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A Qualitative Study Investigating the Experiences of Healthcare Professionals Working in Chronic Fatigue Services

by

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ABSTRACT

FACULTY OF SOCIAL AND HUMAN SCIENCES

Psychology

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A QUALITATIVE STUDY INVESTIGATING THE EXPERIENCES OF HEALTHCARE PROFESSIONALS WORKING IN CHRONIC FATIGUE SERVICES

Elizabeth Ruth May

The first part of this thesis is a systematic review and narrative synthesis of healthcare professionals' experiences of working with people with Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME). A total of 15 qualitative studies met the inclusion criteria. There was significant overlap of themes across the 15 studies. Themes were organised into four categories: *Contesting the Legitimacy of CFS/ME, Emotional Burden, Stereotyping the CFS/ME Patient, and Tension in Clinician-Patient Communication and Relationships*. The review identified a need for further research to better understand differences in understandings of CFS/ME, including the understandings and experiences of specialist CFS/ME healthcare professionals.

The second part of this thesis is an empirical paper describing a study that used Interpretative Phenomenological Analysis (IPA) to explore the lived experiences of healthcare professionals working in specialist CFS/ME services. Interviews were conducted with eight clinicians from a range of healthcare professions. Four superordinate themes were identified: *Safe Haven, Challenges of Understanding, Person-Centredness,* and *Recovery Road*. Some of these findings support issues identified by previous research, but novel themes were also discovered. Clinical implications and suggestions for further research are discussed.

Table of Contents

List of Tables and Figures

Tables

Figures

DECLARATION OF AUTHORSHIP

I, Elizabeth May, declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

A Qualitative Study Investigating the Experiences of Healthcare Professionals Working in Chronic Fatigue Services

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission.

Signed: ....

Date: …..

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Finally, thank you to my wonderful family, friends, and course mates who have supported me every step of the way in completing this thesis.

Chapter 1: What are the Experiences of Healthcare Professionals Working with People with CFS / ME? A Review of the Literature

1.1 Introduction

1.1.1 Definitions of CFS/ME

Fatigue is a term which has been documented throughout historical records. However, the first working case definition of CFS/ME was only published by the Center of Disease Control (CDC) in 1988 (Holmes et al., 1988). Several case definitions now exist; this may be a reflection of the heterogeneity of CFS/ME, both in terms of the types and severity of symptoms experienced. The revised 1994 CDC case definition of CFS/ME (Fukuda et al., 1994) is the most widely accepted, reliable case definition (Johnston, Brenu, Staines, & Marshall-Gradisnik, 2013) and is recommended by the National Institute for Health and Clinical Excellence (NICE, 2007). According to this case definition, CFS/ME is defined as an unexplained, persistent fatigue with a new or definite onset, which is not the result of ongoing exertion, nor is it alleviated by rest, and the fatigue results in a significant impairment to functioning. The fatigue is accompanied by a minimum of four concurrent symptoms: impairment in short-term memory or concentration, sore throat, tender lymph nodes, muscle pain, joint pain without swelling, headaches, unrefreshing sleep, and post-exertional malaise. Finally, the chronic fatigue is not caused by another condition, such as a clinical depression, an eating disorder, or substance abuse. The CDC definition requires symptoms to have persisted for six or more consecutive months (Fukuda et al., 1994), whilst NICE guidelines (2007) state symptoms should be present for a minimum of four months.

There is also some debate about whether the condition should be called CFS or ME and whether the two should be recognised as the same condition. Whilst CFS is more widely used by healthcare professionals, many people with CFS/ME prefer the term ME (Hutchinson, 2002). The term CFS/ME will be used in this paper to encompass both CFS and ME.

1.1.2 Prevalence of CFS/ME

Prevalence rates reported for CFS/ME vary significantly, in part due to the use of different case definitions (Prins, van der Meer, & Bleijenberg, 2006) and the subjective nature of some of the diagnostic criteria (Jason, King, Taylor, & Kennedy, 2000). The population prevalence rate has been reported to be between 0.2% (Nacul et al., 2011) and 2.6% (Wessely, Chalder, Hirsch, Wallace, & Wright 1997).

1.1.3 Aetiology of CFS/ME

A number of potential aetiologies for CFS/ME have been explored. Evidence shows that CFS/ME is often triggered by a viral infection (Buchwald, Pearlman, Umali, Schmaling, & Katon, 1996; Salit, 1997). There is also a link between significant or prolonged stressors and the development of CFS/ME (Hatcher & House, 2003; Sapolsky, 1996). The intensity of the stressor itself seems less important than other factors, including: a perceived lack of control of the stressor, apprehension of chronicity, and subsequent inactivity (McClean & Clauw, 2004). Studies have reported abnormalities in the body’s stress systems (the hypothalamic–pituitary–adrenal axis and the sympathetic nervous system) in a small percentage of people with CFS/ME (Demitrack & Crofford, 1998). Other studies suggest that early life stress is the strongest predictor of changes to the body’s stress systems, which may confound any other factors (Heim et al., 2009; Van Den Eede et al., 2008). Some studies have found that people with CFS/ME have elevated levels of cytokines, involved in regulating the body’s immunity, inflammation, and blood cell production

(Antoni et al., 1994). However other studies, which were of higher methodological quality, did not find any significant differences between the CFS/ME and control groups (Byrnes et al., 2009; Raison, Lin, & Reeves, 2009).

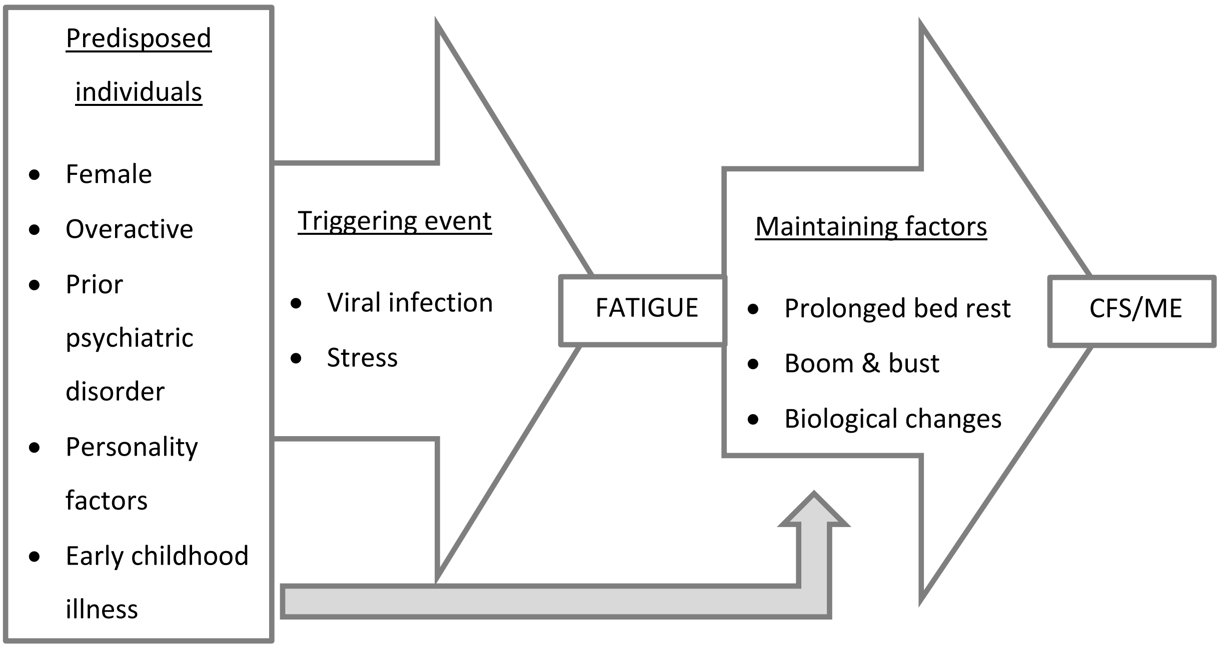
Cognitive impairment in people with CFS/ME has been evidenced by studies of neuropsychological batteries of tests (Majer et al., 2008; Vollmer-Conna et al., 1997). Sleep abnormalities have been researched, (Buchwald, Pascualy, Bombardier, & Kith, 1994) but evidence suggests these are not specific to people with CFS/ME (Moldofsky, 2008). Studies have found high premorbid levels of fitness and activity to be a strong predictor of CFS/ME (Harvey, Wadsworth, Wessely, & Hotopf, 2008; Riley, O'Brien, McCluskey, Bell, & Nicholls, 1990). Personality traits, specifically neuroticism, have been associated with severity of CFS/ME symptoms (Fukunda et al., 2010). Psychiatric disorders and CFS/ME have also been explored. Whilst there is a higher rate of mental health problems in the CFS/ME population (Harvey et al., 2008), evidence has concluded that CFS/ME is clearly separate from psychiatric disorders (Kato, Sullivan, Evengard, & Pederson, 2008; Sharpe & Bass, 1992; Van der Linden et al., 1999).

To summarise, evidence suggests abnormalities exist across a range of domains, but none of these factors alone have been able to fully explain the range of symptoms found in CFS/ME (Prins et al., 2006). CFS/ME is a heterogeneous condition which has a complex and multi-factorial aetiology.

1.1.4 Biopsychosocial Model of CFS/ME

The biopsychosocial model (Harvey and Wessely, 2009) considers a number of factors to be involved in CFS/ME, as illustrated in Figure 1 below. This evidence-based model draws on a number of prospective studies, which have highlighted some important aetiological factors involved in the development of CFS/ME as discussed in the previous section; (Harvey et al., 2008; Kato et al., 2006; Viner & Hotopf, 2004; White et al., 2001).

1.1.4.1 Figure One: Biopsychosocial Model of CFS/ME



Source: Harvey and Wessely (2009)

There may be predisposing factors, such as being female, being overactive, psychiatric history, personality and familial predisposition (Buchwald et al., 2001; Harvey et al., 2008). Research has found viral infection or significant stress to be common precipitating factors (Buchwald et al., 1996; Salit, 1997; Hatcher & House, 2003; Sapolsky, 1996). Whilst evidence shows that the development of CFS/ME has a strong biological underpinning, perpetuating factors are likely to be behavioural, psychological, or social in nature. Behavioural factors include prolonged bed rest (White et al., 2001) and significant fluctuations in activity levels, referred to as the ‘boom and bust’ cycle (Deale, Chalder, Marks & Wessely, 1997). Cognitive factors contributing to the maintenance of CFS/ME include illness beliefs (Joyce, Hotopf, & Wessely, 1997) and a focus on bodily sensations (Moss-Morris, Petrie, & Weinman, 1996). Systemic or social factors have also been found to perpetuate CFS/ME, such as family members encouraging rest and inactivity (Schmaling, Smith, & Buchwald, 2000) and a lack of perceived social support (Prins et al., 2004). Healthcare professionals may also reinforce beliefs that perpetuate CFS/ME, by focusing too much attention on psychological factors, supporting unnecessary medical diagnostic tests, or showing disbelief or scepticism towards CFS/ME as a legitimate illness (Page & Wessely, 2003; Stanley, Salmon, & Peters, 2002).

A key strength of Harvey and Wessely's (2009) biopsychosocial model of CFS/ME is that it is based on the findings from a range of research studies. The model recognises the multi-factorial aetiology of CFS/ME and offers a way of integrating the biological, psychological, and social factors leading to CFS/ME. According to the biopsychosocial model, the maintaining factors are more important than the initial causes in the treatment of CFS/ME. This model provides a useful rationale for behavioural approaches to CFS/ME treatment. This model can also be applied to fatigue resulting from medical conditions, such as cancer, arthritis, or multiple sclerosis (Harvey & Wessely, 2009). However, Harvey and Wessely's (2009) model has been criticised for limiting the biological factors to the triggering role of viral infections and the biological changes in response to the initial fatigue. Additionally, the model does not clearly explain the biological pathways between the initial triggers and consequent symptoms (Maes and Twisk, 2010). If psychological and behavioural factors are emphasised over biological factors, there is a danger that this model will be poorly received by some people with CFS/ME.

1.1.5 Central Sensitisation Model of CFS/ME

An alternative biopsychosocial model has been proposed that conceptualises CFS/ME as one of several central sensitivity syndromes (Clauw, 2010). This model has been used to understand similar conditions, such as fibromyalgia (Yunus, 2007) irritable bowel syndrome (Yunus, 2008), and chronic pain (Woolf, 2011). The central sensitisation model conceptualises CFS/ME as a biologically based amplification of all sensory information. Following a virus or significant stress, the nervous system may become poorly regulated, switching the body into a constant state of high reactivity. As a consequence, all sensory stimuli, including pain, physical senses, and emotions, become amplified. This may be understood using an analogy of a volume control ‘turning up’ all the senses.

Central sensitivity syndromes are characterised by hyperalgesia, an increased sensitivity to pain stimuli. Experimental studies have found evidence of hyperalgesia in people with CFS/ME when responses to pain stimuli have been compared to healthy controls (Geisser et al, 2007; Geisser et al., 2008; Meeus et al., 2008; Meeus, Nijs, Huybrechts, & Truijen, 2010). In contrast, a monozygotic twin-study found no significant differences in sensitivity to cold pain in 15 twins with CFS/ME compared to their healthy co-twins (Ullrich et al., 2007). Whilst the inclusion of monozygotic twins is an important strength of this study, the small sample size meant the study was underpowered. Research has also found that people with CFS/ME have a greater sensitivity to other stimuli, such as visual and auditory stimuli (Hollins et al., 2009; Geisser et al, 2007; Geisser et al., 2008). Functional imaging has provided further evidence of central pain sensitivity in people with other central sensitivity syndromes, including fibromyalgia (Gracely, Petzke, Wolf, & Clauw, 2002), irritable bowel syndrome (Naliboff et al., 2001), and chronic lower back pain (Giesecke et al., 2004).

The central sensitivity model is useful in explaining why there is often overlap and co-morbidities across the central sensitivity syndromes (Yunus, 2007, 2008). Much of the evidence supporting the central sensitivity model has initially focused on fibromyalgia, irritable bowel syndrome, and pain conditions; conditions for which the model was initially developed (Yunus, 1984). Whilst research exploring the role of central sensitivity in CFS/ME is currently limited, nearly all studies to date offer support for this model.

One of the advantages of the central sensitivity model is its ability to explain a group of conditions that have often been termed as "medically unexplained symptoms" or "somatisation syndromes", based on the medical model's difficulty in understanding them. The terminology of this model, classifying this group of conditions as 'central sensitivity syndromes', moves away from these unhelpful terms which tend to be disliked by patients. The central sensitisation model's neurobiological underpinning increases its acceptability to people with CFS/ME (Clauw, 2010), which is an important strength. As a consequence of this acceptability, the central sensitisation model has the potential to improve patient-doctor communication and care (Yunus, 2008).

1.1.6 Treatment Approaches for CFS/ME

The NICE guidelines for CFS/ME (NICE, 2007) recommend Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) based on systematic reviews of the evidence, including ten randomised controlled trials (RCT) of CBT and five RCTs of GET. However two surveys of CFS/ME patient organisation groups reported that some people with CFS/ME found CBT and GET unhelpful or harmful (Action for ME, 2008; ME Association, 2010). The PACE randomised trial compared specialist medical care (SMC) alone or with adaptive pacing therapy, CBT, or GET. 641 participants were included across multiple centres. CBT and GET alongside SMC were found to moderately improve fatigue and physical function scores compared with pacing or SMC alone (White et al., 2011).

1.1.7 Barriers to People with CFS/ME Accessing Treatment

People with CFS/ME report experiencing stigma; including feeling their symptoms are dismissed as being psychosomatic by doctors, family, and friends (Donalek, 2009; Whitehead, 2006). Research has found some general practitioners (GPs) to be sceptical about the existence of CFS/ME (Anderson, Jason, Hlavaty, Porter, & Cudia, 2012; Bayliss et al., 2014; Bowen, Pheby, Charlett, & McNulty, 2005). The stigma and scepticism associated with CFS/ME may lead people with CFS/ME to feel marginalised by health services (Jason, Taylor, Plioplys, Stepanek, & Shlaes, 2002).

In a review and meta-synthesis of qualitative studies on CFS/ME, one theme found across studies of both patients and healthcare professionals was the issue of doctor-patient power dynamics (Anderson et al., 2012). When tension exists in the doctor-patient power dynamic, this can create a barrier detrimental to treatment provision and response (Raine, Carter, Sensky, & Black, 2004).

Finally, people with CFS/ME report that the limited knowledge of doctors led them to experience long-term uncertainty, and sometimes advice was given that led to symptoms worsening (Gilje, Soderlund, & Malterud, 2008).

1.1.8 Aim of the Review

The aim of this literature review is to explore what are the experiences of healthcare professionals working with people with CFS/ME? Qualitative research will be reviewed in order to better understand some of the barriers to treatment access and provision. Existing reviews of qualitative research regarding CFS/ME have looked more broadly either at the experiences of people with CFS/ME (e.g. Drachler et al., 2009) or at the experiences of both patients and healthcare professionals working with this population (e.g. Anderson et al., 2012; Bayliss et al., 2014). However, the broader focus of multi-perspective reviews has limited their ability to investigate the role of healthcare professionals in understanding and overcoming barriers to accessing CFS/ME treatment.

1.2 Method

1.2.1 Search Strategy

The databases psycINFO, CINAHL, and MEDLINE were searched, using the thesaurus to identify relevant search terms. The search used the following terms: “chronic fatigue syndrome” with “health personnel attitudes” or “health personnel” or “health attitudes” or “attitude of health personnel” or “physician attitudes” or “nurse attitudes” or “physician-patient relations” or “delivery of healthcare”, with no restrictions on publication dates. Searches were carried out on 3rd November 2014 and updated on 10th November 2015. A total of 189 papers were identified using these search terms. Once duplicates had been removed, the remaining 176 papers were reviewed, and fifteen articles met the inclusion criteria. The reference lists of the relevant articles were studied but no further papers of relevance were found. A visual representation of this search process is included below in figure one.

