup> June 2014 (Trial Protocol Number: LMS/PG/UH/00216)

**What if I have questions or concerns?**

If you have any concerns or further questions about the research, please feel free to contact me on the contact details listed below.

**What do I have to do if I want to take part?**

If you decide that you would like to take part in the research, please contact me on the e-mail address below, and we will arrange a suitable time and place to meet for an interview. I will also bring along to the interview a consent form, which I will ask you to sign before taking part.

Thank you for taking time to read this.

**Contact details:**

Rebecca Ramsden  
Trainee Clinical Psychologist  
Department of Clinical Psychology  
University of Hertfordshire

r.m.ramsden@herts.ac.uk

## Appendix D: Participant consent form



### PARTICIPANT CONSENT FORM

**Title of Research Project:** Experiences of partners of individuals affected by Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME)

**Researcher:** Rebecca Ramsden, Trainee Clinical Psychologist

	PLEASE TICK
1. I confirm that I have received a copy of the information sheet in relation to the above study. I have read and understood it and have had an opportunity to discuss it.	
2. I understand that I have the right to change my mind about taking part in the study, and can withdraw at any time without giving any reason.	
3. I give permission to be interviewed by Rebecca Ramsden for the purposes of this study, and consent to my interview being audio recorded.	
4. I understand that my information and the audio recording of my interview will be stored securely.	
5. I understand that the information I provide will be anonymised for the purposes of this study. Anonymised sections of the data will be looked at by authorised persons from the University of Hertfordshire in order to assess the quality of this doctoral research project. All will have a duty of confidentiality to you as a research participant.	
6. I agree that anonymised quotes from my interview may be used in any publications. I understand that although every effort will be made to maintain anonymity, the use of direct quotations and the individual nature of the analysis means there is a possibility that those close to me might be able to identify me.	
7. I understand that a professional transcription service may be used to transcribe my interview. In this instance, the recording will be given an identifying code (e.g. Interview A) to maintain your anonymity. Furthermore, the transcription service will have signed a confidentiality agreement.	

8. I agree to take part in the above study.	
---	--

Name of Participant: \_\_\_\_\_

Signature of Participant: \_\_\_\_\_

Date: \_\_\_\_\_

Name of Researcher: \_\_\_\_\_

Signature of Researcher: \_\_\_\_\_

Date: \_\_\_\_\_

(University of Hertfordshire Ethics Committee –  
Trial Protocol Number: LMS/PG/UH/00216)

## Appendix E: Participant debrief sheet:



### DEBRIEF SHEET

Thank you very much for making this study possible.

This study aims to explore the experiences of partners who support and care for an individual affected by Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME). The current research in this area is practically non-existent. However, research has previously been carried out with partner/families of individuals affected by different chronic health conditions. From this, it seems that living with such conditions has a significant impact on those close to the individual affected.

In this study I am interested in exploring:

- How CFS/ME has impacted on you and your partner over time.
- How together, and separately, you have made sense of it.
- What you have found helpful or unhelpful about any support you have received in relation to CFS/ME, and what kind of support you feel would be helpful for you to receive in the future.

Gaining understanding of your experiences as a partner of someone affected by CFS/ME may help the development in future of better information and interventions for others in a similar position.

In the event that participating in this study has raised any issues or concerns for you, please do not hesitate to contact me, or my supervisor, using the details below. We are both available for contact for a period of six months after your interview occurred.

Rebecca Ramsden  
Trainee Clinical Psychologist  
University of Hertfordshire  
Hertfordshire

Supervisor: Wendy Solomons  
Clinical Psychologist  
University of Hertfordshire

E-mail: r.m.ramsden@herts.ac.uk

E-mail: w.solomons@herts.ac.uk

(University of Hertfordshire Ethics Committee –  
Trial Protocol Number: LMS/PG/UH/00216)



## SOURCES OF SUPPORT AND HELP

Talking about your experiences may have left you feeling low or upset. This is quite normal, and often passes after a few days.

However, if these feelings persist there are alternative sources of support and comfort, some of which may already be familiar to you.

- The most immediate sources of comfort and help are likely to be your own family and friends.
- However your GP may also be able to refer you to more specialised local support services, e.g. counsellors, if you feel this may be of benefit.

The following national organisations also offer support:

- ***The Samaritans***

Telephone: 08457 909090

Web address: [www.samaritans.org](http://www.samaritans.org)

The Samaritans is a helpline which is open 24 hours a day for anyone in need. It is staffed by trained volunteers who will listen sympathetically.

- ***Carers UK***

Telephone: 0808 808 7777

Email address: [advice-line@carersuk.org](mailto:advice-line@carersuk.org)

Web address: <http://www.carersuk.org/Home>

Carers UK provides high quality advice and information to carers, and professionals who support carers. There is an advice line and online forum, staffed by experts who have many years of experience of dealing with the problems carers face.

- ***ME Association UK***

Telephone: 0844 576 5326 (open every day 10am-12noon, 2-4pm, 7-9pm)

E-mail address: [meconnect@meassociation.org.uk](mailto:meconnect@meassociation.org.uk)

Web address: <http://www.meassociation.org.uk>

The ME Association funds and supports research into CFS/ME, and provides information, support, education and training to people affected by the condition, and professionals.

## **Appendix F: E-mail sent to point of contact for CFS/ME support groups**

Dear XX XXXXXX,

Further to our discussion earlier today, my name is Rebecca Ramsden. I am a Trainee Clinical Psychologist studying at the University of Hertfordshire, about to enter my final year of training.

I am about to begin work on my major research project, which I need to complete as part of my training. I am keen to carry out research that looks at the experience of living with chronic fatigue syndrome/ME, and am approaching you at this time to see whether [support group] may be able to help me in this regard. I am interested in interviewing partners of individuals affected by CFS/ME in order to gain their perspectives on living with this condition. This is because it seems partner perspectives on CFS/ME are very much under-represented in the research literature at this time. I would be looking to speak to up to 8 partners if possible.

I have attached to this e-mail a participant information sheet, which contains further information on my study, and answers to some of the questions you may have about it.

If anyone affiliated with the support group may be interested in taking part, it would be great if they could contact me on this e-mail address or my mobile XXXXX XXXXXX. Additionally, please don't hesitate to contact me if there any further questions about the project. If anyone affiliated with the support group feels they may wish to take part in the study, we can arrange a convenient date, time and location to meet to carry out an interview.

Many thanks for your consideration of this matter.

With best wishes,

Rebecca Ramsden  
Trainee Clinical Psychologist

Based at:  
Department of Clinical Psychology  
Health Research Building  
University of Hertfordshire  
College Lane  
Hatfield  
Hertfordshire  
AL10 9AB

## **Appendix G: Interview guide**

Before I ask you about your story, I wonder if I can ask how you came to volunteer to take part, and what your hopes may be?

### **Introduction question:**

As you know, as part of this study, I am interested in hearing about the experiences of partners of individuals affected by CFS/ME.

I wonder if you could begin by telling me about when you first became aware of CFS/ME in x's life, beginning at the place you feel is most appropriate to start?

### If initial prompt needed:

I wonder if you could tell me about your experiences as if it were a story, with a beginning, middle and how things will look in the future, perhaps starting with what things were like before x's diagnosis/before x's symptoms were identified as CFS/ME, followed by what life was like immediately afterwards, what it's like now, etc.

General prompts to use throughout interview:

- Could you tell me a bit more about that?
- Can you give me an example?
- What happened next?
- Can you explain a bit more what you mean?
- How did things change over time?
- I was interested to hear about ..... and wondered if you can tell me a bit more about that?

### Main areas for exploration:

1) Relationship with partner

Can you tell me a bit about how CFS/ME has impacted on your relationship with x over time?

When did CFS/ME first come into your relationship?

- (How did it impact around diagnosis/identification of symptoms as CFS/ME?)
- (Early stages post diagnosis/identification of symptoms as CFS/ME)
- (Now?)

2) Understanding/cause

Can you tell me a bit about your process of gaining an understanding of CFS/ME?

What did you do to find out more about CFS/ME?

- (Before diagnosis/identification of symptoms as CFS/ME)
- (Around diagnosis/identification of symptoms as CFS/ME?)
- (Early stages post diagnosis/identification of symptoms as CFS/ME)
- (Now?)

3) Response to CFS/ME

Can you tell me a bit about how you and others round you have responded to the situation?

Can you tell me about the first time somebody asked you what CFS/ME was?

- (Before diagnosis/identification of symptoms as CFS/ME)
- (Around diagnosis/identification of symptoms as CFS/ME?)

- (Early stages post diagnosis/identification of symptoms as CFS/ME)
- (Now?)

4) Impact/consequences

Can you tell me a bit about how your life changed because of x's CFS/ME?

- (Before diagnosis/identification of symptoms as CFS/ME)
- (Around diagnosis/identification of symptoms as CFS/ME?)
- (Early stages post diagnosis/identification of symptoms as CFS/ME)
- (Now?)

5) Coping/adjustment

Have there been any difficulties that have occurred as a result of x's CFS/ME? If so, can you tell me a little about how you have managed these?

- (Before diagnosis/identification of symptoms as CFS/ME)
- (Around diagnosis/identification of symptoms as CFS/ME?)
- (Early stages post diagnosis/identification of symptoms as CFS/ME)
- (Now?)

6) Services/professionals

Can you tell me about any times you have had contact with services/medical professionals in relation to x's CFS/ME?

- And any others?
- And any others?

## 7) Future

Can you tell me about how you see the future, as someone supporting/caring for someone affected by CFS/ME?

- Challenges you anticipate?
- Treatment you would like to receive?
- Support you think you will need?

### **Summary:**

To sum up, what are your final thoughts about what it means to support/care for someone affected by CFS/ME?

What might your advice be to others in a similar position?

What advice would you give to health services/professionals that you feel they need to know about CFS/ME?

## **Appendix H: Transcription service confidentiality agreement**



University of  
Hertfordshire



Appendix 8: Transcription Agreement

University of  
Hertfordshire



Doctorate in Clinical Psychology  
University of Hertfordshire

Transcription confidentiality/ non-disclosure agreement

This non-disclosure agreement is in reference to the following parties:

Rebecca Ramsden, Trainee Clinical Psychologist

And

H W Secretarial Services

The recipient agrees to not divulge any information to a third party with regards to the transcription of audio recordings, as recorded by the discloser. The information shared will therefore remain confidential.

The recipient also agrees to destroy the transcripts as soon as they have been provided to the discloser.