1.2.2 Inclusion Criteria

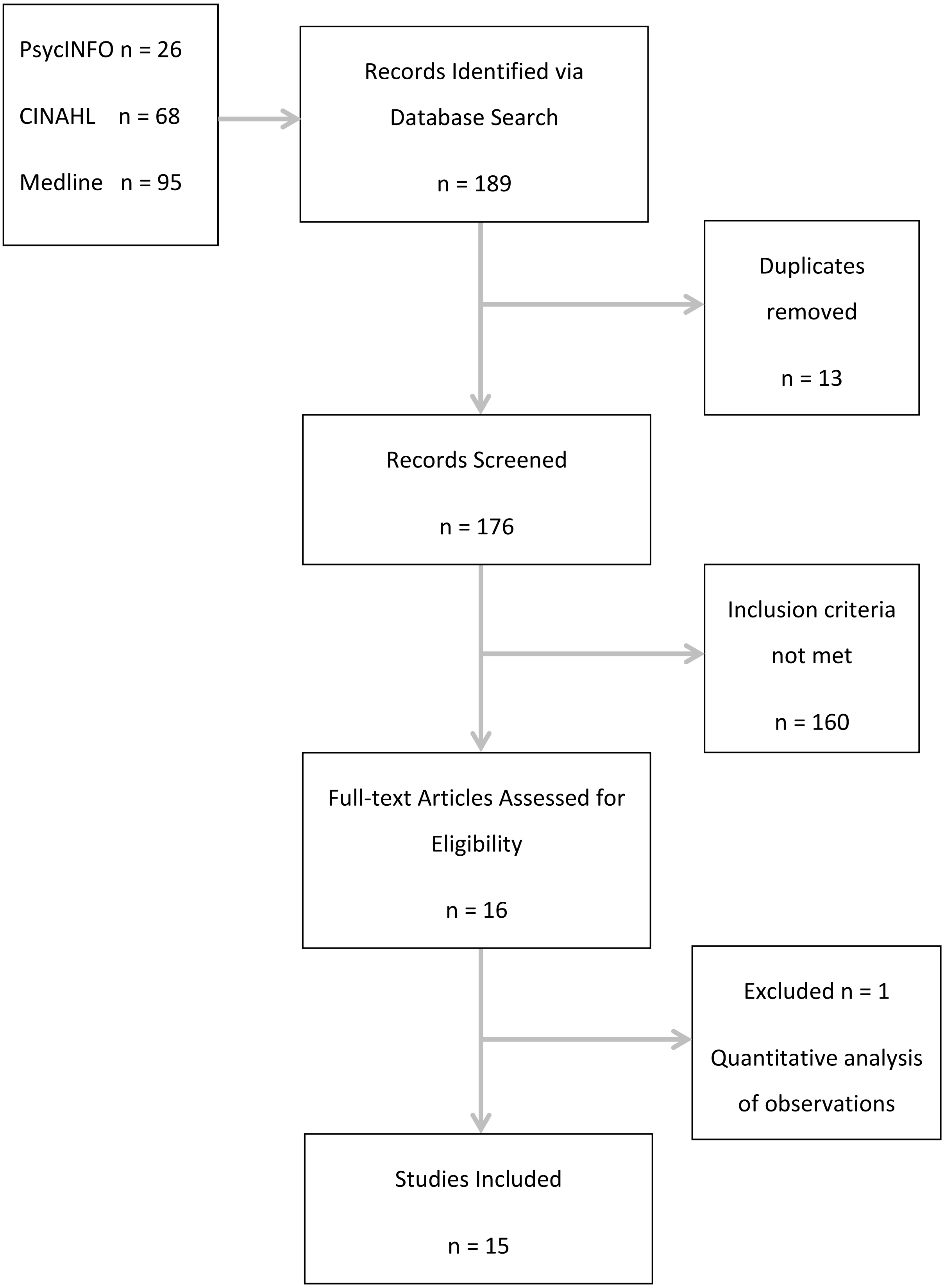
- Empirical Papers published in a peer-reviewed journal, including qualitative methods.
- Sample including healthcare professionals sharing their experiences of working with adults with CFS/ME.
- English language.

1.2.3 Exclusion Criteria

- Papers using only quantitative methods.
- Dissertations and any other texts.

There is currently no approved method for the exclusion of qualitative studies from literature reviews based on methodological quality (Dixon-Woods et al., 2006; Daly et al., 2007; Thomas & Harden, 2008). Additionally, as there were only a small number of studies found to be relevant to this review, the decision was made not to exclude papers solely on the basis of quality.

1.2.4 Figure Two: Flow Chart to Illustrate the Study Selection Process



1.2.5 Quality Appraisal of Included Studies

In contrast to quantitative research, systematic reviews of qualitative evidence are an emerging area and some debate remains about the best way to critically appraise the methodology of qualitative papers (Dixon-Woods et al., 2006). In response to this debate, Thomas & Harden (2008) carried out a ‘sensitivity analysis’, which was designed to explore the impact of including and excluding findings from studies of varying quality on the overall results of the synthesis. They found that studies of poorer quality contributed least to the overall qualitative synthesis.

Checklists can be a useful way of addressing the varied methodological quality of qualitative studies; but it is important to note that these should be used as a guideline rather than in a prescriptive way (Barbour, 2001; Barbour & Barbour, 2003). Furthermore, quality should be considered within the context of the review (Thomas & Harden, 2008). Criteria from the NICE guidance (2012) on the evaluation of qualitative research were used to critically appraise the quality of studies included in this review. In order to use the criteria set out by NICE (2012) as guidance, rather than as a prescribed checklist, the guide was explored in depth and used to create a mind map (see Appendix A). The mindmap considered the following criteria for each study: the appropriate use of a qualitative approach in relation to a clear research question, the quality of the study’s design, whether the data collection methods were clearly described and appropriate, the trustworthiness of the data based on a clear description of the researchers’ roles and the use of triangulation. The quality of the data analysis was evaluated by considering whether there was a clear description of a systematic data analysis method which produced themes that link logically to the results, the richness of data based on a diversity of perspectives, the reliability the results based on the number of researchers involved in data analysis and the reporting of negative or discrepant results, and the clear description of findings which are coherent, relevant, and accompanied by data excerpts. Finally, the discussion of ethical issues, and the clear description of conclusions, implications, and discussion of limitations were considered for each study.

1.2.6 Synthesis

Thematic synthesis (Thomas & Harden, 2008) was used to bring together the findings from the 15 qualitative papers. According to Thomas and Harden (2008), anything under a paper’s results section can be included as data to be extracted and coded in the initial stage of synthesis. Where papers included multiple participant or patient groups, the data extraction focused only on data based on healthcare professionals working with CFS/ME. Secondly, a hierarchical tree structure was created allowing codes to be organised and themes to be developed (see Appendix B). Thematic synthesis offered the opportunity to create a synthesis, beyond the original data, allowing data to be considered in line with the specific review question.

1.3 Results

Fifteen qualitative research papers were selected for review (see Appendix C). The majority of studies were conducted in the UK (n=12). Studies were also carried out in Sweden (n=1), the Netherlands (n=1), and Australia (n=1). This is consistent with Smith (2011), who reported qualitative psychological papers as often originating from the UK. Studies recruited a range of healthcare professionals including doctors (n=9), nurses (n=2), occupational therapists (n=1), and a mixture of different professionals (n=3). Healthcare professionals were recruited from various settings, including primary care (n=9), specialist CFS/ME clinics (n=1), and a population drawn from multiple settings (n=5). Sample sizes ranged from 4 to 46, with a mean of 17 participants. Semi-structured interviews were the most common methodology (n=11), alongside unstructured interviews (n=2), observations of patient-professional interactions (n=1), and nominal groups (n=1). The qualitative analyses used included: thematic analysis (n=7), discourse analysis (n=2), and grounded theory principles (n=2). Some papers failed to clearly describe or follow a specific qualitative analysis (n=4).

1.3.1 Categories of Experiences of Working with CFS/ME

Thematic synthesis of selected papers revealed four main themes describing the experiences of healthcare professionals working with people with CFS/ME, presented in Table One below.

1.3.2 Table One: Categories of Experiences of Working with CFS/ME

Theme	Subthemes	No. (%) of 15 studies Identifying Theme	Studies included in Theme
Contesting the Legitimacy of CFS/ME	Scepticism; the illness status of CFS/ME	11 (73.3)	1, 3, 4, 5, 6, 7, 8, 9, 10, 13, 14, 15
	Limitations of CFS/ME knowledge and understanding	12 (80)	1, 2, 5, 6, 7, 8, 10, 11, 12, 14, 15
	Uncertainty towards diagnosis	9 (60)	1, 3, 5, 6, 7, 8, 9, 13, 15
	Transitioning towards accepting CFS/ME	3 (20)	4, 5, 6
Emotional Burden	Hopelessness	6 (40)	4, 5, 6, 8, 12,14
	Helplessness	5 (33)	1, 4, 6, 12, 14
	Frustration	7 (47)	1, 4, 5, 6, 8, 12, 15
Stereotyping the CFS/ME Patient	Seeing the patient as difficult & demanding	5 (33)	1, 9, 10, 12, 13
	Questioning the morality / truthfulness of the patient	9 (60)	1, 2,4, 5, 7, 9, 10, 14, 15
Tension in Clinician-Patient Communication and Relationships	Conflict between clinician and patient understandings of CFS/ME	13 (87)	1, 2, 3, 4, 5, 7, 8, 9, 10, 11, 12, 14, 15
	Framing using biomedical language	7 (47)	1, 2, 4, 6, 8, 14, 15
	Being “seen” to do something	5 (33)	1, 2, 4, 6, 9

1.3.2.1 Theme: Contesting the legitimacy of CFS/ME.

1.3.2.1.1 *Subtheme: Scepticism; the illness status of CFS/ME.*

Scepticism about the legitimacy of CFS/ME was a key theme, appearing in 11 papers. Doubt towards CFS/ME was discussed in association with its status as an illness rather than a disease, due to its absence of biomedical markers (1, 4, 9, 10). The change in terminology over time has contributed to some professionals questioning the legitimacy of CFS/ME (14). Similarly, others saw CFS/ME as relatively “new” (5, pg. 5), terming it as a “fad” (10, pg. 8) and a “fashionable epidemic” (15, pg. 2); these references to CFS/ME as a short-lived phase add to the scepticism surrounding the illness.

Some participants shared their own disbelief, or referred to other professionals’ disbelief towards CFS/ME as a real illness (1, 5, 6, 7, 8, 13, 14, 15). Discussion of this scepticism in relation to other professionals or colleagues may be a way for individuals to talk about this issue without expressing this view as their own. In some papers, authors pointed out that whilst this scepticism still exists amongst the medical profession, it is important to remember that it does not apply to all healthcare professionals (7, 8).

1.3.2.1.2 *Subtheme: Limitations of CFS/ME knowledge and understanding.*

Limitations in professionals’ knowledge and understanding of CFS/ME was another key theme found in 12 studies. Participants were open about their limited understanding and uncertainty surrounding CFS/ME and its treatment approach (1, 5, 7, 8, 10, 14, 15). One participant discussed uncertainty despite having more than fifteen years of experience working with CFS/ME patients (10). Participants viewed CFS/ME as a complicated condition (1, 2, 8, 12, 15). The variability seen across CFS/ME patients was seen to contribute to the complexity of this illness (1, 2, 8, 15). Some professionals also considered CFS/ME to be difficult to treat (1, 7), or even untreatable (6).

Another factor relating to the uncertainty held towards CFS/ME was the insufficient training, or absence of any training, mentioned by several papers (5, 7, 15). Participants expressed a need for further training (5), including a need for better awareness of specialist services to enable referrals (6, 7, 8). For some, their uncertainty had motivated them to develop an understanding and treatment approach based on their own experiences and interactions with family, friends, and patients with CFS/ME (15). Whilst a minority referred to becoming well-informed on CFS/ME research (15), participants referred to incorporating socio-cultural knowledge (4) and media sources (11) to contribute to their understanding of CFS/ME.

1.3.2.1.3 *Subtheme: Uncertainty towards diagnosis.*

Diagnosis was an issue explored in nine papers. Following on from topics discussed above, scepticism due to the absence of biomedical evidence (3, 8, 9, 15) and limited knowledge (7, 13), were both factors contributing to doctors' reluctance to diagnosis CFS/ME. This uncertainty was seen as a barrier for doctors who were concerned about being held accountable for their diagnoses (8, 15).

Participants expressed a dichotomy, describing diagnosis as both a hindrance and a help (5, 6, 7, 8). On the negative side, diagnosis was seen as potentially leaving patients with a sense of hopelessness towards recovery (1), due to the absence of a clear management strategy (6, 7). In contrast, diagnosis was seen as an important validation of patient's distress (8, 15). Participants saw a positively framed diagnosis as potentially empowering (7).

1.3.2.1.4 *Subtheme: Transitioning towards accepting CFS/ME.*

Three papers made some suggestion of a movement towards viewing CFS/ME as a legitimate illness. Some participants used past tense to refer to their doubts around CFS/ME (6), implying that they have moved on from this position. One paper described participants progressing from a place of uncertainty and disbelief towards a realisation that CFS/ME is a genuine illness and consequently developing a more understanding stance (4). Similarly, other participants described a powerful shift towards becoming more understanding and accepting of CFS/ME through their own personal encounters with CFS/ME (5).

1.3.2.2 Theme: Emotional burden.

Another key theme was the emotional impact experienced by healthcare professionals working with people with CFS/ME. Participants talked about feeling hopeless, helpless, and frustrated. Participants expressed a reliance on their colleagues for emotional support in their work with people with CFS/ME (6, 12). The key emotions discussed by healthcare professionals mirror some of the emotions described by people with CFS/ME.

1.3.2.2.1 *Subtheme: Hopelessness.*

Participants referred to a sense of hopelessness across six studies. Several references were made to participants' experiences of working with people with CFS/ME as heart-sinking (4, 5, 14). This hopelessness relates in part to the view held by some participants that CFS/ME is difficult to treat. Participants discussed their experiences with some patients struggling to get better (5, 12, 14). In contrast, there was some hopefulness expressed by other participants with more positive experiences of patients' progress (8, 12, 14). Healthcare professional participants recognised that seeing patients make improvements was an important factor to their job satisfaction; some described their work with this client group as unrewarding (6), whilst others described it as enormously rewarding (12). This is an example of the great variation in the engagement and treatment of patients with CFS/ME, both within and across studies.

1.3.2.2.2 *Subtheme: Helplessness.*

Another important emotion appearing in five studies was a sense of helplessness (1, 4, 6, 12). Some professionals felt their role as an expert was challenged in their work with CFS/ME (6, 12, 14). Helplessness was associated with professionals' uncertainties about CFS/ME and its apparent lack of treatment approach or management strategy. In contrast, other participants discussed a number of generalised strategies, which participants described as important in their work with people with CFS/ME, including: listening, engaging in a collaborative therapeutic alliance, being supportive and empathetic (5, 7,8, 12, 15).

1.3.2.2.3 *Subtheme: Frustration.*

Frustration appeared in the discourse of participants in seven studies (1, 4, 5, 6, 8, 12, 15). Despite recognising the importance of a collaborative therapeutic relationship, much of this frustration seemed to be about the tension commonly described between healthcare professionals and individuals with CFS/ME (15). In contrast, some participants described a professional frustration at the misunderstanding towards CFS/ME from society, workplaces, and institutions, which was empathetically aligned with the patient group (8).

1.3.2.3 Theme: Stereotyping the CFS/ME patient.

Another key theme revealed was the stereotyping of patients with CFS/ME.

1.3.2.3.1 *Subtheme: Seeing the patient as difficult and demanding.*

Patients were characterised as being demanding, difficult, resistant, and treatment-seeking by participants in five studies (1, 9, 10, 12, 13). It is interesting that patients were seen as being both resistant and treatment-seeking at the same time, with one participant referring to this patient group as "lost puppies" (12). One participant saw patients with CFS/ME as needing to push for their diagnosis and treatment, and pointed out that this was less likely to happen with patients from a black and minority ethnic (BME) community (3). In contrast to the negative connotations of being demanding and treatment-seeking, some participants saw the potential for patients to be well researched and able to present the GP with useful information (8).

1.3.2.3.2 *Subtheme: Questioning the morality / truthfulness of the patient.*

Negative references to the honesty of patients were made in nine studies. Participants described doubt towards the trustworthiness of patients' illness accounts (1, 2, 4). Patients were perceived as being poor copers (9, 14, 15) who exaggerate or unnecessarily pathologize normal symptoms (1, 7, 14, 15). Participants distinguished between genuine and dubious cases (5, 9, 10). One participant described genuine cases as the more textbook post-viral cases (9), whereas others saw the genuine cases as those with a more unusual set of symptoms, interpreted as not being paraphrased from the CFS/ME diagnostic criteria (10).

Some participants saw patients as failing to make every effort to get better (14); implying patients may be partly to blame for their illness. Similarly, patients were also referred to as lazy and transgressing the work ethic (7, 14). One study reported this derogatory portrayal of CFS/ME occurring through the training they had received (5). There were some references to CFS/ME cases being undesirable and a low priority (1, 7, 15).

1.3.2.4 Theme: Tension in clinician-patient communication and relationships.

The final theme emerging across studies was a tension in the clinician-patient relationship, particularly in terms of differences in how CFS/ME is understood.

1.3.2.4.1 *Subtheme: Conflict between clinician and patient understandings of CFS/ME.*

Participants from 13 studies referred to tension between professionals and patient, relating to conflicting views on the causes and management of CFS/ME (4, 12, 14, 15). Participants were aware of a disparity between patients and healthcare professionals, with patients tending to perceive symptoms as physical or neurological and professionals tending to view them as psychological manifestations (2, 3, 7, 9). One participant interpreted the biomedical focus of patients as a way of them seeking acceptability and avoiding the responsibility of facing their psychological issues (10).

Other participants believed a wider range of biopsychosocial factors were involved in symptoms of CFS/ME (2, 5, 8, 11). Some participants questioned whether CFS/ME was relevant to their role as a physical health professional, either because CFS/ME was not seen as a physical health problem (1, 5, 12), or because CFS/ME was viewed as too complex (15).

1.3.2.4.2 *Subtheme: Framing using biomedical language.*

Seven studies referred to framing using biomedical language. There was a sense of caution and perceived resistance expressed amongst participants when it came to introducing the topic of psychosocial factors with patients (1, 14). The stereotyped resistance discussed earlier may link more specifically to reluctance towards psychological intervention. A number of participants reported using biomedical discourse to engage patients in these discussions (2, 4). In contrast, others felt there was a danger in medicalising CFS/ME as this suggests it may be curable by the medical model (6, 15). In turn, this may reduce the patients' active role in managing their CFS/ME, which could lead to disappointment and poorer prognosis (8).

1.3.2.4.3 *Subtheme: Being "seen" to do something.*

Participants felt it was important to examine and rule out biomedical factors first, as discussed in five studies (1, 2, 4, 6, 9). Healthcare professionals expressed a need to be seen to do something, even if they did not expect to find anything (1, 2, 4). Participants also felt an initial biomedical focus communicated that they were taking the patient seriously (6, 9). Whilst CFS/ME is a diagnosis of exclusion and so ruling out biomedical factors is important, there was also some implication that these tests were partly conducted as a consequence of the tension between patients' and professionals' differing understandings of CFS/ME.