The recipient agrees to return and or destroy any copies of the recordings they were able to access provided by the discloser.

Signed: *H Williams*  
Name: *H. WILLIAMS (Trading as*  
Date: *19/10/14* *H W Secretarial*  
*Services*



## Performance

- Taken from Riessman (2003)
  - Why was the narrative developed in that way, and told in that order?
  - In what kinds of stories did the narrator place him/herself?
  - How does he/she locate him/herself in relation to the audience, and vice versa?
  - How did s/he strategically make identity claims through his/her narrative performance?
  - What other identities are performed and suggested?
  - What was the response of the listener/audience, and how did it influence the development of the illness narrative and interpretation of it?

## Structure

- Taken from Harper (2012)
  - How is the structure of the narrative organised?
  - How internally consistent is this story?
  - How does the story move? Does it wander? Develop logically?
  - How persuasive is the story?

## Diversity/difference/power

- Burnham's (1993) GRRACCEESS
  - Gender
  - Race
  - Religion
  - Age
  - Ability
  - Class
  - Culture
  - Ethnicity
  - Education

- Sexuality
- Spirituality

### Audience

- Taken from Harper (2012)
  - Who is the audience, literal and figurative, for this story?
  - How does the speaker perceive you, and how do you think this impacts on what they say/don't say?
  - How do they think you view them?
  
- Taken from Mishler (1991)
  - Who might be the ghostly audiences present in the room?

## **i) Analytical process**

### **Stage 1:**

Following listening to the research interview and reading its transcript, I listened to audio-reflections from my encounter with Sue, excerpts from which are included below:-

“Very interesting that in terms of her narrative versus the male narratives that kind of, I’ve had before, the huge emphasis was on the impact on the relationship, and how ‘unnoticed’ almost Sue felt in her relationship with her husband. Which is really different from the male narratives.”

“She sort of talked about how her husband didn’t do things to help himself, how his outlook was really negative. This seemed a complete contrast to the male narratives up to now, in which female partners were all portrayed as trying to do things, even if they were small things.... I thought that was a really interesting contrast. It would be great to be able to speak to another female, as I don’t know if there’s something about gender in that, if that’s something about female responses to living with chronic illness versus male responses to living with chronic illness.... not sure”

“I think I was struck by how much reference Sue made to how much she had suffered. Again that was very different from the male narratives up to now. The males have all been about, you know, ‘it’s part, you know, it’s what I do’ – this felt different for Sue...”

### **What were the most strongly heard stories?**

- ‘James’ CFS/ME came as a total surprise to me, and it doesn’t appear similar to others I know who have the condition’
- ‘I have doubts around how my husband is approaching his condition’

- 'I have a longstanding history of caring for others'
- 'I have my own chronic health issues which I don't feel are taken as seriously as they should be'
- 'My life has been/is burdened by the demands of my caring for others and my chronic illnesses, and James' CFS/ME hasn't helped with this'

## Stage 2:

Below are some excerpts from the notes I made following reading through the transcript of Sue's narrative several times, focusing on both 'content' and 'performance':-

### Initial thoughts:

Highly tangential narrative – makes it hard to follow Sue's 'train of thought' at times.

Key 'storyline' however is the toll James' condition has taken on her given her own history of caring and chronic illnesses. Toll seems to have been particularly great from 2005 to present day.

### How was the story told?

- Lots of laughter which appeared to juxtapose at times with what was being said – what was that about?
  - o *'But you know, my overall sort of, is positive, you know? And I think, we can, and his is f\*\*\*ing negative. (Laughs)*
- The tone of what was being said did not appear to match with the laughter that followed – I wonder whether this laughter was to some extent for my benefit? Perhaps to make Sue's quite 'dissatisfied' stance in the narrative more palatable for me?
- The storytelling feels quite 'edgy' at times – Sue often can be seen to tell her story and then bring in a quite socially challenging response or expression e.g. swearing.
  - o *And you think "f\*\*\* me, you're suppose to be better after you've been away on holiday"*

- You get a strong sense of underlying frustration or resentment 'spilling out'
- Sue repeatedly positions herself as a 'carer' of others and a 'stay-er' – I wonder whether Sue was drawn to do this as a means to counter her stories of 'dissatisfaction'?

#### In what kinds of stories did she place herself?

- Stories of 'carer' and 'caring'
- Stories of sufferer of chronic illness which she feels to have been unacknowledged by others
- Stories of difficulties in her relationship with her husband because of his response to his CFS/ME
- Stories of 'non-witness' to the onset of her husband's CFS/ME
- Stories of being a 'stay-er', 'carrier' of others

#### How was it organised?

- Narrative did not feel particularly organised
- Sue begins with a story of her experiences around the time her husband received his CFS/ME diagnosis – outlines from the start a sense of surprise at her husband's condition being CFS/ME
- Quickly moves to positioning of own physical health issues, before moving to stories of caring for others from very early age.
- Then lots of different stories emerge and interweave including the history of her relationship with her partner, story of their son's own physical health issues that summer, stories around the family receiving a lack of support from social care in 2005, differences between her and her husband's outlook on life to name but a few.
- Notably Sue brought her husband into the room at one stage as a means of checking details on the chronology of his illness, despite the researcher requesting just to speak with her by herself.