1.4 Discussion

This systematic review used thematic synthesis to explore the experiences of healthcare professionals working with people with CFS/ME. There was significant overlap across studies, seen in the resulting themes. The most prevalent theme was the conflict between clinician and patient understandings of CFS/ME, discussed in 13 out of 15 studies. Much of this tension relates to differences in beliefs about CSF/ME, with healthcare professionals tending to place less emphasis on the biological factors associated with CFS/ME. For some healthcare professionals, symptoms were viewed as psychological manifestations, which may reflect scepticism and a poor understanding of CFS/ME; two issues which presented as other prevalent themes.

A less prevalent, but important theme, was a transition towards becoming more accepting of CFS/ME. This theme showed a powerful link between belief in CFS/ME as a legitimate illness and the development of a more understanding, empathetic attitude. Part of the scepticism towards CFS/ME relates to absence of biomedical markers which can be seen as a shortcoming of the biomedical model. This highlights the need for a better framework for understanding CFS/ME, which validates CFS/ME as a legitimate condition.

Several other studies also shared a more accepting stance towards CFS/ME. For example, participants in some studies described their experience as rewarding and expressed hopefulness (Horton et al., 2010; Peters et al., 2011; Raine et al., 2004), diagnosis was seen as validating and empowering (Horton et al., 2010; Hannon et al., 2012; Woodward et al., 1995), and empathetic frustration was conveyed towards some of the challenges experienced by individuals with CFS/ME (Horton et al., 2010). The greater level of understanding may be partly linked to the inclusion of some healthcare professionals from specialist CFS/ME services within the samples from two of these studies (Horton et al., 2010; Hannon et al., 2012).

1.4.1 Critical Review

1.4.1.1 Methodological quality of the review.

1.4.1.1.1 *Strengths*.

This is the first review to focus specifically on the attitudes and experiences towards CFS/ME held by healthcare professionals. It is hoped that focusing in greater depth on the perspectives held by professionals will help these attitudes be better understood, in order to help address issues such as tension in the clinician-patient relationship. It is important to understand such barriers to treatment so that these barriers can be overcome, enabling more people with CFS/ME to access treatment. A systematic model of synthesis was used (Thematic Synthesis, Thomas & Harden, 2008), improving the replicability of future syntheses. Guidelines for appraising qualitative research were applied, adding to the strength of this review.

1.4.1.1.2 *Limitations.*

It is possible that the search strategy may not have revealed all qualitative literature relevant to the review question. The search was limited to peer-reviewed, published studies so any grey literature was not included. Variations across the research design, participants, case definition, and quality may have influenced the findings of primary studies and, in turn, this synthesis. The thematic synthesis was carried out by one coder, which means there is a potential for researcher bias.

1.4.1.2 Methodological quality of the included studies.

1.4.1.2.1 *Strengths.*

All studies used a clear research question and justified their use of qualitative methods. The majority of studies clearly described their methodology, including employing multiple researchers to improve the quality of the analysis, and clearly discussing their implications, strengths, and weaknesses (3, 4, 5, 6, 7, 8, 12). Nearly all studies included detailed findings sections, including excerpts to evidence their interpretations. Other studies made some attempts to improve the quality of their research by externally auditing their thematic interpretations (11) and by using two researchers in the analysis (14).

1.4.1.2.2 *Limitations.*

The methodological robustness of the qualitative studies varied. Most studies used purposive sampling (3, 4, 5, 6, 7). There may be some bias as a result of differences between participants who agreed to participate and those who chose not to, particularly for studies reporting low response rates, such as; 29 out of 70 nurses (11) and 22 out of 46 GPs (14). Chew-Graham et al. (2009) reported that some professionals were reluctant to participate as they felt they had nothing to offer. Some participants were recruited via previous studies (1, 4, 5, 6). For example, one interviewer had previous knowledge of the patients’ views of particular professionals, which may have biased findings (1). Some studies did not clearly state how participants were recruited (7, 10, 11, 13).

Some of the sample sizes were small; Horton et al. (2010) included six professionals, and Peters et al. (2011) included three nurses and two supervisors. To counteract their small sample, Peters et al. (2011) only included themes which were corroborated by their substantial patient data set; this is not ideal given the disparity evident between patients with CFS/ME and professionals. Nurse participants were interviewed by Peters et al. (2011) at two time points across a two and a half year period. It would have been interesting to compare and contrast the nurses’ experiences across these time points. Woodward et al. (1995) chose to give participants interview questions beforehand; this may have biased the responses of some participants.

A small number of studies stated the method of analysis used but would have benefited from describing their procedures in further depth (7, 9, 10, 14). Moore (2000) reported using “thematic interpretations” but the analysis lacked depth. No specific analytic procedure was identified by Prins et al. (2000) or Woodward et al. (1995). Following on from the poorly described data analysis, Moore (2000), Prins et al. (2000), and Woodward et al. (1995) reported their findings in terms of the quantitative occurrences of participants’ responses, for example, by stating what percentage of participants were in agreement with a particular belief. Raine et al. (2004) did not use any interview extracts in their findings section, instead focusing mainly on their questionnaire data.

1.4.2 Implications

1.4.2.1 Clinical.

A clear implication in response to the limited knowledge and understanding found across all studies is the need for clinical training to reflect the complex and variable nature of CFS/ME.; an important recommendation discussed in many of the papers. Indeed Chew-Graham et al. (2009) warn of the danger of having insufficiently brief training.

Secondly, there may be a need in some areas to increase awareness of local, specialist CFS/ME services. One study reported an individual opinion that specialist CFS/ME services were a waste; such misconceptions are a barrier to patients accessing services. Healthcare professionals may benefit from information on the evidence-based treatment approaches to CFS/ME to promote hopefulness that CFS/ME is treatable.

1.4.2.2 Research.

Some of the key themes discussed in this review go beyond the limitations of the training and experience of the professionals participating and reflect some broader issues in the field of CFS/ME. Research needs to focus on developing an improved understanding of CFS/ME.

Several barriers to accessing and delivering treatment for CFS/ME have been identified. The most prevalent theme found in this review reflects an important barrier; the tension arising from differences in the understandings of CFS/ME held by healthcare professionals and people with CFS/ME. There is a need to better understand this tension, with the aim of identifying ways to overcome this barrier. This review found disparity in the experiences and attitudes of different healthcare professionals, perhaps relating in part to individual levels of expertise in the field of CFS/ME. The current literature has primarily focused on the experiences of GPs, with a small number of studies including a wider range of healthcare professionals. No published research has focused solely on the attitudes and experiences of healthcare professionals who are specialists in working with people with CFS/ME. An in-depth awareness of the experiences of CFS/ME experts would contribute to understanding and overcoming barriers, such as tension in clinician-patient communication.

Chapter 2: Empirical paper

A Qualitative Study Investigating the Experiences of Healthcare Professionals Working with CFS/ME

2.1 Introduction

2.1.1 The Impact of CFS/ME on Individuals

CFS/ME can have a significant impact on all life domains. Impairments to memory, cognition, and stamina have a negative impact on ability to work and activities of daily living, leading to loss of employment for many people with CFS/ME (Anderson et al., 2012; Ware, 1998; Soderlund, Skoge, & Malterud, 2000). There can also be a significant impact on relationships (Schweitzer, Kelly, Foran, Terry, & Whiting, 1995; Tuck & Wallace, 2000; Woodward, Broom, & Legge, 1995). Overall, CFS/ME leads to a reduced quality of life (Comiskey & Larkan, 2010).

2.1.2 Access to CFS/ME Treatment

A number of specialist CFS/ME services have been set up across the UK following a report from the CFS/ME Working Group (Hutchinson, 2002). These multi-disciplinary teams cover two-thirds of the population of England (NHS Improvement Network, 2013). NICE guidelines (2007) recommend CBT and GET as effective treatments for CFS/ME. The PACE RCT found CBT and GET alongside SMC to be more effective in improving fatigue and physical function than pacing or SMC alone (White et al., 2011). One-fifth of people in the CBT and GET groups met criteria for full clinical recovery at one-year follow-up (White, Goldsmith, Johnson, Chalder, & Sharpe, 2013).

There can be some reluctance from people with CFS/ME towards referral to specialist CFS/ME services, particularly when this is seen as a psychological referral

(Horton-Salway, 2002). Some doctors have also shared an unwillingness to refer people with CFS/ME to specialist services because of unfamiliarity with treatment approaches, or a belief that they are unnecessary (Raine et al., 2004).

2.1.3 Differences in Models of Understanding CFS/ME

A review of the CFS/ME literature revealed some differences about how CFS/ME is understood by healthcare professionals and patients (Åsbring & Närvänen, 2003; Banks & Prior, 2001; Bayliss et al., 2013; Chew-Graham et al., 2008; Chew-Graham et al., 2009; Hannon et al., 2012; Horton-Salway, 2002; Horton-Salway, 2007; Horton et al., 2010; Moore, 2000; Peters et al., 2011; Raine et al., 2004; Woodward et al., 1995). Patients are more likely to perceive symptoms as physical, whilst healthcare professionals are more likely to view them as psychological manifestations (Banks & Prior, 2001; Bayliss et al., 2013; Hannon et al., 2012; Horton-Salway, 2002). Larun and Malterud (2007) suggest this difference is because people with CFS/ME base their understanding on their personal experiences of symptoms, whereas doctors' beliefs are shaped by the absence of a biomedical marker.

Differences in how CFS/ME is understood can lead to tension in the clinician-patient relationship. In turn, this can have a negative impact on the individual's sense of identity and coping strategies (Larun & Malterud, 2007). Evidence reports people with CFS/ME can feel their symptoms are discredited, which can lead to avoidance and disengagement from health services (Åsbring, 2001; Åsbring & Närvänen, 2002; Åsbring & Närvänen, 2004; Taylor, 2005; Ware, 1992).

2.1.4 Study Rationale

The experiences of people living with CFS/ME have been well documented in the current literature; a systematic review by Drachler et al. (2009) found 32 studies using quantitative or qualitative methods to explore the expressed needs of this client group.

People with CFS/ME identified a need for respect and empathy from healthcare services (Drachler et al., 2009). A meta-synthesis by Anderson et al. (2012) found 34 qualitative studies including both patients and healthcare professionals as participants. However, as discussed in the previous literature review, most of the studies including healthcare professionals have focused on the experiences of GPs, with very few studies including other healthcare professionals. Nearly all studies included in the previous literature review focused on the experiences of healthcare professionals within primary care, before the point of access for specialist CFS/ME services.

One published study aimed to explore healthcare professionals' ideas of best practice in CFS/ME by selecting six participants who were nominated as being helpful and effective practitioners by people with CFS/ME (Horton et al., 2010). The sample included three specialist and three non-specialist healthcare professionals, thereby representing different viewpoints informed by varying levels of knowledge and experience with CFS/ME. This excerpt from a healthcare professional working in specialist services suggests that experiences before the point of access to specialist services only tell part of the story; "I think most people by the time they've got to us they've been round the houses so many times or they've seen other consultants or they've been to the GP backwards and forwards" (Horton et al., 2010, pg. 5).

Horton et al. (2010) identified a need for improving the skills and knowledge of healthcare professionals and suggested this should be informed by the experiences of those working in specialist CFS/ME services, as well as by the experiences of people with CFS/ME. Whilst the experiences of people with CFS/ME have been explored in detail, no study has focused solely on the attitudes and experiences of healthcare professionals who are specialists in working with people with CFS/ME. A qualitative approach is best suited for an exploratory study investigating the experiences of specialist CFS/ME professionals.

2.1.5 Research Aims

This study aims to explore and describe the experiences of healthcare professionals working in specialist CFS/ME services within the UK National Health Service. Developing an in-depth understanding of the experiences of CFS/ME specialists will contribute to a better understanding of some of the barriers to accessing treatment, including the tension arising from differences in how CFS/ME is understood by healthcare professionals and people with CFS/ME. Ultimately, this knowledge may help overcome barriers to accessing treatment and improve the quality of services provided to people with CFS/ME.

2.2 Method

2.2.1 Methodological Approach

The aims of this research required a methodology that can explore the experiences of healthcare professionals in sufficient detail and depth to capture the complexity of CFS/ME. However, as direct access to other people's 'pure experience' is not possible, Interpretative Phenomenological Analysis (IPA; Smith, Flowers, & Larkin, 2009) was selected as such a method. IPA aims to access the experience of another person by exploring both the meaning that the individual has applied to their experience, and how they have made sense of their experience. The researcher becomes engaged in a 'double hermeneutic' as they attempt to make sense of the participant trying to make sense of their own experience (Smith et al., 2009). IPA's focus on the meaning-making of individuals allows a depth to data analysis, producing a richness of experience that may be lost by approaches focusing on general themes (Smith et al., 2009).

IPA has an idiographic approach, treating each participant's story as an individual case study in the initial stages of data analysis, before similarities and differences are explored across cases (Smith et al., 2009). IPA aims for smaller samples, with participants selected as experts in their area of experience, allowing the focus to remain on depth (Smith & Osborn, 2008). Therefore, the use of IPA methodology is particularly well suited to this study, which is interested in understanding the experiences of CFS/ME specialists.

IPA requires researchers to adopt a phenomenological attitude, which recognises that it is not possible to entirely bracket or separate our own personal biases and interpretations; rather we can reflect on these and strive to hold them at bay in order to adopt an open, non-judgemental approach (Larkin, Watts, & Clifton, 2006). An open, phenomenological attitude allows the focus to remain on the participant's experience. IPA adopts an inductive approach, allowing themes to emerge from the data, rather than the analysis being led by prior theories or knowledge.

2.2.2 Participant Recruitment

All healthcare professionals working for a specialist CFS/ME service were invited to participate in the study via an email from the clinical lead. For inclusion in the study, participants were required to be employees of the North Bristol NHS Trust working for the specialist CFS/ME service. There were no restrictions on profession or extent of experience with the CFS/ME clinical population. Healthcare professionals who were interested in participating were invited to contact the author by email. Participants were emailed a participant information sheet detailing the study (see Appendix D). Ten healthcare professionals volunteered to participate in the study; one clinician was excluded because she was not employed by the trust and one interview was cancelled as the clinician could not attend. Eight participants were interviewed and included in the final analysis. For professional doctorates using IPA, a sample size between four and ten is recommended (Smith et al., 2009). All participants signed a consent form (see Appendix E) to confirm that their participation was voluntary, agreeing to the recording of the interview and the use of anonymised verbatim quotes.

2.2.3 Participant information

Pseudonyms have been used throughout this paper, including in excerpts, and all identifying information has been removed to protect the anonymity of the participants. Of the eight participants, seven were female and one was male. Three were occupational therapists, two were clinical psychologists, two were specialist physiotherapists, and one was a clinical health psychologist. Participants had been qualified for a mean of 17 years (range 5 to 26 years), and had worked with people with CFS/ME for a mean of 7 years (range 2.5 to 10 years). No participants had a personal diagnosis of CFS/ME, although one participant reported personal experience of some CFS/ME symptoms. Four participants had family members or friends who had a diagnosis of CFS/ME.

2.2.4 Procedure

Face-to-face, semi-structured interviews were conducted by the author. A semi-structured interview with six to ten open questions is recommended in IPA research (Smith et al., 2009). A brief demographics questionnaire was given to participants prior to the interview (see Appendix F). Participants were briefed to confirm consent and were reminded that they could stop the interview at any time. The interview schedule comprised of eight main questions, focusing on personal experiences of working with adults with CFS/ME and how they have made sense of these experiences (see Appendix G). These questions were revised and developed through supervision and feedback from two pilot interviews. Prompts and probing questions were asked, when appropriate, to encourage participants to elaborate on answers. Participants were offered a summary of the findings on completion of the study, which all participants requested (see Appendix H). Interviews were held at the participants' places of work and were digitally recorded. Duration of interviews ranged from 51 minutes to 72 minutes, with a mean time of 63 minutes. Interviews were sent to an external transcription service to be transcribed verbatim.

2.2.5 Ethical considerations

Ethical approval for this research project was granted by University of Southampton Psychology Ethics Committee, and by North Bristol NHS Trust Research Governance (see Appendices I & J).

2.2.5 Data analysis

Analysis followed the guidelines for conducting IPA research by Smith et al. (2009). The researcher first read through each interview transcript whilst listening to the audio recording, checking the accuracy of the transcription and adding italics to words that participants placed vocal emphasis on. Transcripts were re-read several times, allowing the researcher to become immersed in the data. The second stage of data analysis involved looking at the transcript in more depth through detailed note-making. Exploratory coding was made in three areas: *descriptive comments* focused on describing content*; linguistic comments* considered the use of words and language, and *conceptual comments* were more interpretative and questioned the underlying meaning of participants' accounts. Emergent themes were developed by re-reading exploratory comments with the aim of capturing the meanings of participants' experiences. This systematic approach to IPA data analysis ensured that new themes were given the opportunity to emerge from each case (Smith et al., 2009).

Emergent themes were listed and grouped into clusters according to similarities, on a case-by-case basis. A mind-map was then used to visually explore connections between themes at group level. This gave rise to a number of superordinate themes and subthemes. Superordinate themes and subthemes were organised into a master table, which included excerpts supporting each theme. The final organisation and naming of themes developed through the process of review and quality assurance procedures.

2.2.7 Validity and Quality

Yardley (2000) has proposed a set of guidelines for assessing the validity of qualitative research, based on four broad principles. The first principle is *sensitivity to context*, which has been demonstrated through: an awareness of existing knowledge and literature in the area of CFS/ME, reflection of the socio-cultural circumstances of participants, and consideration of the interactional relationship between researcher and participant. *Commitment and rigour* have been evidenced by the systematic, detailed attention given to the research topic and data throughout data analysis. Thirdly, *transparency and coherence* have been sought in the clear write-up of the method and findings sections of this paper. Additionally, an example section from one interview has been included in Appendix K to aid transparency of the data analysis process. The fourth principle is *impact and importance*; as the first study to explore the experiences of specialist healthcare professionals working in CFS/ME, it is hoped the findings will impact on understanding and help overcome barriers to treatment access and quality.

Specific steps have been taken to improve the quality of this research. Two pilot interviews were conducted to develop the interview schedule and the researcher’s interview skills. One pilot interview was analysed as a learning exercise for the researcher.

The first annotated interview script was examined by the research supervisor and discussed in supervision, to check the validity of the researcher's exploratory coding.

The researcher presented the research to the South West Regional IPA Group and led a group exercise to promote validity of the research findings. A set of quotes were presented for each theme and group members were invited to suggest suitable theme titles and feedback whether they felt each set of quotes belonged together as one theme. The group discussion supported some themes, but also led to the revision of other themes (see Appendix L).