#### Repetition of stories/ideas:

- Repetition of stories of self as carer

- Repetition of stories of self as sufferer of chronic health issues herself – conditions that leave her equally incapacitated but are less ‘recognised’ than CFS/ME
- Repetition of dissatisfaction at husband’s approach to his condition at times

What was my influence on the telling?

- I felt like Sue was keen to portray the significant impact of her husband’s condition on her, and so the questions I asked appeared to have minimal bearing on the reports she offered.
- I basically felt like I ‘left her’ to speak for much of the interview – on reflection I think this was because I found it difficult for the most part to keep up with her train of thought.
- However, I am drawn to question my influence as a female researcher – Sue speaks at one stage about the ‘male conditioning’, also about her history of involvement with the women’s movement. She also positions her emotional response to living with her husband’s condition a great deal – I wonder whether these aspects to Sue’s story would have emerged so much with a male researcher?

**Stage 3: Narrative Impression**

Sue’s narrative was characterised by a somewhat disorganised, fragmentary narrational style, which led the narrative to lose its ‘thread’ on several occasions.

Sue was observed to repeatedly place herself in stories that spoke of a longstanding propensity for ‘caring’, as well as her status as a sufferer of chronic health issues herself. Notably, Sue was observed to speak of discrepancy between how her physical health issues, and her husband’s CFS/ME, are viewed. Such stories served to construct a strong sense of ‘burden’ for Sue; burden that appeared exacerbated by a lack of support from others, as well as her husband’s condition itself. As such, Sue’s narrative appeared underpinned by a strong sense of frustration, and even exasperation on occasion.

Sue was also observed to portray significant tensions that had arisen in her relationship with her husband, which she appeared to link to how James had approached his condition at times. In contrast to all other narratives co-constructed, Sue was observed to portray a strong sense of surprise at the extent of her husband's difficulties prior to being officially diagnosed.

Notably, Sue can be observed to laugh at multiple points throughout the narrative. At times however, such laughter appeared somewhat at odds with what was being described. I am now drawn to question whether laughter was being drawn on by Sue in an attempt to reduce the burden of the stories being told, both for herself and for me. There is not much sense of many 'ghostly audiences' being held in mind until the end of her narrative, when Sue can be seen to 'address' those responsible for social care provision within the UK regarding the short-comings of the current system.

#### **Stage 4: Focus on key 'storylines' – principal topics, events or 'identities'**

##### **Storyline 1: Identity as 'carer' and 'sufferer of chronic health issues'**

Aspects of Sue's storytelling that link to this storyline are:

- Sue's introduction of her own chronic health issues comes in very early on in her narrative, notably when I had asked her about when she had first become aware of her partner's condition – this introduction of her own health issues at this stage was felt to 'jar' somewhat, and as such constructed for the researcher a strong sense of Sue wanting to get this aspect of her story 'heard'
- Sue also could be seen to position from early on the story of her caring responsibilities, notably tracing these back to starting at the age of 1 when her grandmother came to live with her family. Again this constructed for the researcher a strong sense of Sue wanting this aspect of her story to be heard.
- Sue's telling of all of her caring responsibilities served to construct for the researcher a strong sense of pressure and stress– impression of Sue as a woman who held 'much in mind' – ?reflected in the tangential, fragmentary narrational style.



A few quotes I highlighted on the transcript for this storyline are:-

- *'I mean one of things that's very important for this whole narrative, um, is that I've got a history of chronic illnesses myself'*
- *'Um and so you know all of this business with James and his ME, um, is against the backdrop of my life being, you know, a complete succession of caring for different people'*
- *'I mean there's, there's more caring in my life even....'*
- *'...it's sort of funny, it's kind of ironic but, you know, because I'd got this long history of chronic illness myself...'*
- *'I've got a pattern of... like I've got a caring pattern....'*

Storyline 2: Tensions in relationship with husband

Aspects of Sue's storytelling that link to this storyline are:

- Sue positions at one stage how she and her husband have essentially two different 'outlooks' on life, hers being 'positive' and his being 'negative'. This is positioned by Sue in no uncertain terms.
- Sue goes on to position her perspective on what constitutes a healthy relationship. She also can be seen to portray what helps partners of individuals affected by chronic illness manage the stress of such, and how for her, her partner making steps to 'get himself together' is important.
- Returns on several occasions to how has felt her partner to at times not take such steps, and as a result this having pronounced impact for her own emotional well-being.

Some of the quotes highlighted on the transcript for this storyline were:

- *'But I think that one key place where we're really different is that I have, uh, essentially an optimistic outlook on life.... But you know, but my overall sort of, is positive, you know? And I think, we can, and his is f\*\*\*ing negative. (Laughs). Essentially. (Laughs)'*
- *'I always feel that what you, there's only ever ever any point staying in a relationship when you get more positive out of it than negative. And if it tips over in to more negative than positive, you should get out really'*

- *'But he wasn't, you know, doing his share of what needed to be done...'*
- *'But (pause) him deciding that he was going to do this Gupta Training helped as well, you know. Partly because I think it actually had had a bit of a material effect. But partly because you actually feel that, you know, he's actually trying to take charge (pause)... and he's not just being a kind of complete victim to his disease....'*

### **Stage 5: Individual narratives**

Brief narratives written for each storyline are included below:

#### **Storyline 1:** Identity as 'carer' and 'sufferer of chronic health issues'

*'I've got a history of chronic illnesses myself...[and] my entire life  
I have been a carer for diff-, different people...'*

Sue can be seen to introduce her own history of chronic health issues and caring for others very early on in her narrative account, notably in response to a question posed by the researcher asking when she had first become aware of her partner's condition. The introduction of these aspects of self 'jarred' somewhat for the researcher, and as such it was felt Sue was particularly keen that these aspects of her story should get heard. Indeed, Sue's repeated positioning of these aspects of 'self' throughout her narrative further indicated to the researcher the importance for Sue that they should get heard. Sue's narrational activity in this regard created a strong sense that she had to 'hold much in mind' as a result – an impression further enhanced by Sue's somewhat fragmentary and tangential narrational style.