The table of themes, including example excerpts, was reviewed by the research supervisor and discussed in supervision (see Appendix M). An independent audit was conducted by a trainee clinical psychologist with experience in using IPA, which Smith et al. (2009) describe as a useful tool to improve the validity of one's research. A paper trail consisting of an interview schedule, one annotated transcript, a table of emergent themes, a master table of themes, along with a draft report of the research findings, was given to the auditor, who was asked to check that there was a clear and logical path from the initial interview data to the final results. Overall, comments were in general agreement of themes (see Appendix N). This demonstrates use of researcher triangulation to facilitate validation of the research findings.

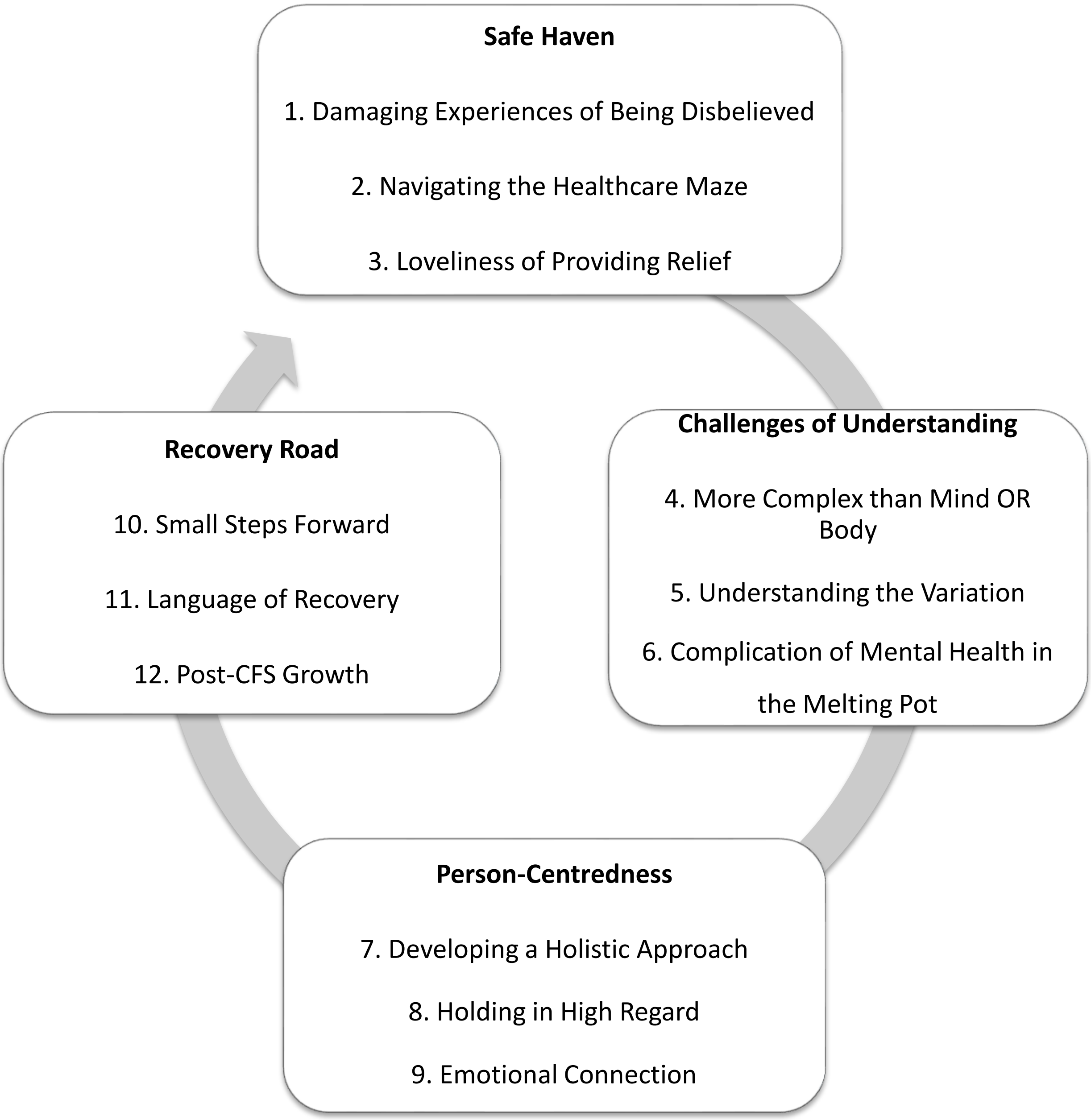
Smith et al. (2009) suggest that assessing the recurrence of themes is important for larger IPA studies that include more than six participants, as this enhances the validity of findings. Recurrence was measured in this study, with all themes prevalent for at least half of the participant group. Each theme presented in the findings includes relevant excerpts to promote further validity (Hefferon & Ollis, 2006).

Reflexivity is an important practice in qualitative research, enabling the researcher to consider their own role in the research process (Elliott, Fischer, & Rennie, 1999; Yardley, 2000). From the outset, this included a consideration of the reasons for choosing this topic and exploring personal thoughts and emotions about the subject of CFS/ME. A reflective journal was used to record reflections throughout the research project (see Appendix O).

2.3 Findings

Through interpretative phenomenological analysis of the interview data, four super-ordinate themes and 12 subthemes emerged, representing the experiences of healthcare professionals working in specialist CFS/ME services. Themes are presented in figure two below. The recurrence of themes is presented in table two.

3.1 Figure Three: Representation of Superordinate and Subthemes



2.3.2 Table Two: Table to Present Recurrence of Themes

Superordinate Themes and Subthemes	Prevalence	Participants Supporting Theme
Safe Haven		
1. Damaging Experiences of Being Disbelieved	8/8	Anna, Becky, Claire, Debbie, Elaine, Francis, Gemma, Hannah
2. Navigating the Healthcare Maze	5/8	Anna, Becky, Claire, Debbie Francis
3. Loveliness of Providing Relief	7/8	Anna, Becky, Claire, Debbie, Elaine, Francis, Hannah
Challenges of Understanding		
4.More Complex than Mind OR Body	8/8	Anna, Becky, Claire, Debbie, Elaine, Francis, Gemma, Hannah
5. Understanding the Variation	7/8	Anna, Becky, Claire, Elaine, Francis, Gemma, Hannah
6. Complication of Mental Health in the Melting Pot	7/8	Anna, Becky, Claire, Debbie, Elaine, Francis, Hannah
Person-Centredness		
7. Developing a Holistic Approach	6/8	Anna, Becky, Claire, Elaine, Francis, Gemma
8. Holding in High Regard	7/8	Anna, Becky, Claire, Debbie, Francis, Gemma, Hannah
9. Emotional Connection	8/8	Anna, Becky, Claire, Debbie, Elaine, Francis, Gemma, Hannah
Recovery Road		
10. Small Steps Forward	8/8	Anna, Becky, Claire, Debbie, Elaine, Francis, Gemma, Hannah
11. Language of Recovery	8/8	Anna, Becky, Claire, Debbie, Elaine, Francis, Gemma, Hannah
12. Post-CFS Growth	4/8	Becky, Elaine, Francis, Hannah

2.3.3 Superordinate Theme: Safe Haven

Most participants talked about the negative experiences faced by some people with CFS/ME before they arrived at the specialist CFS/ME service. There was acknowledgement that some people with CFS/ME had felt disbelieved, judged, and had sometimes faced many obstacles before they were referred to the specialist service. These difficulties were a stark contrast to the overwhelming relief that some experienced once they had arrived. Many participants described their positive experiences of being able to provide a place of safety and understanding in response to the search for legitimacy and help. There was a sense of the CFS/ME service being a 'safe haven'; a place of safety after a difficult journey.

2.3.3.1 Subtheme 1: Damaging Experiences of Being Disbelieved.

Participants all had some experience of people with CFS/ME feeling disbelieved by others, including healthcare professionals, family members, friends, and in the workplace.

> **Debbie**: "I think there is a *big* element of feeling disbelieved by some people, erm … I think often they've come across friends, relatives, maybe even the medical profession, people who don't *seem* as if actually they - they think it is a valid condition and I think that must be very frustrating" (P3, 74 – 80).

Furthermore, there was a shared sense of the damaging impact this could have on individuals with CFS/ME.

> **Claire**: "people don't understand it very well, um, and there is something about CFS that people still think that they're making it up, you know, well …
>
> Interviewer: Mm.
>
> Claire: … that it's Yuppie flu or something similar to that and I think that really sets it apart and I just … I think attitudes of clinicians … and GPs are so

> fundamental in how it's managed and how the patient manages themselves and they get all the wrong messages from clinicians, so I think it's a condition that's *really* subject to at iatrogenesis really, the damage that can be done by medical professionals …" (P6, 290 – 303).

Claire refers to two factors that can be damaging here; the issue of disbelief towards CFS/ME and unhelpful self-management advice from medical professionals. She describes the misconceptions about CFS/ME as something made up as setting it apart from other conditions. This narrative indicates that it is the uncertainty surrounding CFS/ME and its legitimacy that make this condition more subject to iatrogenesis than other conditions. The same concept is presented by Anna, who describes the search for legitimacy as an obstacle to recovery.

> **Anna**: "They're *judged* as a person. They're *judged* how they live with. They're *judged* how they don't work. It goes on and on endlessly, so I think this constant *search* for legitimacy … until you have that actually recovering is nigh on impossible ..." (P27, 1354 – 1357).

The following excerpt illustrates how the difficulties in clinician-patient relationships before people access the specialist CFS/ME service can be another damaging factor.

> **Anna**: "… the relationships have been so damaged … so I think, um, it … there is a real sense in *some* discussions in *some* situations of an us and them …" (P15, 725 – 726).

Anna refers to an "us and them", indicating that there is sometimes a separation between healthcare professionals and people with CFS/ME. She talks about this challenge to the therapeutic relationship in the context of the negative experiences with healthcare professionals that people may come to the service with.

2.3.3.2 Subtheme 2: Navigating the Healthcare Maze.

Several participants talked about the pathway for people with CFS/ME to access the specialist service, which was described as a long and complex process. There was a strong sense of uncertainty, as illustrated by the following excerpts:

> **Claire**: “They’re just pushed from pillar to post …” (P7, 335 – 336).
>
> **Becky**: “it’s still another appointment with …
>
> Interviewer: Mm.
>
> Becky: … no answers, with nobody who’s actually been able to kind of signpost them somewhere, or give them some good advice, so they’ve … they’ve been through a lot of hoops …” (P11, 548 – 553).

The phrases “pillar to post”, and “*ping* ponging around” by Anna (P9, 421), give an impression of repeated rejections and a sense of no-one knowing where to find an answer to help. This uncertainty was described as frustrating.

> **Anna**: “I think by the time you’ve managed to navigate through Primary Care to a Specialist Service you are probably even more fatigued than you were at the beginning and I, yeah, so I think it sucks” (P26, 1297 – 1299).
>
> **Debbie**: “they’ve always kind of found a way in, but sometimes it has been quite a long journey for people to do that and I think that is frustrating for them” (P3, 84 – 86).

In contrast to the idea of a long, frustrating journey, there was some indication that when the referral pathway is smoother, then the experience for participants and patients was improved.

> **Francis:** "we're often seeing people in the CFS/ME Service really in the early days, you know four months, five months, six months in to the condition and that's much nicer, because you can help people quicker" (P6, 180 – 182).

2.3.3.3 Subtheme 3: Loveliness of Providing Relief.

Participants described a sense of joy and satisfaction in being able to offer a supportive, understanding attitude to people with CFS/ME entering the service. The relief for the person with CFS/ME was described as powerful, which can be understood in the context of the disbelief and uncertainty faced before accessing the specialist service.

This first excerpt from Anna portrays the powerful impact of the relief for the person with CFS/ME, causing them to burst into tears:

> **Anna**: "… and so I said to her this *isn't* all in your mind. You're *not* going mad, um, you have a condition. She just burst into tears with relief" (P5, 220 – 221).

Anna makes sense of this relief in relation to how people with CFS/ME have often been treated with a misconception that CFS/ME is made up or in their mind. Below, Francis echoes this idea that the relief relates in part to validating the condition as legitimate.

> **Francis**: "I think the best bits … if somebody is not knowing what it is going on, it is a really worrying condition sometimes, people have palpitations, they might think they have got a heart condition, they might think they have got dementia, they might think they have got cancer.
>
> Interviewer: Mm.
>
> Francis: And the relief that you can bring for some people *just* by helping them reach the same consensus about the diagnosis is really important and if they know what kind of problem they are dealing with, erm again shifting away from

> this idea it is in people's heads or that they are lazy or are not pushing hard enough takes the pressure off people and then sometimes people are just in a much better situation to manage and move forwards, so that is a really nice thing when that happens" (P21, 692 – 702).

Francis describes this process of delivering understanding, resulting in relief, as one of the best aspects of the work. Many participants in the current study expressed some pleasure in offering validation, which seemed to be a rewarding experience.

> **Hannah**: "Um, I think there's a *loveliness* of… of somebody coming in the room and you *knowing*, and them having… this is their first positive experience – you understanding. And you're saying, 'Yep, yep, yeah, that's normal, yeah' – and it's a… there's a sort of relief on their faces…" (P2, 97 – 100).

In this excerpt, Hannah relates the "loveliness" of providing relief as being the first positive experience of the person with CFS/ME feeling understood, hinting at the many negative experiences of not being understood that may have come before. This resonates with the narratives from Anna and Francis, but Hannah develops this concept further:

> **Hannah**: "So, I think one of the big things is… is that… [pause] making them feel at home. I can't think of another way, but it's, you know, 'No, this is okay. This… we know this stuff.' You… you know, it's giving them a sense of… belonging isn't the right word, but a sense of … *knowing* – truly knowing that this… this is it – this is what it is and people know about it. I'm not alone. Umm it legitimises it." (P2, 119 – 124).

Here Hannah is searching for the right word to make sense of her experience, moving between "home", "belonging", and "knowing". For the researcher, these words conjured a sense of safety. Hannah has placed herself in the shoes of the person with

CFS/ME with her words “I’m not alone”. If the sense of relief is understood in the context of the prior struggle with searching for legitimacy, then the specialist CFS/ME service may be seen as a place of safety or refuge, where this struggle for legitimacy ends, opening up the prospect of recovery. This reflects Anna’s excerpt from earlier: “I think this constant *search* for legitimacy … until you have that actually recovering is nigh on impossible ...” (P27, 1356 – 1357). The same idea can also be seen in Francis’ narrative, which suggests that once the person feels understood, this puts them in a much better place to move forwards.

2.3.4 Superordinate Theme: Challenges of Understanding

There are three subthemes here, which may all be seen as factors contributing to the difficulty in making sense of CFS/ME. Firstly, the dualist framework which differentiates physical problems from mental and emotional problems presents a challenge to understanding CFS/ME. Secondly, CFS/ME is a heterogeneous condition, making it more complex and challenging to understand. Thirdly, CFS/ME often presents alongside symptoms of depression, anxiety, or other mental health problems, further complicating matters.

2.3.4.1 Subtheme 4: More Complex than Mind OR Body.

Participants made sense of CFS/ME by understanding the need to look beyond a framework that distinguishes between mind and body. This issue was seen as an obstacle to treatment, as described by Francis here:

> **Francis**: “I think the other big obstacle is erm a sort of dualist approach to health problems as well and that is still very, very common, erm that there is this common recognition that health problems are either real and physical, or *all* in the mind and that’s just not how life is, that is not how people are, that’s not

> how systems work, we are all a lot more complicated than that, but patients come in with that model, we are trained in the medical profession with that model of dualism and I think if you tackle a complex problem like Chronic Fatigue Syndrome/ME with a dualist model, you'll end up trying to sort it in to one of two unhelpful boxes, it is either *all* in the mind and we have met patients where certainly they have had that message quite clearly or it is in my body and something needs to be fixed ….." (P13, 427 – 436).

Participants used the central sensitisation model (Clauw, 2010), to make sense of CFS/ME. Many participants, including Anna below, switch to using the collective "we" pronoun, reflecting a shared understanding across the team. This model recognises the strong biological underpinnings of CFS/ME, which validates the experiences of people with CFS/ME, and rationalises the recommended CBT and GET treatment approaches.

> **Anna:** "The model we use here is, um, we use the Dan Clauw stuff really, so we talk to people about, um, being sort-of hyper aroused, that their systems have just gone out of kilter … and, you know, sort of neurologically, immunologically, you know, that all the systems are connected … and I also talk always about, um, understanding, having a very *English* sense of trying to divide the body from what goes on inside your head and your brain …
>
> Interviewer: Mm.
>
> Anna: … and that we know far far more about the huge interaction … so and … and people understand that, you know, people understand it." (P33, 1631 – 1641).

2.3.4.2 Subtheme 5: Understanding the Variation.

There was a shared expression of the heterogeneity across CFS/ME. This was conceptualised as contributing to the complexity of CFS/ME, making it more difficult for it to be understood. Two types of variation were described. Firstly, symptoms can fluctuate over the course of a day and over time on an individual basis, as described by Hannah here:

> **Hannah**: "Because of the variation in the symptoms. [Pause]. It's not just them not being understood. They don't understand it themselves, so then it's really difficult… When somebody points the finger, they feel they're probably right, so they take it on board. There's that element to it. But, because somebody can have a good day, where they could walk the dog for 20 minutes and *look absolutely* normal, they get home – nobody can see them when they get home – and they're laid up for the rest of the day, because their most important thing is to get their dog out, going for a walk. It *doesn't*… it's not linear ... It's so varied and people don't see the whole picture" (P6, 302 – 311).

Secondly, much variation exists across the wider group of people with CFS/ME. Participants shared ideas about whether CFS/ME is a broad term which may actually encompass several sub-groups.

> **Gemma**: "We just don't understand yet. I don't know really, I think it's – I think it's probably because it's an umbrella term in some ways, and it's a *syndrome* rather than a distinct condition." (P 18, 905 – 907)
>
> **Francis: "**So there are probably … sub-groups or maybe it's a spectrum, maybe that's the best way to think about it." (P19, 643 – 644)

Participants were experiential experts here in the sense that they have more direct experience of seeing the heterogeneity of CFS/ME presentations, compared to non-specialist healthcare professionals.

> **Becky**: "… cos I do believe unless you see people a *lot* with CFS/ME and see the variants and see that it's not a formula to get people better, it is as … as I think you've picked … I said an art you've picked up on, I think it is more complicated, er, actually, um, you know, I think it's an investment as a therapist" (P43, 2142 – 2145).

Becky refers to the process of delivering treatment as an art form, meaning there is a flexibility required based on the individual's presentation. She describes this as an "investment", implying that it takes time, commitment, and experience to develop the necessary therapeutic approach.