#### **Storyline 2:** Tensions in relationship with husband

*'I mean, I couldn't believe, before I went away, that I could ever  
feel anything less than entire seething resentment the whole time....'*

From early on in her narrative, Sue can be seen to speak of the differences that exist between her and her husband. For example, at one stage Sue describes how she and her husband have essentially two different 'outlooks' on life – hers being

positive and his being negative. Sue can be observed to repeatedly speak throughout her narrative of certain difficulties that have arisen for her in her relationship with her husband, and to relate these difficulties to the approach her partner has taken in relation to his condition at times. However, as her narrative draws to a close, Sue can also be seen to position her belief that she and her husband have *'done fantastically well'* given the circumstances they have been in. This constructed for the researcher a sense of Sue wanting to offer a 'balanced' representation of her relationship during the research encounter.

### **Stage 6: Connection to collective areas of focus**

Following completion of the analysis of all six participants' narratives on an individual basis, narratives were considered collectively. Reading across narratives, two broad areas of collective focus could be seen to emerge – *'stories from then'* and *'stories from now'*, within which specific constructions of the participant ('self'), the affected partner ('partner'), their 'relationship', 'others' (including family members, friends/acquaintances, health professionals, other professionals and wider society) and 'CFS/ME' were seen. Notable areas of similarity and difference across participants were observed, with some similarities in how 'stories from now' were told being seen to emerge down gender lines. Below I have included quotes or stories from Sue that can be seen to fit with particular 'sets' of constructions.

### **'Stories from then'**

#### **'Life before'**

##### **Constructions of partner**

- In line with all other participants, could be seen to position partner's physical activeness prior to condition onset:
  - o *'you know he was just kind of pressing on regardless really'*
- Also in line with Louise, Sue could be seen to offer constructions of her partner that spoke to his 'character'
  - o *'I wasn't prepared to have a relationship with somebody who didn't do 50% of the housework and the child care... Umm anyway, so the*

*thing is that he was completely brilliant.... and he always did, I mean when [son] was very tiny, from the time [son] was born, he always did do, you know, the looking after him'*

### Constructions of 'self'

- Sue positions herself as having been active in woman's movement
  - o *'I've been very involved in the women's movement all of my adult life... And you know the reason why I decided that James was somebody, a man, who I could stand to have relationship with, was that.... it was immediately clear to me that you know he spoke well of his mother and spoke well of his sister...'*
- Works to construct Sue as independent, not seeking to 'depend' on partner.

### **'Early encounters with CFS/ME'**

#### Constructions of CFS/ME

- Unlike any other participant, Sue positions her husband's condition as having come as a complete surprise
  - o *'it was like actually, this kind of came as complete news to me, in a funny kind of way, that he was even feeling this bad.'*
- Sue doesn't position that she observed in her husband any form of radical physical decline around the time it first developed – again in total contrast to other narratives of partners.
- Later though, she can be seen to speak of a period of profound physical collapse for her husband:
  - o *'it got very bad in 2005... he basically, he became.... more or less completely bed-ridden...'*
- This can also be seen in Tom and Stewart's narratives.

## **'Seeking help/the response of others'**

### **Constructions of self and relationship**

- Sue can be seen to position herself as relatively absent from her husband's decision to seek medical input – something that is in direct contrast to all male accounts
  - o *'...I don't know if he had been to the doctor a few times and hadn't told me, he might have.....'*
- Could relate to dynamic in relationship, but ?relate to narratives around gender, and in particular how men view illness - ?not worry others

## **'Stories from now'**

### **Constructions of CFS/ME**

- Sue can be seen like Louise to position the physical limitations of her partner in the present day due to his condition
  - o *'if we go over [to his mother's] to see her, and you know James needs to lie down for half an hour, three quarters of an hour, in the middle of the afternoon, it's not a big deal, you know'*
- This is similar to all other participants.

### **Constructions of 'others'**

- Observed to position the unhelpfulness of health professionals in the present day
  - o *'...basically I have to say that the ME Unit at [hospital] has been completely useless. (Laughs) Com:pletely useless. James goes in and sees this specialist... once a year, and he goes "oh well, you still seem the same, go away, come back and see me next year", you know?'*
- Again, this is similar to Louise, but also to Oliver, Tom and Stewart.

### **Constructions of partner**

- There was a strong sense of Sue questioning the approach her husband took to his condition at times:

- *'essentially (pause) he hasn't (pause) really (pause) he wasn't really (pause) getting himself back together after that...'*
- *'...but you know, I just felt like "you've just got to do something here, you've just got to"'*
- Although this looked slightly different in Louise's narrative, there was nevertheless a similar questioning of how her partner had approached his condition at times.