2.3.4.3 Subtheme 6: Complication of Mental Health in the Melting Pot.

The relationship between mental health problems, such as anxiety and depression, and CFS/ME surfaced in most accounts. There was a shared understanding amongst many participants that depression was often a consequence of CFS/ME:

> **Debbie**: "I mean you-you often get the oh well they just told me I was depressed story, erm and I can *see* how that happens, you know we often end up having a chat about that. There is a lot of *overlap* and-and obviously we see people who have Chronic Fatigue and *because* of that, have become depressed, and I think it tends to be that way around, rather than the other way round" (P3, 91 – 95).

There was an acknowledgement that CFS/ME can sometimes be dismissed or misinterpreted as depression, relating to issues of disbelief and legitimacy that have previously been discussed. Debbie refers to "the oh well they just told me I was depressed story", which gives an impression that this is a common narrative that resonates with many different people with CFS/ME. Francis suggests that this is partly a consequence of depression being a more common illness, which is therefore more likely to present in primary care:

> **Francis**: "I think patients are sometimes more advanced than the GPs and GPs hold their hands up and say they don't know enough about this condition. I suspect one of the problems is that an average GP will see a lot more depression than Chronic Fatigue, so in terms of common things being common, a GP will *suspect* depression before they suspect Chronic Fatigue Syndrome, particularly for those people that don't have a clear cut absolute post-infective pattern …" (P12, 380 – 386).

The experience of other participants was that co-morbid mental health problems may exist, which can complicate an individual's presentation.

> **Anna:** "it's really important to *deal* … if somebody is also depressed, anxious, you know, has whatever and whatever going on, that they also get that as well …
>
> Interviewer: Mm.
>
> Anna: … yeah, I kind of know that we won't, you know, if the CFS is sorted it won't necessarily sort, you know, it depends what comes first and what's, you know, all of that stuff … but it's always kind of in my melting pot to be aware of" (P33, 1645 – 1653).

> **Hannah**: "Um, if there's any other mental health problems in the… in the melting-pot, that can make it very tricky. So, if people have got an element of anxiety, depression, OCD, something… they can *perpetuate* themselves – you know, each other" (P8, 365 – 367).

Both these examples using the metaphor of a melting pot, which suggests here that there may be several factors mixed together, which together, have an impact on the individual.

2.3.5 Superordinate Theme: Person Centredness

The following themes reflect the more general, person-centred approach and processes described across the course of treatment. Firstly, there was a shared experience of taking a holistic approach despite differences in professional backgrounds. Secondly, participants expressed a deep sense of respect and admiration for the people they worked with. Thirdly, an emotional connection was described by participants, both in terms of empathising with the patient, the emotional impact of their work, and the important support network they formed as a team.

2.3.5.1 Subtheme 7: Developing a Holistic Approach.

Participants were from a range of healthcare professions and as such had a dominant approach according to their specific training. There was a greater emphasis placed on physical activity by professionals trained in physiotherapy and occupational therapy, and a greater emphasis on cognitions, emotions, and behaviours by those trained in clinical or health psychology. All participants spoke about incorporating both behavioural elements, such as getting a baseline of activity and gradually building activity levels up, and psychological elements, such as targeting anxieties and unhelpful cognitions.

However, what came across more strongly than individual differences in approaches was a shared experience of a holistic approach. The integrated, flexible approach described fits well with the experiences of CFS/ME as complex; encompassing physical, emotional, and mental domains, as heterogeneous, and often co-occurring with depression and/or anxiety.

> **Gemma**: "I think as a condition it affects every element of someone's *life* and using all those different skills with a focus on what … people's individual *goals* is core to the treatment. So it felt like a really rich area of work , it didn't feel like [Pause] erm I suppose sometimes in more physical health… so called physical health settings, I don't like those distinctions, it's the emphasis is you know on doing things in particular areas and much faster, or missing out sections of the people's wider experience. And then in mental health it can get very… again very particular and maybe missing out some of the sort of *physical* elements. But I think maybe OTs and in mental health we don't, but, well some people do. So it was a real opportunity to do a bit of both" (P5, 209 – 219).

Gemma later goes on to describe the interdisciplinary nature of the work as providing "a… there's sort of *development* opportunities there as well for me." (P6, 256 – 257). This reflects a shared experience amongst participants that the holistic, integrated approach required of working with CFS/ME demanded new skills and approaches to be learnt and developed. In the excerpt below, Francis describes the role as satisfying in the context of it being more demanding:

> **Francis**: "We are the first port of call in the CFS/ME Service, so patients come in and they expect more from us, it is not *just* seeing a physiotherapist, we all of us become specialists, so we are our key worker if you like for all of our patients, each person that we assess, they are the people they are likely to come back to if there is any issues, so it is a much *broader* role which is nice, but erm within that we recognise that sometimes people need some specialist help, whether that is

> about a work issue or whether it is psychological issue that they are managing and then we will refer them off for support in that area, but most of the time it's the clinician who assesses, who becomes that person's kind of first port of call, first person to contact with questions and issues, which is *nice*, it is quite a satisfying role, *but* more demanding" (P6, 191 – 200).

2.3.5.2 Subtheme 8: Holding in High Regard.

There was a shared recognition of the demands of the treatment process for the recipient, describing therapy as asking a lot from people with CFS/ME.

> **Gemma**: "They're kind of understandably frustrated, but actually in *some* ways some people kind of go 'Well I just want to keep going with this', you think well that's quite amazing really because… they really are" (P20, 969 – 971).
>
> **Francis**: "I… I'm full of admiration" (P15, 506).
>
> **Claire: "**… I certainly find some of them really inspiring" (P3, 147)
>
> **Anna**: "They're very vulnerable. They're bringing possibly one of the most … difficult aspects of their lives to me and, um, I have ultimate respect for *that* relationship that … the *power* that gives me and the vulnerability that that brings them (P25, 1230 – 1234)".

These excerpts express some strong emotive responses from participants' experiences of working with this clinical group. Many healthcare professionals will have personal and professional values relating to the importance of respecting patients. This made it challenging to give this theme a name to accurately reflect the shared experience, which came across as a real and powerful appreciation for the people they work with.

2.3.5.3 Subtheme 9: Emotional Connection.

There was a shared experience of an emotional empathetic response towards people with CFS/ME. This excerpt continues from Anna's previous quote, where she talks about the vulnerability of people with CFS/ME during the therapeutic process.

> **Anna**: Um, oh I feel quite emotional [pause]. That's interesting. [Pause]. And I think when I get frustrated with the people who are so negative about services …
>
> Interviewer: Yeah.
>
> Anna: I think … I wish they knew this is how we feel [cries]." (P25, 1236 – 1242).

Anna became tearful in the context of talking about the vulnerability of people with CFS/ME and went on to say it was the struggle that people go through that touches her. Anna expressed a sense of injustice at the lack of compassion shown to people with disabilities. For Anna, there is a connection with her emotional response and the negativity towards services voiced by a minority. Anna expresses a frustration that healthcare professionals and services within this field can sometimes come under attack, when they are doing the best they can to help this group. The emotional reaction here, and from Hannah below, is evidence of the strong emotional connection and genuine care from participants towards the individuals they work with.

> **Hannah**: "… I think the best bits are about giving… giving somebody … comfort by just showing you understand. I'm getting all… all emotional now." (P6, 257 – 258).

Here, Hannah feels emotional in the context of the fear experienced by people with CFS/ME, and how the process of showing empathy and understanding can lead this to be replaced by relief and appreciation, as discussed in an earlier theme.

Whist there was some shared experience of the challenging aspects of working with CFS/ME, this experience varied across participants. Some participants described the challenging aspects as enabling the rewarding aspects:

> **Claire:** "the thing with Chronic Fatigue is that I think it can be *really* challenging and then it becomes so rewarding when you actually get people on board and they get better …" (P4, 173 – 175).

Others talked about how, on occasions, the work felt draining:

> **Elaine**: "I just can sometimes feel quite exhausted, especially if the you know the last few clients have been more difficult or struggling more to put in place the information and you don't, you feel like you are having the same conversations as you had on the last appointment and the appointment before and you wonder whether you are making headway … and it's knowing … how hard you can, not push those patients, but challenge them to their own thinking styles to say 'well we seem to have been here before and how do you think we could see things differently in order for us to progress', and it can be quite [sigh] yeah, it can be quite draining …" (P6, 184 – 191).

The deep sigh is an expression of Elaine feeling weary, as she contemplates the draining aspects of her work. The issues touched upon in this excerpt are characteristic of therapeutic work in most health and clinical areas. Elaine switches from talking in the first person, "I", to the second-person personal pronoun, "you". This slight detachment from her personal experience may reflect a coping mechanism of not taking the frustrating aspects of this work personally. Others acknowledged the demands of their work:

> **Francis:** "but there is that potential there to be really disappointed and it is kind of managing that really. Erm I guess in the early days, that was more of a risk, but that doesn't help me, it doesn't help them, it is just spotting it. You know, it is just that normal human reaction isn't it, somebody has had a major disappointment, a blow, it would be possible to tune in with how they are feeling, but then that is two people in the hole then. It's not helpful for them, but yeah it is there, there is some element of that feeling there as well." (P22, 728 – 734).

Francis is talking about disappointment in the context of setbacks. There is some element of experiencing disappointment, connected to the patient's disappointment. Francis uses an image of two people in the hole; this illustrates the importance of keeping some professional distance, in order to remain in a position to help the person out of the hole of disappointment. With this example of experiencing a setback, Francis talks about tuning in with the person's feelings; this gives a sense that they are in it together, instead of feeling frustration or blame towards the person because of the setback.

A second part of the emotional connection related to being part of the team.

> **Gemma**: "Having that support is really important, and not just formal supervision It's that being sort of connected. So I think we're… here, I think that we're very lucky that we are quite connected, we're quite an established team. A lot of us have been working in the field for a *long time*, I think that's really helpful, but also we're connected nationally" (P24, 1172 – 1177).

> **Becky**: "… and I think my experience of … of working with CFS/ME is it attracts people … therapists who are *good* and kind of, I don't know, maybe they're just a good compassionate bunch to each other as well as to patients. Maybe that's part of what you need to be, but we absolutely help each other out in a way I've *never seen* before …" (P44, 2204 – 2207).

The team's support was described as important and necessary in participants managing the emotional impact of their work. Many participants expressed value, warmth and positivity towards their team members. There was a strong sense of support and connection amongst the team.

2.3.6 Superordinate Theme: Recovery Road

The final group of themes relates to ideas and experiences about recovery. Participants described starting small and gradually on the path to recovery. Whilst there was a shared use of the word recovery, the meaning applied to this word varied across participants. A smaller group shared an experience of people they had worked with being transformed through the process of recovery, similar to the idea of post-traumatic growth.

2.3.6.1 Subtheme 10: Small Steps Forward.

There was a shared concept of starting off with small steps and building progress gradually. Small steps were described in the context of moving forwards in the right direction.

> **Elaine**: "but no matter how small the change, that's important, and as long as you are going in the right direction, that's progress" (P12, 392 – 394).

Elaine emphasised the importance of any change, no matter how small, as long as the person was progressing forwards. Below, Francis also refers to the importance of each little step by saying they are each worth celebrating:

> **Francis:** “Erm the milestones are good, they are worth celebrating, little steps, getting out the house, socialising, doing voluntary work, getting back to education, getting back to work, whatever it is, those milestones are really important for people and there is a number of those along the way” (P21, 706 – 709).

Francis places the importance of these milestones in their value to the person working towards them. Similarly, Debbie and Hannah below talk about how changes can enable people to live life again, whatever this may mean to the individual.

> **Debbie**: “I think this idea of little and often erm does make lots of sense and you do see people erm managing it much better, you know getting-getting … big elements of their life back” (P11, 354 – 355).
>
> **Hannah**: “[Pause]. I think it can be just the smallest of things that they take away, that all of a sudden switches the way they’re living their life“ (P8, 368 – 371).

Here, Debbie and Hannah speak about their experiences of the contrast between small steps resulting in big shifts, which felt almost paradoxical. Debbie talks about “little and often”, yet the result is “big”. Hannah describes the change resulting from a take away message as resulting in a “sudden switch”;’ this gives the impression of a significant, powerful transition.

Another contrast described was how some changes could be “*simple*”, yet it was rarely an easy path to get there. Below, Anna is celebrating in the context of a person she was working with who had made a positive change:

> **Anna:** “That makes me really really happy, let alone him bless him, you know, so it’s that … when you *see* … when you can *see* people making *real changes*, I mean what I love is that they’re *so simple*, you know, that in a way it’s not rocket science but … that to actually help someone do it I think there is quite a skill to it” (P11, 538 – 556).

2.3.6.2 Subtheme 11: Language of Recovery.

Participants shared a belief that people with CFS/ME could recover, but ideas about what recovery meant varied across participants. Participants generally used the word “recovery” rather than “management”, suggesting a hope that CFS/ME is a condition people can get better from.

> **Anna**: “Um [pause]. I like the word recovery. I have a very recovery approach. People need hope, um … and … one of my take home messages that people … is that people can improve and do improve and that, um, having a condition with the word *chronic* in … isn’t gonna make you smile … but doesn’t actually mean what you might assume … (P16, 762 – 769).

Here, Anna talks about a recovery approach in terms of making attainable “improvements”. Others also spoke about a recovery approach:

> **Becky**: “Although we look at a more recovery based model the majority of people we see will have elements of fatigue for most of their life…” (P9, 410 – 411).

This reference to a recovery based approach is in the context of many people continuing to live with aspects of CFS/ME. Becky uses the plural pronoun “we” here, perhaps attaching the recovery model more generally to the team’s approach. A recovery approach may be a way of enabling hope, but this is balanced with some acceptance that not everyone will fully recover. The excerpt below also picks up on this idea that most people with CFS/ME may have elements of the condition for their lifespan:

> **Debbie**: *“Some seem* to … fully recover… I think it is probably a condition that most people *need* to be aware of and need to watch out.” (P12, 407 – 408).

Being watchful and attentive for symptoms of CFS/ME suggests that symptoms come and go, but will always be there to some extent and therefore will always need to be managed. Although the excerpts use the word “recovery”, the two dialogues above refer to a chronicity that would fit with more of a management model, than a recovery model. Below, Gemma directly explores the differences between a management model, which assumes a condition is chronic, and a treatment model, which implies that recovery from the condition is possible.

> **Gemma**: “We don’t know if we’re doing a *management* model or a *treatment* model, and at the moment the two look very similar. So … that’s quite difficult I think for the patients, but as a therapist it’s quite hard to know because you don’t really *know*. With some people you think ‘Hmm it’s definitely going to be more management, and other people you think ‘Oh no actually that’s quite … straightforward, there’s certain things have happened, there’s progress already’.
>
> Interviewer: So what would look different if you were using the kind of treatment model, or the management model?

> Gemma: Well it wouldn't, I think *that's-that's* the difficulty I don't think it does. I think we do the *same* thing, and for some people they kind of come back and say 'Oh I feel so much better' and other people go 'Not really, but my quality of life's a bit better'. So we just don't know." (P6, 274 – 281).

Gemma highlights that the main difference between a management approach and a treatment, or recovery-focused, approach is the extent of the outcome. Gemma uses plural pronouns, "you" and "we". Again, this may be a way of attaching the recovery model to the team's general approach. Gemma makes several references to it being difficult to know whether the approach is based on a management model or recovery model. This reflects the uncertainty held by several participants towards recovery and the different meanings it may hold.

In contrast to some of the more tentative meanings of recovery, a smaller group of participants spoke about their belief in recovery as fully and completely possible:

> **Claire**: "I think, um, there's a lot of scope for recovery … and I have always believed that they can get completely better, so that's, you know, so I wanted to go back into it, cos I just don't believe that people should have to have Chronic Fatigue for their whole lives" (P2, 93 – 97).

Claire speaks in a more absolute way about recovery, conveying a strong hope and belief in recovery as people getting completely better. Whilst she owns this recovery approach, she uses the word "scope" to recognise that recovery may not be a possibility for everyone. Francis talks about recovery as:

> **Francis**: "In my book recovery is completely better, I am a bit of a one for using words as they are in the dictionary, so recovery is having recovered, not having CFS/ME any more" (P15, 483 – 485).

Francis understands recovery to mean completely better from CFS/ME. His experience has shown that some people can and do recover but this has related to “few”, not all, people with CFS/ME.

> **Francis**: “I have had a few people do really well, that I can say they have recovered with a capital R… (P14, 474 – 475).

2.3.6.3 Subtheme 12: Post-CFS Growth.

Post-CFS growth was a concept shared by some participants, about the powerful transitions that they experienced with some people with CFS/ME who they had worked with. The experience of CFS/ME sometimes led people to question the way they had been living their lives. Participants talked about two groups of people; some people seeking recovery in terms of going back to how their life was before, and others who wanted to move forwards and adapt their way of living life:

> **Elaine**: A lot of people try and fight their condition, don’t want to let it beat them, erm … and they want to stay as they were before, so they keep pushing and pushing and even though there are consequences to that, of days where they can’t do anything, they find it really hard to stop the push and the fight with their old life, it is like a bereavement process I guess. A change from the old to the new is a bereavement of their old self to the new self.” (P9 – 10, 305 – 311).

Elaine talks about “the fight” as her experience of people with CFS/ME battling to hold onto their old life. She likens this to the process of bereavement; where a level of acceptance is achieved, which allows the person to move forwards with their life. Just as with the loss of a loved one, no-one would choose CFS/ME. Accepting the condition may put an end to the fight; letting go of one’s old life to enable moving forward. For Elaine, the meaning of a person’s “old life” is the same as their “old self”. The concept of bereavement gives the impression of a significant transformation, resulting in a "new self".

> **Francis**: "Erm I think *some* people it is not so much getting better as finding a different way of living life, it is not going back to the old life, it is actually figuring out how to manage things and do things differently and it may be finding completely different goals … or a different way of approaching life. Particularly if they have got ill possibly because of pressures that they were under from themselves or from other people. I have certainly met a few people that were probably just asking too much of themselves and getting really run down, under a lot of pressure, and for *them* getting better is about learning how to do things differently … and it might be having a completely different lifestyle in order to build up health and stay well in the future and I think there is a few folk I have worked with who will say that that's what they have learnt from the illness, not that they wanted the illness to learn it, but they have taken something from it, some benefits, some silver-lining I guess. Just approaching life differently" (P19, 617 – 629).

Francis has made sense of his experience of people approaching life differently in the context of the contribution that unhelpful lifestyle factors may have had in the initial development of CFS/ME. He uses the metaphor of a "silver-lining" to describe the development of a new way of life as a positive aspect to come out of having CFS/ME, despite not wanting or choosing to have CFS/ME. This concept is similar to the notion of Posttraumatic Growth (Calhoun & Tedeschi, 2014), which describes a positive change resulting from an individual's struggle with a distressing, traumatic event.

Below, Becky talks about her experience with people making transformations after living through CFS/ME:

> **Becky**: "then occasionally you get somebody who makes a reasonable recovery and changes their lives, changes their occupation perhaps … or their friendships, you know, realise who their friends are. Changes their whatever, and we have had people who say I … I … I'm glad. I'm glad I had that health …
>
> Interviewer: Mm.
>
> Becky: … condition because it made me stop and actually re-evaluate and I could still be … I'm trying to think … I'm sure it was somebody last week. Yes it was. A young man, God, and he's … he has depression as well and he said … he's developing his own business now and it's going … it's started. He's put a lot of … invested a lot of time and effort and it's just started to pay some dividends, and he said I'm really glad I had this health condition because otherwise I'd be still in an office job nine till five working for someone else, and this has enabled me to take time out, um, and kind of look at what's really important to me and I … I … I just think that's *amazing*." (P37, 1829 – 1846).

Becky expresses the magnitude of the lifestyle changes by describing how people have even been glad that they had CFS/ME. This gives the impression that the transformation can be significant enough to warrant the suffering and distress experienced with CFS/ME. Perhaps this reflects a deeper level of acceptance; a recognition that the past experience of CFS/ME cannot be changed, whilst choosing to focus on what changes can be made in order to move forwards. s

2.4 Discussion

IPA was used to explore the experiences of eight healthcare professionals working in specialist services for people with CFS/ME. Four superordinate themes were found, including: ‘Safe Haven’, ‘Challenges of Understanding’, ‘Person-Centredness’, and ‘Recovery Road’.

Some findings supported previous literature on CFS/ME. Healthcare professionals shared experiences of people with CFS/ME not feeling believed, which has been well documented in the literature (Anderson et al., 2012; Bayliss et al., 2014; Bowen et al., 2005; Gilje et al., 2008; Horton et al., 2010; Jason et al., 2002). One participant suggested the issue has gone from one of not being believed, to not being understood.

Participants understood CFS/ME to be a complex condition, which cannot be conceptualised by a traditional medical model separating physical and psychological aspects. The variability seen across people with CFS/ME was another theme, which was seen as contributing to the complexity of CFS/ME. The heterogeneity of CFS/ME has been well documented in previous research (Åsbring & Närvänen, 2003; Banks & Prior, 2011; Horton et al., 2010; Woodward et al., 1995). Jason, Corradi, Torres-Harding, Taylor, and King (2005) have proposed distinguishing subtypes of CFS/ME according to biological, cognitive, and emotion domains. Jason et al. (2005) suggest that subtyping variations of CFS/ME may be helpful in clarifying the processes underlying the condition. It was important to healthcare professionals that CFS/ME was distinguished from depression, an issue also reported by Horton et al. (2010). Participants recognised that mental health problems were often co-occurring with CFS/ME, making the presentation and treatment process more complex.

A person-centred approach was shared across participants. The importance of adopting a holistic approach, bridging the gap between physical and psychological aspects, came across strongly. Similar themes were found by Horton et al. (2010), although the use of IPA allowed these concepts to be explored further and captured in greater detail. For example, the holistic approach and the relative “newness” of CFS/ME posed challenges, but were also aspects of healthcare professionals’ experiences that they found interesting and rewarding.

The process of diagnosis has been explored by other studies, including Horton et al. (2010) but again, this was explored in greater depth by the IPA approach. Demonstration of understanding resulted in a powerful sense of relief for the person with CFS/ME. This gave healthcare professionals a sense of providing a place of safety and belonging after a long period of uncertainty, which was a positive experience for participants. There was a strongly empathetic response from healthcare professionals. Whilst some participants described the work as occasionally draining, this was in contrast to a general experience where, when frustration was experienced, it was empathetically aligned with the struggle of the person with CFS/ME. Similarly, there was a brief reference to empathetic frustration reported by one participant in Horton et al.’s (2010) study, but this was explored in greater detail within the current study. The earlier literature review identified that other healthcare professionals working with people with CFS/ME relied on colleagues for emotional support (Chew-Graham et al., 2009; Peters et al., 2011). Participants valued their team as an important support network; again it was possible to explore this in greater depth through the use of IPA.

There were also themes found in this study that have not been identified by previous research, particularly concerning the thoughts, meanings, and emotions of healthcare professionals. There was a shared experience of people with CFS/ME making and celebrating recoveries, often starting with small and gradual steps. The beliefs that healthcare professionals hold about recovery from CFS/ME have not been researched before. Recovery was talked about in a tentative way, reflecting the different meanings of recovery. A smaller group of participants held strong beliefs that full recovery was absolutely possible, but again recognised that this was not always the result for all people with CFS/ME. The NICE guidelines state that recovery should be aimed for, but recognises that full recovery is rare (NICE, 2007). The concept of growth occurring as the result of suffering with CFS/ME was the least prevalent theme, but was salient to those participants that had experience of it. The idea of post-CFS growth or transformation has not been discussed in previous research.

Another important concept that emerged was how highly healthcare professionals regarded people with CFS/ME, in terms of the respect and admiration expressed. This high regard for people with CFS/ME is a powerful contrast to the negative stereotypes identified in the earlier literature review. The findings suggest generally positive experiences of therapeutic relationships between specialist CFS/ME healthcare professionals and people with CFS/ME. This is in contrast to the previous literature review, which described tension in the clinician-patient relationship, perhaps as a consequence of attempts to separate physical and psychological aspects of CFS/ME (Chew-Graham et al., 2008; Peters et al., 2011; Raine et al., 2004; Woodward et al., 1995). The literature review identified a tendency for healthcare professionals to view symptoms as psychological manifestations whereas people with CFS/ME viewed symptoms as physical (Banks & Prior, 2001; Bayliss et al., 2013; Hannon et al., 2012; Horton-Salway, 2002). Participants in the current study understood CFS/ME within Clauw's (2010) model of central sensitisation, which acknowledges the strong biological underpinnings of CFS/ME alongside behavioural and psychological components. Therefore, a framework for developing a shared understanding of the multi-dimensional factors involved in CFS/ME may be a way to improve the clinician-patient relationship.

This study has developed an in-depth understanding of the experiences of CFS/ME specialists, with the hope that this will contribute to overcoming some of the barriers to treatment access and improve the quality of services provided to people with CFS/ME. One of the barriers identified by the previous literature review was the tension arising from differences in how CFS/ME is understood by healthcare professionals and people with CFS/ME. This was not evident by healthcare professionals in the current study, despite CFS/ME being seen as a complex, difficult to understand condition. Participants recognised the important roles of time and experience in allowing them to grasp the heterogeneity of CFS/ME presentations.

2.4.1 Strengths and Limitations of the Study

This is the first study known to the author that has focused on interviewing healthcare professionals working in specialist CFS/ME services as experiential experts on working with people with CFS/ME. The use of IPA methodology enabled a more in-depth investigation of the participants' experiences. Thereby, this study has contributed to the CFS/ME body of literature, developing a greater understanding of working with CFS/ME from the healthcare professionals' point of view. A number of steps were taken to promote the validity of the findings, by ensuring themes were grounded in the data, including independent auditing, supervision, and adopting a reflexive approach.

Participants were interviewed at their workplace and were working for the specialist CFS/ME service. This limited potential recall biases, although it was recognised that participants' experiences may have changed over the course of their professional experience, which some participants reflected on. One potential limitation of interviews as a data collection method is the reliance on people to be open and honest. It is possible that participants held back due to concerns about what the researcher or readers might think. However, participants were very engaged in the interview process and there was no impression of people holding back.

The sample size of eight was in line with recommendations for IPA (Smith et al., 2009). IPA is more concerned with quality and richness of data, over quantity. The benefit of this study's small sample was to focus on capturing the complexity of human phenomena. The presence of divergence and convergence within themes suggests that some experiences were shared across the sample, whilst others reflected the unique experiences of individual participants (Smith et al., 2009). Four participants reported having family members or friends with CFS/ME, which may have influenced some of their experiences. The limited sample size makes it difficult to generalise findings to the experiences of others working with CFS/ME. The specialist CFS/ME service where participants were recruited from was one of the first to be set up in 2004, it has been involved in clinical research, including the PACE trial, it is led by a clinical psychologist, and adopts a model of central sensitisation (Clauw, 2010). Healthcare professionals working in specialist CFS/ME services with different characteristics may report different experiences. This explorative study supports the need for larger scale research to determine generalisability of results.

2.4.2 Clinical Implications

This study has explored how CFS/ME specialists have come to understand the condition through their lived experiences working with this client group. The in-depth understanding of CFS/ME held by these specialist clinicians may be useful in helping non-specialist healthcare professionals who want to develop a better understanding of CFS/ME. This is particularly important given that previous literature has highlighted that scepticism and limited knowledge from GPs can be a barrier to CFS/ME treatment.

One way of improving non-specialists understanding of CFS/ME could be through promoting a biopsychosocial model, such as the central sensitisation model (Clauw, 2010), as a way of bridging the gap between physical and psychological aspects of CFS/ME. The central sensitisation model recognises the strong biological underpinnings of CFS/ME, which may increase its acceptability for people with CFS/ME. The dissemination of this model through training and education of medical and other healthcare professionals may help reduce negative experiences of people with CFS/ME not feeling believed. Developing a shared understanding between healthcare professionals and people with CFS/ME may also help improve clinician-patient relationships.

Healthcare professionals expressed how the variation of CFS/ME can only be understood through the experience of seeing numerous people with CFS/ME. The expertise from specialist healthcare professionals could be shared with GPs and other healthcare professionals, who have more infrequent contact with people with CFS/ME. Sharing the expertise and understandings of CFS/ME specialists, through training and education, may promote attitudes of empathy and respect for people with CFS/ME, in place of negative stereotypes identified by previous research.

Training to develop GPs' understandings of CFS/ME may also reduce misdiagnosis of CFS/ME as depression. Training should include clear self-management advice to prevent people with CFS/ME developing unhelpful strategies. There is a need to continue improving the referral pathway, through information, education and building partnerships between specialist CFS/ME services and with GPs, so access is quicker and more straightforward.

Improving awareness of the positive aspects of services may help overcome some of the barriers that prevent people with CFS/ME accessing specialist treatment. The specialist CFS/ME service was described as a place of understanding, relief, and support. Healthcare professionals were passionate about their work, evidenced by the level of emotion expressed. Treatment approaches may benefit from being holistic; integrating physical, psychological, and environmental factors in a flexible way, working in line with what is important to the person with CFS/ME.

A better awareness of the scope for recovery, through education and training, may improve referral rates to specialist CFS/ME services. It is important for GPs to share a sense of hope that people can recover from CFS/ME, which in turn may increase the willingness of people with CFS/ME to engage with specialist services.

The skills of clinical psychologists are well-suited to working with individuals with CFS/ME, for example using formulation skills to work within the central senstitisation model, and using integrated approaches to work in a holistic manner incorporating both physical and psychological maintenance factors. Furthermore, the communication and teaching skills of clinical psychologists will be important in the development and delivery of training programmes, drawing together the different elements discussed above.

2.4.3 Implications for Future Research

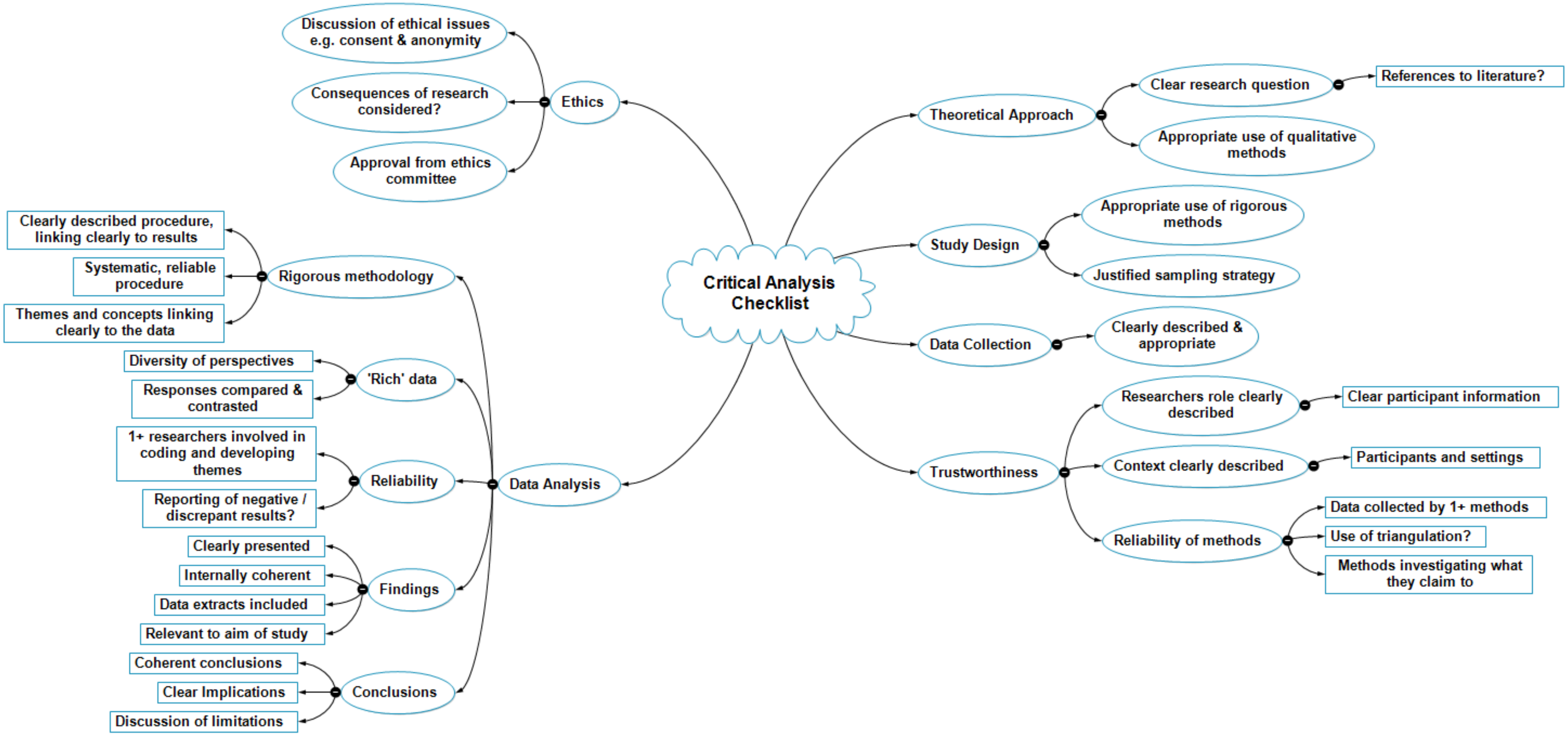
One of important clinical implications of this research is about disseminating training programmes to improve non-specialists' understanding of CFS/ME. Research will need to evaluate the effectiveness of any future training programmes. For example, the Illness Perceptions Questionnaire-revised for CFS/ME (IPQ-R; Moss-Morris et al., 2002) could be adapted for healthcare professionals and their responses could be compared before and after the training programme. The research skills of a clinical psychologist would allow them to test the effectiveness of a training programme.

Further research is needed to expand current understanding of CFS/ME, including continuing work to explore subtypes of CFS/ME. Whilst there is evidence underpinning the central sensitisation model, most of this applies to other central sensitivity syndromes, such as fibromyalgia. Future research needs to explore the role of central sensitivity in people with CFS/ME.

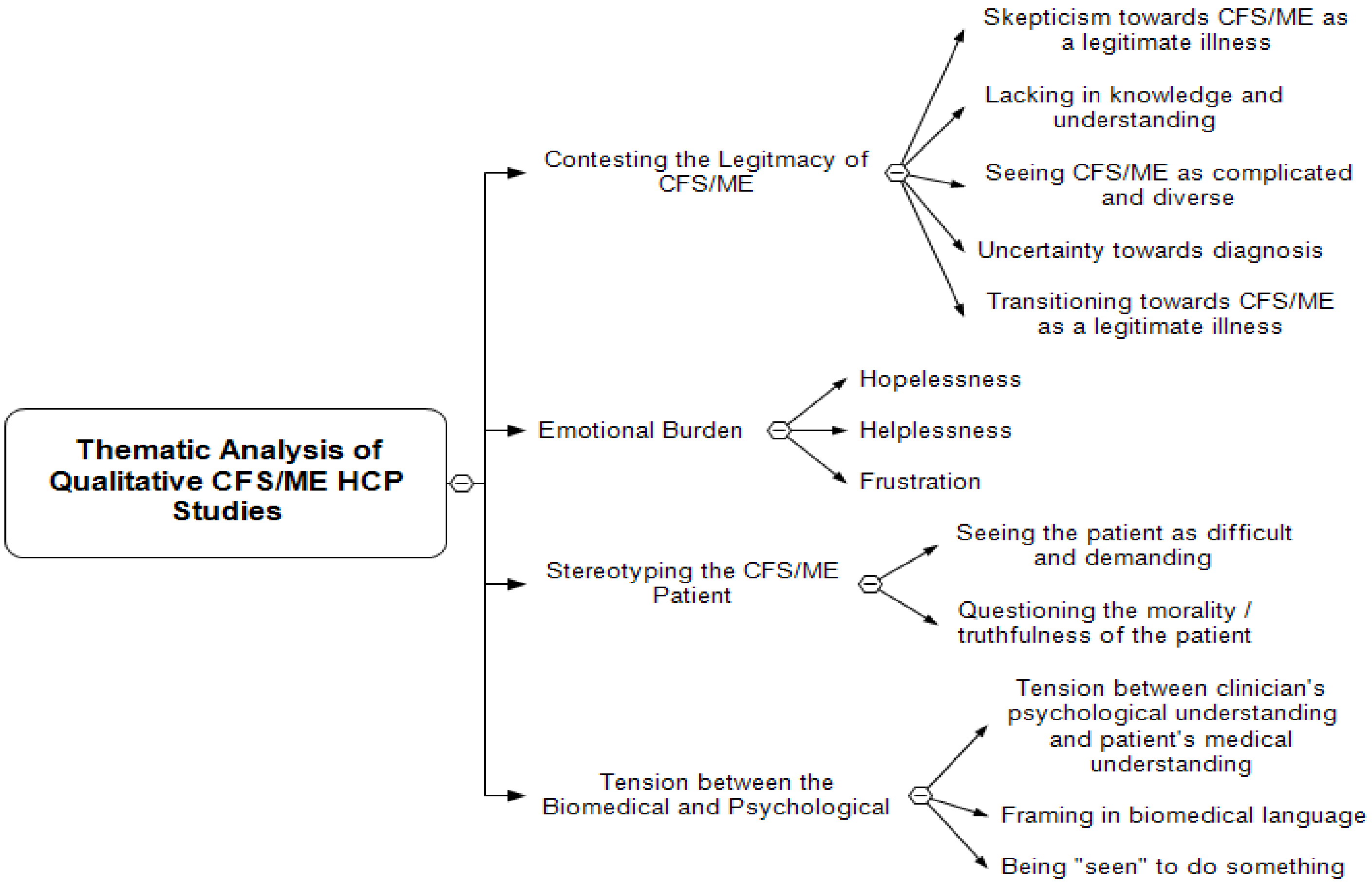
Finally, this explorative study found a wealth of knowledge and experience in specialist healthcare professionals who are experts in working with people with CFS/ME. Future research could explore the experiences of healthcare professionals across a larger sample of people working with CFS/ME, across a range of CFS/ME services, in order to produce more generalisable results.