### Constructions of 'self'

- Sue can be seen to position significant implications for her own psychological well-being from living with her partner's condition, and her partner's approach to his condition at times
  - *'I did go through a bit of a patch last year where I just, you know, I suppose with it being our 25<sup>th</sup> anniversary we were having a party and, I don't know, just the sort of.... you know, not feeling very happy with him made it hard for me to through myself into the party really....'*
- This served to construct less of a sense of assimilation by Sue of her husband's condition into her life – that the condition still represented a source of acute 'biographical disruption', with a lack of 'biographical flow' or 'narrative reconstruction' present – this was similar to Louise, but in contrast to the majority of male narratives.

### Constructions of relationship

- Sue can be seen to position a sense of togetherness in her relationship with her husband
  - *'Um but I, I mean I do think we've done fantastically well...'*
- But can also be seen to position a sense of 'isolation' in the relationship too – permeates throughout the narrative.
- This is strongly reminiscent of what can be seen in Louise's narrative too – it appears for both female participants there are things that can't be said, or heard, by their partners, which seems to exacerbate distress caused by the condition.

## ii) Excerpts from Sue's narrative account

R: Okay, so as you know, so as part of the study I'm really interested in, in finding out about the experiences of partners of people affected by ME (005: Yes) over time, and I wonder whether, to begin with, whether it's possible for you to tell me about when you first became aware of ME in [Partner's] life, (005: Right) beginning at the place that you feel is most appropriate to start.

005: Yes, (.) okay, well, yeah. I mean, in a way, the whole thing is kind of a bit weird, if you like, because (.) umm (.) basically what happened was, that (.) he had this (.) hospital appointment at [hospital]. (.) Um, now he tells me it was 2000, right, so but I actually can't remember exactly, but I'm sure he'd remember (.) properly. Um, so um, we went for this appointment to [hospital] and basically (.) it was to the chronic fatigue clinic and he, they said he had ME. And, but the thing is that, I mean, (sighs) it was like, actually this kind of came as complete news to me, in a funny kind of way, that he was even feeling this bad. Because you know he had been (.) I mean he must, I don't know actually, I've never really discussed this with him. Although we are you know pretty open with each other, I suppose, you know even in kind of the closest relationships, there's stuff that you keep to yourself and you know men, I hate to say this really, but do tend to keep stuff more to themselves. (Laughs) Um anyway, so I don't know if he had been to the doctor a few times and hadn't told me, he might have, or I don't even quite know, but basically, yeah, you know, he... you know, this was it. I mean obviously, you know, it wasn't the most serious case of ME because, you know if it had been then I would have been aware of him sort of in a state of total collapse. But I wasn't, you know. I mean he did seem kind of quite tired but the thing is, I mean, one of the things that's very important for this whole narrative, um is that I've got a history of chronic illnesses myself. Um and so, um I've always been kind of, got very tired um, and so (.) somehow I guess I just, you know well even when we went for that first meeting with the specialist at [hospital], you know and he was asking [Partner] all these questions, and [Partner] was giving all these answers, and I'm sitting there thinking, 'well I could say that', you know, pretty much. Umm, so yeah, so it was a very, it was kind of quite a gradual (.) development and I, (.) did I know? I mean I've, I've had

loads of (.) pe- friends who've had ME or not so much, well some actually as its turned out close friends, but also umm (.) kind of acquaintances. Yes, I think I, so I would have known about ME be-, well before this happened to [Partner] actually. Yeah, I'm just casting my mind over (.) the people that I knew. Definitely that was well before 2000, yes, yes, yes. So I definitely knew about ME quite in some detail. But I suppose this was a in way maybe why I wasn't sort of, I was a bit taken aback by (.) you know this announcement suddenly that [Partner] had ME because he certainly wasn't anything like as bad as (.) people that, (.) other people that I knew.

R: Right.

005: You know, I mean I've got one particular friend, let me think when she developed it, umm (exhales) a bit hard to say but it could have been like more or less as early as , well it was yeah, at least the early 90's probably.

R: Right.

005: And I mean she was like completely floored by it and she's still, I mean she's never, she still suffers from it and probably will for the rest of her life, you know? (R: Mm) Umm, sorry, that's my front door

R: Okay, shall we stop, okay.

005: Yes, I think....

005: .... of my life story if you like, is that my entire life I have been a carer for diff-. different people. You know, my grandmother came to live with us when I was less than one year old. She had um dementia, well Alzheimer's. Um and (.) she uh was sent over to stay with my mother because, well my parents, because of course she had quotes nothing to do but be at home all day with a little person. And then my grandmother died before I was three, And then my sister was born disabled when I was four and a half. And I still look after my sister. I mean she lives independently with her partner um quite nearby. But her partner's also got mental and physical health problems. Um, and so you know all of this business with [Partner] and his ME um is against the backdrop of my life being you know a complete succession of caring for different people. Um, and, you know, and then things kind of land on one's plate that you know you're not looking for, and my next door neighbour, who um I'm very close friends with,