Appendices

Appendix A – Mind Map of Criteria for Critical Analysis of Qualitative Studies



Appendix B – Thematic Analysis of Qualitative CFS/ME HCP Studies: Hierarchical Tree Structure



Appendix C – Studies Included in Literature Review

Study	Participants	Primary Objectives	Methodology	Country	Quality Appraisal
1. Åsbring & Närvänen (2003)	**26 physicians** (GPs and specialists)	To investigate Swedish physicians' perspectives on patients with CFS/ME or Fibromyalgia.	Method: Semi-structured interviews Analysis: Based on Grounded theory principles (including constant comparison and thematic saturation but without theory development) Recruitment: CFS/ME/FMS patients identified physicians	Sweden	2-2-1
2. Banks & Prior (2001)	114 observations and 16 audio recordings with **4 physicians** (3 physicians, 1 Psychiatrist) In a specialist CFS clinic	Explore lay and professional ideas about CFS/ME.	Method: Patient-Dr observations, patient interviews, audio recordings Analysis: No clear description. Analysed accounts of illness rather than beliefs about illness. Recruitment: CFS clinic	UK (Wales)	2-2-1
3. Bayliss et al. (2013)	11 patients, 2 carers, **9 GPs**, **5 nurses**, **4 CFS specialists** (2 physiotherapists, 2 nurses)	Explore BME patient, health professional and community leader's views on the barriers to the	Method: Semi-structured interviews Analysis: Thematic analysis Recruitment: Invited by letter / phone	UK (England)	2-2-2

	5 BME community leaders) GP practices, nurses, and CFS/ME clinic	diagnosis and management of CFS/ME in the BME population.			
4. Chew-Graham et al. (2008)	**14 GPs** 24 patients Primary care / GP practices	Explore how CFS patients and physicians understand the condition.	Method: Semi-structured interviews Analysis: Thematic analysis using constant comparison principles Recruitment: Purposeful sampling via a previous study	UK (England)	2-2-2
5. Chew-Graham et al. (2009)	**29 Practice nurses** GP practice	Explore practice nurses’ beliefs about CFS patients and their perceived role regarding management.	Method: Semi-structured interviews Analysis: Thematic analysis Recruitment: Identified via a previous study and invited by letter / phone	UK (England)	2-2-2
6. Chew-Graham et al. (2010)	**22 GPs**	Explore GPs’ views on their role in diagnosing and managing CFS patients.	Method: Semi-structured interviews Analysis: Thematic analysis Recruitment: Identified via a previous study and invited by letter / phone	UK (England)	2-2-1

7. Hannon et al. (2012)	44 (**9 GPs, 5 practice nurses, 4 CFS/ME specialists:** 2 physiotherapists, 2 nurses)	Explore patient, carer, and health professionals' views on the development of CFS/ME training and resources for primary care.	Method: Semi-structured interviews Analysis: Thematic analysis Recruitment: Invited by letter / phone	UK (England)	2-2-2
8. Horton et al. (2010)	**6 practitioners** (3 CFS/ME specialists: doctor, OT, physio and 3 non-specialists: GP, occupational health, holistic practitioner)	Explore healthcare professionals' views of best practice.	Method: Semi-structured interviews Analysis: Thematic analysis Recruitment: Nominated by participants of a previous study for being particularly helpful and effective practitioners	UK (England)	2-2-2
9. Horton-Salway (2002)	**10 GPs**	Explore GP's construction of CFS/ME patient identities and the definition of their illness.	Method: Unstructured interviews Analysis: Discourse analysis Recruitment: Nominated a patient support group	UK (England)	2-2-1
10. Horton-Salway (2007)	**10 GPs**	Explore the discourse of GPs and CFS/ME support group members to understand how they construct CFS/ME as an illness.	Method: Unstructured interviews (and group discussion from support group) Analysis: Discourse analysis Recruitment: Unclear	UK (England)	2-2-1

11. Moore (2000)	**20 OTs** Range of settings	Investigate attitudes of OTs towards CFS/ME.	Method: Semi-structured interview (collecting both quantitative and qualitative data) Analysis: Thematic methods – no depth to analysis Recruitment: Unclear	UK (England)	2-1-1
12. Peters et al. (2011)	46 patients, **3 Nurses, 2 supervisors** Primary care settings	Identify potential barriers and solutions for nurse practitioners in implementing psychosocial interventions for CFS/ME.	Method: Mixed methods including semi-structured interviews with developed topic guide Analysis: Thematic analysis Recruitment: Purposeful and matched sampling.	UK (England)	2-2-2-
13. Prins et al. (2000)	**12 GPs**	Explore GPs understanding and diagnosis of CFS/ME.	Method: Semi-structured interview Analysis: No analytic procedure identified. Mixed quantitative e.g. “50% of doctors believed…” with interview data used to explain and clarify results of questionnaire data. Recruitment: Unclear	Netherlands	2-1-1
14. Raine et al. (2004)	**46 GPs**	Explore GPs’ perspectives about CFS/ME and IBS symptoms and treatment.	Method: Nominal groups (clinical guideline opinion groups). Scenario evaluation. Analysis: Grounded theory variant Recruitment: Random sample	UK (England)	2-2-1
15. Woodward	**20 GPs** and 50 patients	Compare GP and patient perspectives on CFS/ME and its	Method: Semi-structured interviews with developed topic guide	Australia	2-1-1

et al. (1995)		management.	Analysis: No analytic procedure identified. Mixed quantitative e.g. “50% of doctors believed…” Recruitment: GPs recruited from Royal College.		

The Quality Appraisal score was calculated based on the CFS Meta-synthesis Quality Appraisal Form described by Bayliss et al. (2014), which considers the following three questions:

1. Relevance – How relevant is the paper in relation to the review question?
    0 = Not at all relevant
    1 = Somewhat relevant
    2 = Very relevant
2. Value – How much does the paper contribute to answering the review question?
    0 = Contribute very little value
    1 = Contributes some value
    2 = Contributes a lot of value
3. Methodological Robustness – How methodologically robust is the study?
    0 = Serious methodological issues
    1 = Some methodological issues
    2 = Methodologically robust

Papers receiving a score of 2-2-2 may be considered as Key Papers.

Papers receiving a score including 2s and 1s may be considered Adequate and Relevant Papers.

Papers receiving a score including a 0 should be considered to be Flawed or Not Relevant.

Appendix D – Participant Information Sheet

ERGO Study ID: 9777

Version 1 (04/04/14)

A Qualitative Study Exploring the Experiences of Clinicians working in CFS/ME Services

Participant Information Sheet

Researcher: Liz May

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

I am Liz May, a Trainee Clinical Psychologist at the University of Southampton. I am requesting your participation in a study looking at the experiences of healthcare professionals working in specialist Chronic Fatigue Syndrome (CFS/ME) services. This will involve an individual interview lasting about one hour. During the interview, you will be asked about your experience working with adults with CFS/ME. A brief demographics questionnaire will also be given, which should take no longer than ten minutes to complete.

Why have I been chosen?

All clinicians currently working at the Chronic Fatigue Syndrome (CFS/ME) service within North Bristol NHS Trust are invited to participate in this study.

What will happen to me if I take part?

If you agree to take part, you will be asked to complete a brief demographics questionnaire. This should take no longer than ten minutes to complete and will ask about your profession and how long you have worked in the CFS/ME service. A convenient time for an interview will be arranged. The interview itself will last for about one hour. During the interview, you will be invited to share you opinions and experiences of working with adults with CFS/ME. Interviews will be recorded. Once the interview is completed, there will be an opportunity for you to ask any further questions about the research study.

Are there any benefits in my taking part?

By taking part in this study, you will be helping us understand more about what it is like to work with adults with CFS/ME. It is hoped that this understanding will further improve the care of people with CFS/ME. As well as being a valuable learning experience for others, I hope that this opportunity to share your own experiences will be interesting for you.

Are there any risks involved?

It is possible that the discussion of your personal experiences of working with people with CFS/ME may be mildly upsetting. If this is the case, support will be offered to you if needed.

Will my participation be confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence. Your identity in this study will be treated as confidential. Interviews will be recorded on a password-protected device. Interview recordings will be sent to an external transcription service that will follow appropriate procedures for maintaining confidentiality. A coding system will be used for the questionnaire and interview transcript so your name will not be known publicly. All data will be kept in a locked filing cabinet in a secure building. Electronic data will remain anonymous and be kept on a password-protected computer. The use of verbatim quotes will remain anonymous.

What happens if I change my mind?

Participation in this study is voluntary. It is up to you to decide whether to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

If you decide to take part, you are still free to withdraw any time and without giving a reason. This will not affect your legal rights or your work within the CFS/ME service.

What happens if something goes wrong?

In the case of concern or complaint, you may contact the Chair of the Ethics Committee, Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: +44 (0)23 8059 4663, email slb1n10@soton.ac.uk

Where can I get more information?

If you have any further questions, please contact the researcher, Liz May, by email em1v11@soton.ac.uk

Appendix E – Consent Form

ERGO Study ID: 9777
Version 1 (04/04/14)

A Qualitative Study Exploring the Experiences of Clinicians working in CFS/ME Services

CONSENT FORM

Researcher name: Liz May

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (Version 1, 04/04/14) and have had the opportunity to ask questions about the study ☐

I agree to take part in this research project, including being interviewed, and agree for my data to be used for the purpose of this study ☐

I agree that this interview will be recorded. ☐

I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected ☐

Name of participant (print name)………………………………………………….

Signature of participant…………………………………………………………..

Date………………………………………………………………………………

Appendix F – Demographics Questionnaire

ERGO Study ID: 9777
Version 1 (04/04/14)

UNIVERSITY OF
Southampton

A Qualitative Study Exploring the Experiences of Clinicians working in CFS/ME Services

Demographics & Experience Questionnaire

1. Gender: please tick one box.

☐ Male ☐ Female

2. Age: please tick one box.

☐ 18 – 25 ☐ 26 – 30 ☐ 31 – 35
☐ 36 – 40 ☐ 41 – 45 ☐ 46 – 50
☐ 51 – 55 ☐ 56 – 60 ☐ 61 – 65 ☐ Over 65

3. Marital status: please tick your current status.

☐ Single ☐ Married ☐ Civil Partnership
☐ Separated ☐ Divorced ☐ Committed Relationship
☐ Widowed ☐ Do not wish to comment

4. Ethnicity: How would you describe your ethnic background?

White	Asian or Asian British	Black or Black British
☐ British	☐ Indian	☐ Caribbean
☐ Irish	☐ Pakistani	☐ African
☐ Any other White background	☐ Bangladeshi	☐ Any other Black background
	☐ Chinese	
	☐ Any other Asian background	
Mixed	Other	
☐ Any other mixed background	☐ Any other ethnic background	☐ Do not wish to comment

5. What is your current job title?

………

6. How long have you been qualified for?

…………………………………………………………………………………………………

…………………………………………………………………………………………………

7. How long have you been in your current post?

…………………………………………………………………………………………………

…………………………………………………………………………………………………

8. Do you have any other experience of working with people with CFS/ME?
☐ Yes ☐ No
If yes, please give details below:

…………………………………………………………………………………………………

…………………………………………………………………………………………………

9. Do you have any personal experiences of CFS/ME?
☐ Yes ☐ No

10. Have any of your close family or friends experienced CFS/ME?
☐ Yes ☐ No

11. Would you like a summary of the research findings once this study is completed?

☐ Yes ☐ No

If yes, please provide your contact details below:

Name: ………………………………………………………………………………………

Address or Email: ………………………………………………………………………

…………………………………………………………………………………………………

Appendix G – Interview Schedule

1. **To start with, can you tell me a little bit about how you came to work with people with Chronic Fatigue Syndrome or ME?**

2. **So, in your experience, what's it *like* working with people with CFS/ME?**
    - How does it compare to any other roles that you have worked in?
    - Perhaps you could talk about a particular client you have worked with who has stuck in your mind?

3. **Would you say there are any particular good and bad bits about working with people with CFS/ME?**

4. **In terms of how you work with people with CFS/ME, is there a particular way in which you choose to work?**
    - How does that fit with how you understand CFS as a condition?

5. **Can you tell me a little about your experiences of recovery or the outcomes of your work with people with CFS/ME?**

6. **What do you think helps in the recovery of CFS/ME?**

7. **Has the way in which you think about CFS/ME changed over time? If so, How?**

8. **Is there anything else that's important, which I haven't asked you about yet, or that you would like to talk about?**

Appendix H – Summary of Research Findings

A Qualitative Study Exploring the Experiences of Clinicians working in CFS/ME Services

Dear …

Thank you again for sharing your experiences of working in CFS/ME services. I am so grateful for your willingness to participate and for the openness and insight that was shown in every interview. I was touched by the respect, empathy, and hopefulness that was shared with me.

As previously discussed, I am writing to share a summary of the findings with you. If you have any questions or would like to discuss these findings further, please feel free to contact me.

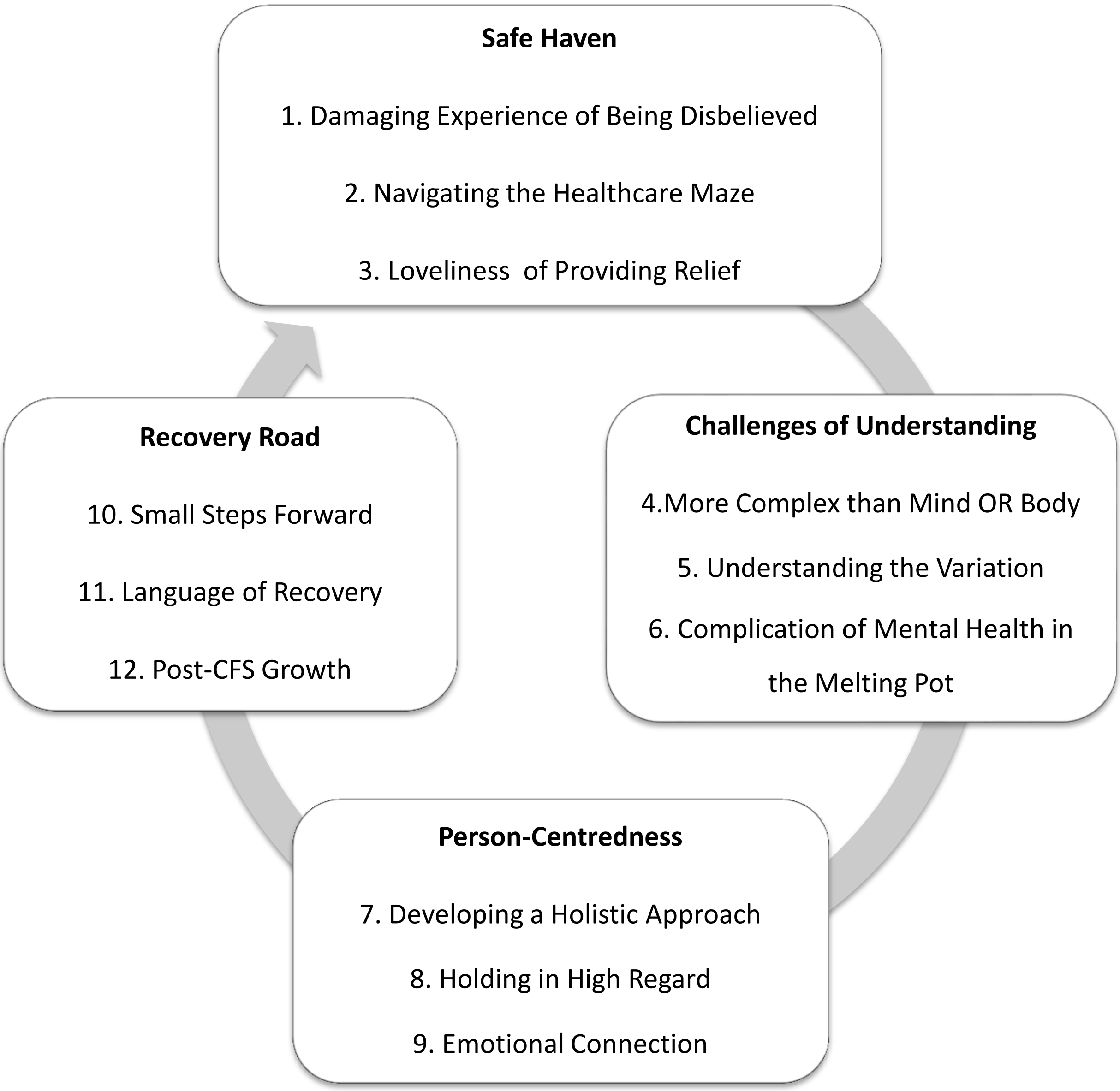
Many thanks,

Liz May

Trainee Clinical Psychologist
University of Southampton

Appendix H

Four main themes were identified: *Safe Haven, Challenges of Understanding, Person-Centredness,* and *Recovery Road*, each with three subthemes, as represented in the figure below:



Safe Haven

The first group of themes capture the journey experienced by patients before, and on their way to arriving at the specialist CFS/ME service. There was a sense of the CFS/ME service being a 'safe haven'; a place of safety after a difficult journey.

1. Damaging Experiences of Being Disbelieved: Participants talked about the negative experiences faced by some people with CFS/ME before they arrived at the specialist CFS/ME service. There was acknowledgement that some people with CFS/ME had felt disbelieved and judged before coming to the specialist service.

2. Navigating the Healthcare Maze: Participants talked about the frustrating, to and fro, journey that was experienced by some patients in their search for help and support.

3. Loveliness of Providing Relief: These difficulties were a stark contrast to the overwhelming relief that some patients experienced once they had arrived. Many participants described their positive experiences of being able to provide a place of safety and understanding in response to the search for legitimacy and help.

Challenges of Understanding

These three themes are all seen as factors contributing to the difficulty in making sense of CFS/ME.

4. More Complex than Mind OR Body: Firstly, the dualist framework which differentiates physical problems from mental and emotional problems was seen as presenting a challenge to understanding CFS/ME.

5. Understanding the Variation: Secondly, CFS/ME was seen as a heterogeneous condition, which makes CFS/ME more complex and challenging to understand.