her daughter got diagnosed with a life threatening illness two and a half years ago, and she's only, well she turned 12 last week. So she's been very ill and she's been in Great Ormond Street now since September. And [neighbour] in a state you know, understandably. So you know, I know that, you know, if she comes knocking for wanting something, you know you don't just kind of go, 'can't deal with this sorry, busy', you know? Um, and uh (.) yes, anyway, that's (R: Mm) so that's that. And then I've had this other, I mean, this year, this year has been unbelievably terrible. I have like every 10 years (laughs) or so I have a year of complete terror, terribleness, (R: Oh dear) and this year's been that year really. Um, I've had any number of disasters and my godson ended up in (.) serious trouble, um and is in prison now, you know, so (R: Oh dear, gosh). Anyway, anyway, so this, so in a way, this kind of, as I said, this all just provides the backdrop, I mean, there's, there's more caring in my life even, I mean my Mum got Alzheimer's and my Dad looked after her, but obviously I was around. And then, then my Aunt got Alzheimer's. And then my Dad died very suddenly. And so my Aunt was in New York and then I had to bring her back here to um (.) um an old age home, where was actually very well looked after, but you know so I was her carer for six or seven years till she died. Um you know and this all overlapped you know? Well that started in '97 and then [Partner] got diagnosed round about 2000, so you know there's always this backdrop, and then there's my sister you know, and um yeah. So, so I mean just to go back to the central story about [Partner], which is that um I mean, you know we, we got together in '88 and (exhales) I don't know, I mean it's kind of ... it's sort of funny, it's kind of ironic but, you know because I'd got this long history of chronic illness myself, um which kind of stems from, well two completely different things, one is um a slight amount of chronic liver damage and the other is, um, a um dislocated pelvis or sacroiliac joint which you know used, well I've had you know for a few years, this last time that it happened, although, touch wood was now nine years ago, but it lasted for much longer than usual, and I was on crutches and in bed and really unwell for nearly two years actually this last time. But since then it's been better, but anyway, so the thing is that, you know, because the liver in a way has a more ongoing thing, uh effect on me, and um (.)so you know like when I get a cold, say, then you know I'm like disproportionately ill, you know, that

when people go (grand voice) 'oh there's something going round', you know, (laughs). And everybody else gets whatever it is that's going round and they're ill for a week. Well I'll be ill for two or three weeks, you know that sort of thing. And uh you know, so ... in fact, so ... when I met [Partner], well I'd, I'd actually met him a couple of times, very very briefly, earlier in '88. But when I actually properly met him was at this weekend gathering that we were, we met at in [City]. And then um, he was living in [City] at the time and I was living in [City]. And so then there was a sort of reunion of the people, some of the people who'd met up, in [City], about six weeks later. And um (.) you know I wasn't really very well. I had a kind of nasty cold or maybe not even a cold but I just really wasn't feeling up to scratch. But um another mutual friend of ours offered to take me up in the car to [City], and so that was ... yeah ... umm ... so I umm (.) yeah, I probably wouldn't have gone to [City] that weekend, but I knew this was my opportunity to cement my relationship (R: laughs) with [Partner]. And you know, the thing was I kind of picked him, you know because he just seemed (.) well he seemed really solid, which he is as a personality, you know, but he seemed really solid in terms of his health and you know just his general ... yeah, well, whatever, you know, like ... I suppose partly cos I'd had this whole kind of history already at that time of um dealing with other people's health problems. I mean my Mum was still alive actually when um I met [Partner]. But um so a lot of stuff came on after [Partner] and I got together. But you know I had already got this long history of caring and chronic illness and stuff and, you know somehow or other, in my ... maybe I wilfully ignored it, but I couldn't see that there was anything the matter with him you know? Um but he always did have slight symptoms of um like... for example, in the very early days of our relationship, um he had a car which he then got stolen, actually, (laughs) fairly soon after he moved to [City] (R: Oh gosh). Which actually I wasn't in some ways not that bothered about, but it just seemed ... but you know, but the point is that, you know, he would drive and then he'd get really really bad pains in his shoulders and I never, you know, well you don't, I think, you don't make any kind of connection with that, you know? But he just would go, 'oh this just made me very tense' and whatever. Um but of course, when the ME developed, one of his major symptoms is, has always been terrible pains across the top of his body,

across his shoulders and in to his head and everything, very bad headaches and things. So you know obviously the underlying, some of that underlying stuff was there, it was always there, but you know, just didn't kind of notice it really. So yes, so the ME, yes, I guess it came on (.) kind of gradually really and then it (.) it just got, I kept, I suppose it got worse, yeah, well it did really. Mostly because, well I me-, who knows, but it seemed like you know, umm he just wasn't, um you know he was just kind of pressing on regardless really which is not what you ought to do, you know? Um, you ought to just kind of take it easy. And um, so he'd got a grant to set up this organisation that he had been wanting to set up you know for a long time, to kind of, you know, this sort of politics of science thing that I mentioned before. And uh, and so he actually got this grant to do this and then he ... but he just wasn't ... it was, it's really hard to describe really, it's like (.) I suppose neither of us in a way were, were taking the ME seriously enough basically. (R: Mm-hmm) I mean it's really hard to know, really really really hard to know, okay? But I think you could argue that if he had absolutely kind of stopped doing what he was doing and taken it really easy, umm, at the beginning, maybe it would not have dragged on for the last 15 years. (R: Mm) You know, but you can't really say that, but, but I think, you know, that is ... that definitely is a, is a question that has to you know remain really ... cos the thing is, that before he got this grant, I can't remember now exactly what year it was, it was, but it was in the early 2000's. Um, and then, for quite a few, several years before that, he'd actually been um earning his living as um writing and researching this kind of uh I suppose you'd call it kind of (.) activist magazine, kind of information magazine, which he would send out. It was still way before you know all these newsletters and stuff were online you know? Um, and so that was how he earned his living. And I mean the reason that I'm kind of saying about this is because he would just spend hours and hours and hours on his computer, which we all know is really bad for you. But you know, and again, he'd come off the computer, eventually, at the end of the day, and he'd just have these awful sort of pains across his shoulders and stress. I mean this is before I think he got the ME, but umm (.) yeah, I think, I do think that that's what brought ... contributed, was a major contributor to him getting the ME. I mean the other thing that I'll say, which um again, this is sort of putting things not in very

chronological order, but it's kind of I think important to say, is that um, one of the things that has completely freaked ... well it's freaked all of us out to be honest, but has completely freaked me out um , in this year, is um that in the middle of July, [son], our son, got quite bad glandular fever. And um, and he was actually in hospital for about a week and he was still living in Leeds at that time, so he wasn't at home. Um, and anyway so I, I kind of, a bit late in the day, in a way, cos he, he wasn't very straight forward with us about what was the matter with him. Um but I went up there to sort of look after him and cheer him up for two or three days, before he came back to [City]. Um but anyway, I mean, the thing was that, that [Partner] had glandular fever, just between I think this is right, I think it was before ... between goi- leaving school and going to university (R: Right). I think that was when it was. Anyway, and I already knew that glandular fever can lead to ME. And um, but in a very vague sort of way. But anyway, then I got completely freaked out when [son] got glandular fever and um, so I went on the internet and did a bit of research. And it transpires that one in 10 people who have glandular fever go on to develop ME. (R: Right) So I mean I have been very very freaked out about all of this. And um I've been trying to kind of deal with [son], well, as I said to you just before you know, he is virtually grown up, so you know it is a bit hard to, um you know, you can't treat him like a kid. I mean, I haven't been able to for quite a while, (laughs) but you know what I mean? Um anyway, but I mean I ... he was, he was very sensible for a while, you know after he had it, but he's obviously slipped back in to you know his usual ways of behaving, ah so you can hear the drilling now. We are having our kitchen refurbished, (laughs) for the record. It'll be lovely when it's finished. (R: Oh dear). Anyway, yeah, so um yeah, but one of the things is that [son] you know again, especially, well because he's a different generation as well, you know is he spends loads and loads of time on the computer, you know? And I have really said to him, you know because the trouble is, you don't want to freak the poor kid out. On the other hand, you want to be kind of as straight forward as possible you know? Um, and um anyway so about three or four weeks ago now, he and I had a frank and fearless discussion about all this and that. And we went through you know drink, drugs, sex, computer, you know (laughs) and, and I mean he understands the stakes, you know he's lived with his Dad having ME you know

most of his life, so you know he's ... I mean I remember walking down the road with [son] when he was quite a bit younger, you know, when he was I don't know 12 or 13, you know, no maybe not as young as that, but quite a lot younger, anyway, and him saying to me, oh you know, 'if [Partner]'s got ME, and your health's not all that good, does that mean I'm going to get ME?' And I went 'oh no, darling, it doesn't mean, it's not inevitable', you know. But you know I might have said, because I tend to be ... I think honesty is the best policy, I said, 'well you know it's not impossible that you could get it, you know, but there's no reason to think you will get it'. Um but you see, I (.) I think that, well [Partner]'s said this as well actually, but um you know it, it's struck me that the reason why [son] got glandular fever was because you know he was at this kind of cusp point of his life. And you know, he, what happened was he was very happy at university, he'd got his Degree, he didn't know what he wanted to do with his life, I don't think most kids do at that age. Um he decided he was just going to spend the year in, in [City] and work behind a bar and started doing a bit of writing for this music magazine and things, and great things, you know no problems with doing that. But then all of his friends, you know they, they all, for various complicated reasons, lots of his friends were there studying still, for the fourth year. So it seemed to make sense for him to stay in [City] and then you know to come back to [City], and then but now this is when the rest of your life starts. And that's obviously very pressurising, it's a very key moment. I mean, this was the thing, this was what happened to me as well was when I was, how old was I, I was 2:4, 23, I was 23. And I'd left university and I was very happy at university, I left university, I was very very unhappy because my friends had all dispersed cos I took this job I hated, because I didn't, didn't feel that I knew that I could do what I wanted with my life. And then I got Hepatitis very badly and that's what has lead to my life long chronic illnesses I would say. And so you know, it does seem like there's a bit of a pattern here, you know cos that was when [Partner] got his glandular fever. (.) Anyway, so, so yes, so this has all been a bit kind of out freaky for me. [(Laughs)]

R: [Mm, absolutely] I mean, it, it sounds like the, the, the impact of the ME has been huge (005: Yeah) and that its really alongside the, the, your own chronic health issues and (005: Yeah). I wonder I mean, I ask

people this question, I always say to people you know, please tell me as much or as little as you feel comfortable (005: Yeah, Yeah) telling me. I suppose one area that I'm interested in hearing about is, is how the ME has impacted on your relationship with [Partner] over time, (005: Yeah, Yeah) so perhaps from, from when he first started (005: Yes) developing the symptoms up to now?