6. Complication of Mental Health in the Melting Pot: Thirdly, CFS/ME often presents alongside symptoms of depression, anxiety, or other mental health problems, which can further complicate matters. A clear distinction was made between CFS/ME and depression, and participants suggested that depression often occurs as a consequence of CFS/ME.

Person Centredness

The following themes reflect the more general, person-centred approach and processes described across the course of treatment.

7. Developing a Holistic Approach: There was a shared experience of a holistic approach despite differences in professional backgrounds. Participants talked about incorporating both graded activity and elements of CBT techniques, working in line with patient’s personal goals.

Working across physical and psychological domains was seen as a positive experience, allowing professionals to develop a broader range of skills.

8. Holding in High Regard: Participants expressed a deep sense of respect and admiration for the people they worked with.

9. Emotional Connection: An emotional connection was described by participants, both in terms of strongly empathising with the patient, the emotional impact of their work, and the important support network they formed as a team.

Recovery Road

The final group of themes relates to ideas and experiences about recovery.

10. Small steps forward: Participants described starting small and gradually on the path towards recovery. Some participants talked about how even a small shift could end up having a substantial impact on improving the patient’s quality of life.

11. Language of Recovery: Whilst participants shared the word ‘recovery’, the meaning applied to this word varied across participants. Some talked about recovery in terms of patient’s making improvements and learning to live their life, despite having some residual symptoms. Others saw complete recovery as an attainable goal, with patients living a full life, free from any CFS/ME symptoms.

12. Post-CFS Growth: A smaller group shared an experience of people they had worked with being transformed through the process of recovery, similar to the idea of post-traumatic growth. For a subgroup of patients, the experience of CFS/ME was seen as an opportunity to re-evaluate aspects of their life, leading to positive changes.

Appendix I – University of Southampton Ethics Approval

I am writing to confirm that the University of Southampton is prepared to act as Research Sponsor for this study under the terms of the Department of Health Research Governance Framework for Health and Social Care (2nd edition 2005). We encourage you to become fully conversant with the terms of the Research Governance Framework by referring to the Department of Health document which can be accessed at:

http://www.dh.gov.uk/en/Aboutus/Researchanddevelopment/Researchgovernance/DH_4002112

If your study has been designated a Clinical Trial of an Investigational Medicinal Product, I would like to take this opportunity to remind you of your responsibilities under Medicines for Human Use Act regulations (2004/2006), The Human Medicines Regulations (2012) and EU Directive 2010/84/EU regarding pharmacovigilence If your study has been designated a 'Clinical Investigation of a Medical Device' you also need to be aware of the regulations regarding conduct of this work.

Further guidance can be found:

http://www.mhra.gov.uk/

The University of Southampton fulfils the role of Research Sponsor in ensuring management, monitoring and reporting arrangements for research. I understand that you will be acting as the Principal Investigator responsible for the daily management for this study, and that you will be providing regular reports on the progress of the study to the Research Governance Office on this basis.

Please also familiarise yourself with the Terms and Conditions of Sponsorship on our website, including reporting requirements of any Adverse Events to the Research Governance Office and the hosting organisation.

If your project involves NHS patients or resources please send us a copy of your NHS REC and Trust approval letters when available. Please also be reminded that you may need a Research Passport to apply for an honorary research contract of employment from the hosting NHS Trust. Both our Terms and Conditions of Sponsorship and information about the Research Passport can be found on our website:

http://www.soton.ac.uk/corporateservices/rgo

Failure to comply with our Terms may invalidate your ethics approval and therefore the insurance agreement, affect funding and/or Sponsorship of your study; your study may need to be suspended and disciplinary proceedings may ensue.

Please do not hesitate to contact this office should you require any additional information or support. May I also take this opportunity to wish you every success with your research.

Submission ID : 9777
Submission Name: A Qualitative Study Investigating the Experiences of Healthcare Professionals Working in Chronic Fatigue Services
Date : 23 Apr 2014
Created by : Elizabeth May

Appendix J – North Bristol NHS Trust Ethics Approval

Dear Hazel,

Title: A Qualitative Study Investigating the Experiences of Healthcare Professionals Working in Chronic Fatigue Services

CI: Mrs Elizabeth May

IRAS number: 159585

REC number: NA

R&D Reference: 3399

Start Date: 12.09.2014

End Date: 19.12.2014

I am pleased to confirm North Bristol NHS Trust (NBT) NHS permission for the above study.

FULL R&D APPROVAL

You have permission to begin recruitment.

I understand that the University of Southampton will act as sponsor for this study.

We acknowledge that this project does not require ethical review by a NHS Research Ethics Committee under the UK Health Departments' Governance Arrangements for Research Ethics Committees (GAfREC), however it may be necessary to contact the University Research Ethics Committee (UREC).

Please notify us of the date of your first patient first visit. If you experience any problems recruiting, please contact the R&I office for advice and support.

We wish you every success with your study. We are keen to support good research at North Bristol NHS Trust and are pleased that you have decided to conduct your project here.

The lead Research Facilitator Officer for this study is Mary Kisanga, who will remain your ongoing main point of contact. They can be reached at the following email address: research@nbt.nhs.uk<mailto:research@nbt.nhs.uk>.

Approval is given on the understanding that this project be carried out according to Good Clinical Practice and UK Statutory Instrument, and within the guidelines of the NHS Research Governance Framework for Health and Social Care, and NHS Trust policies, procedures, and SOPs which are available online at http://www.nbt.nhs.uk/research.

In particular you have responsibility for:

- Ensuring that all participants sign informed consent (whenever applicable).
- Adhering to the protocol and ensuring your co-workers do the same.
- Ensuring all recruitment figures are uploaded to the Edge database on a weekly basis.
- Providing us with information about any amendments to the protocol, changes in funding, personnel or end date.
- Informing us of any research-related adverse events.
- Ensuring that any staff working on this study at this site have been issued with a contract with NBT (honorary, substantive or bank) or a letter of access before they commence work on the study at this site.
- Maintenance of an Investigator Site File and/or Trial Master Files.

Researchers who hold substantive or honorary contracts with North Bristol NHS Trust (NBT) will be covered against claims of negligence by patients of NBT under the Clinical Negligence Scheme for Trusts (CNST). This scheme does not cover ‘no fault’ compensation and the Trust is precluded from taking out separate insurance to cover this. Any patient or volunteer taking part in the study is entitled to know that if they suffered injury as a result of participating in the study they would first have to prove negligence in a court of law before they could gain compensation. If the study involves patients of any other Trust or healthcare organisation, you will need to confirm the indemnity arrangements with that organisation.

In addition, other information may be requested from time to time and lay summary of the results will be requested from you at the end of the study.

This full R&D approval document will need to be filed in your Investigator Site File and/or Trial Master Files.

In accordance with the NBT Research Monitoring and Audit policy, this study is subject to audit by the R&I Office. We will contact the Principal Investigator to make appropriate arrangements for this.

Many thanks

Dr Nicola Williams
Deputy Director
Research & Innovation
North Bristol NHS Trust

Tel: 0117 323 6468
Fax: 0117 323 6192
http://www.nbt.nhs.uk/research

*If your study is being sponsored by NBT, Investigator Site Files and/or Master Trial Files are available from the R&I office.

Appendix K – Example Section of Data Analysis

Code: Descriptive Coding Linguistic Coding Interpretative Coding

Emergent Themes	Transcript	Exploratory Coding

REMOVED TO PROTECT CONFIDENTIALITY

Appendix K

REMOVED TO PROTECT CONFIDENTIALITY

Appendix K

Appendix K

Appendix L – Feedback from IPA Group and Outcome

Original Theme	Comments and Suggestions for Titles and Grouping of Themes	Final Theme
Safe Haven		**Safe Haven**
Patient's Unwanted Journey	- Vagaries of diagnosis - Long journey to treatment - Journey / pathway to finding help - Maze - Frustration & searching - exhausting	Navigating the Healthcare Maze
Ultimate Respect	- Empathy - Admiration for patient's struggle - Respect - Mirroring / attunement	Respecting the Task Ahead / Emotional Connection (Support) *Some quotes were about respect and admiration for the patient's struggle; these were moved to 'Respecting the Task Ahead'. Other quotes were about empathy for the patient; these were moved to 'Emotional Connection (Support)'.*
A place of relief	- Empathetic, understanding, & recognition - Providing comfort, relief, support - Validating experience, relief, satisfying	Loveliness of Delivering Relief
Limitations of Understanding		**Challenges of Understanding**
Disbelieving as Damaging	- Not believed, not recognised… - Disbelief *Suggestion that this theme belonged more with the 'safe haven' group of themes; a counter to the safe haven?*	Damaging Experience of Being Disbelieved *Moved to safe haven grouping*

Making Sense of Mind-Body Connection	- Psychological complexity of CFS/ME - Oversimplification; all in the mind as a derogatory term. ‘Physical’ = ‘real’. - Dualist model	More Complex than Mind OR Body
Varying as Complicating	- Physical basis for CFS/ME - Variations in presentation relating to a lack of understanding	Varying as Complicating
Mental Health as Co-Morbidity	- Several different links between CFS/ME and depression; misdiagnosis, mixed presentation, CFS/ME as a trigger for depression, depression and anxiety as magnifying CFS/ME… - Chicken & egg: which comes first?	Co-morbid Mental Health as Another Piece in the Puzzle
Therapeutic Responsibility		**Therapeutic Processes**
Patient’s Responsibility without blame	- Treatment approach unclear: role of individual responsibility. Quotes felt emotive for both patient and therapist. - It’s about lifestyle changes; there’s no quick fix. *I was trying to capture that the medical model does not have an effective treatment to “cure” CFS/ME. Treatment demands a lot from patients and participants showed a great deal of respect for patients in this context.*	Respecting for Patient’s Willingness
Self within Context of Team	- Collaboration and peer support - Supportive working environment of a high quality - Team support	Emotional Connection (Support)
Developing an Integrated Role	- Holistic service - Expertise and skill development; Holistic	Developing a Holistic Approach

	- Holistic *‘Holistic’ felt like a better word than’ integrated’ to capture this theme.*	
Small and Steady Steps	- Treatment approach - Small steps *Suggestion that this theme was moved to ‘Recovery’ as it is more about making progress than the treatment approach / process.*	Small Steps Forward *Moved to ‘Recovery Road’*
Language of Recovery		**Recovery Road**
Hoping for Recovery, Expecting Change	- Sense of having to be realistic, not kidding ourselves - Realisation; coming to terms - Sense of optimism - Recovery model: negotiating terms of recovery	Language of Recovery
COMPLETE Recovery	- Recovery - Meaning of recovery *Suggestions that ‘Hoping for Recovery, Expecting Change’ and ‘COMPLETE Recovery’ could be merged, with differences as evidence of divergence*	
Post-CFS Growth	- Positive transformation – *real* change - New life (*more* than growth) *Used transformation to capture ‘new’ birth, more than just growth.*	Transformation to a New Life *After further reflection, I changed this back to Post-CFS Growth, as I felt this was a more accurate reflection of experiences, acknowledging the painful process of growth.*

Representation: The IPA group suggested that, instead of presenting the themes in a table, a circle or an upward cycle could be used to represent the journey, ending with positive recovery or transformation.

Appendix M – Feedback and Discussion with Supervisor

Feedback from my research supervisor supported themes as being clearly organised and titled. The comments below reflect the titles that I felt unsure about and had requested other ideas and suggestions; this helped me reflect on new ideas and reach final theme titles that I felt captured the theme accurately.

Original Theme	Comments	Final Theme
1. Damaging Experience of Being Disbelieved	Clear	1. Damaging Experience of Being Disbelieved
2. Navigating the Healthcare Maze	Clear	2. Navigating the Healthcare Maze
3. Loveliness of Delivering Relief	Clear	3. Loveliness of Delivering Relief
4.More Complex than Mind OR Body	Clear	4.More Complex than Mind OR Body
5. Variants: Seeing the Whole Picture	5. CFS/ME an “Umbrella term”	5. Understanding the Variation
6. Comorbid Mental Health as Another Piece in the Puzzle	6. Overlap with Mental Health	6. Complication of Mental Health in the Melting Pot
7. Developing a Holistic Approach	Clear	7. Developing a Holistic Approach
8. Respect for Patient’s Willingness	8. Respect for Openness	8. Holding in High Regard
9. Emotional Connection	9. Human Connection	9. Emotional Connection
10. Small Steps Forward	Clear	10. Small Steps Forward
11. Language of Recovery	Clear	11. Language of Recovery
12. Post-CFS Growth	12. Life after CFS	12. Post-CFS Growth

Appendix N – Independent Auditors Comments

Original Theme	**Comments**	**Final Theme**
1. Damaging Experience of Being Disbelieved	This theme makes a lot of sense – and you have examples within the theme of instances when the GP had been 'really useful' which is really interesting as it adds that element of 'disparity of views' within a theme. Something of the confusion that patients had experienced before they have accessed the service also came through which is covered well under the 'Damaging Experience' title.	1. Damaging Experience of Being Disbelieved
2. Navigating the Healthcare Maze	This sounds like a good summing up of the patients experience – It's really clear.	2. Navigating the Healthcare Maze
3. Loveliness of Delivering Relief	The content of this theme makes sense. I wondered if the idea of 'delivering relief' is perhaps more suggestive of an overall intervention rather than that initial stage of feeling validated / understood and believed? I know a couple of the quotes seem to reflect the broader continuation of work, but most seemed to be related back to the 'safe haven' of finally being with someone who gets it. Perhaps it could be 'Loveliness of bringing or finding relief'??	3. Loveliness of Providing Relief Reflection: Changed 'delivering' to 'providing' to reflect that this is something provided *from* the professional *to* the patient, but more reflective of the initial stage of treatment.
4.More Complex than Mind OR Body	This theme is really clear.	4.More Complex than Mind OR Body
5. Understanding the Variation	It seems like your participants were talking about a spectrum, umbrella terms or overlapping/grey which I think is nicely realised in the word 'variation'.	5. Understanding the Variation
6. Complication of	It seems that the complication and lack of	6. Complication of

Mental Health in the Melting Pot	understanding comes from diagnostic shortcomings / diagnostic overshowing which might be a more direct way of titling the theme. But the title of the theme is close to the participant wording which is important. It also is clear so I would leave it as it is.	Mental Health in the Melting Pot Reflection: Title kept the same to reflect that whilst this issue complicates diagnosis, it also complicates the formulation and treatment processes.
7. Developing a Holistic Approach	I was thinking as I was reading through about whether it is a 'holistic' or 'multi-disciplinary' approach and exactly what the difference would be?	7. Developing a Holistic Approach
8. Holding in High Regard	I wasn't sure about the quotes following: *In relation to the limitations of the medical model – responsibility falling to the patient?* I sort of see how they fit; the link just seems a little more tenuous. I wondered if it might fit under 'small steps forward' in terms of how they make steps forward in the absence of traditional approaches??	8. Holding in High Regard Reflection: I have used quotes that better reflect the respect and admiration shown by participants.
9. Emotional Connection	I think this is really nice – you have brought out some lovely and very honest accounts of the work which is amazing.	9. Emotional Connection
10. Small Steps Forward	The theme is really clear and the examples make good sense of it!	10. Small Steps Forward
11. Language of Recovery	Really rich theme! …and very IPA!	11. Language of Recovery
12. Post-CFS Growth	Again, a really rich and interesting theme.	12. Post-CFS Growth

Appendix O – Extracts from Reflective Journal

Fore-understandings and Personal Assumptions

"My interest in CFS/ME and reason for choosing this area of research comes from my personal experience of seeing several people I care about living with CFS/ME. From my own experience, I have not seen any of my family or friends with CFS/ME benefit from local CFS/ME services. The people I know who live with CFS/ME experience it as a very physical illness and they continue to wait for research to find a physiological cause. My personal experience is that because CFS/ME is experienced as a predominantly physical illness, people may be less likely to access CFS/ME services, which offer activity-based, psychological treatments. I have witnessed the extreme hopelessness that is sometimes experienced by people with CFS/ME. Part of my reason for engaging in this research is to try and understand CFS/ME better myself. I also hope that this research will make a contribution to understanding some of the barriers to people with CFS/ME accessing available treatments, so that these barriers may be addressed in the future."

After initial meeting with my clinical research supervisor: "In this supervision meeting, I was asked about the reasons I was asking particular questions. Reflecting on the questions I asked during supervision has led me to recognise an assumption that I was not previously aware of. I had assumed that CFS/ME must be a difficult and frustrating area to work in, and that clinicians' experiences are therefore likely to be negative. I think this assumption comes from the frustration and hopelessness that I have seen others experience when there is no improvement in their CFS/ME symptoms. On occasions, I have experienced this frustration and hopelessness to a lesser degree myself. I have also heard about CFS/ME services that have struggled with recruitment. Similarly, I initially struggled to find a clinical supervisor able to supervise this project. I think all these factors have contributed to this assumption that CFS/ME must be a difficult area to work in.

However, I feel very encouraged from hearing Hazel talk about her work with CFS/ME in such a positive way. She expressed a belief in a recovery focused model, which has significantly challenged my previous assumption. This reminds me of my IPA training, where Kate Hefferon and Elena Gil-Rodriguez spoke about how we may not become aware of our assumptions until they have changed, through the process of our research! I feel much more open-minded and feel I have no expectations about what participants are going to share; I feel excited to hear about their experiences."

Appendix O

Reflections Following Interviews

"I was conscious about what other people thought about me and my intentions i.e. why I was asking the questions I was asking. I worry that I came across as more interested in the 'challenges' rather than the positive aspects of working with CFS. I think this reflects my own assumptions about whether working in CFS/ME is a positive or negative experience; I am trying to keep open-minded and not make assumptions in either direction."

"Hannah was reflective in her responses, often taking time to consider her responses before replying. I am encouraged by feedback from her later on, saying that she had got a great deal out of reflecting during the interview. I am glad that she felt able to use the interview to reflect on her experience and share this openly and honestly with me."

Data Analysis

"I feel like I am being disloyal to the participants by interrogating what they are saying through the different levels of encoding e.g. by making interpretations and exploring similarities and contradictions."

After discussion in supervision: "I am not tearing the interview apart but *deconstructing* it. This differs from normal conversation as we are not usually under scrutiny; hence the analysis sometimes feels uncomfortable for me. I need to remember that I am not interested in tearing words apart but I am being curious about the participant's experience."

Returning to data analysis after maternity leave: "Re-listening to the interviews, I am struck again by how interesting I find each individual – I find them confident, empathetic, passionate, knowledgeable, and inspiring. I love their positivity towards CFS/ME; they inspire hope in me that complete recovery is possible… Reflecting back on my initial assumptions, I wonder how to make sense of these experiences that I have been immersing myself in, in comparison to my previous experiences; friends and family members who haven't made much improvement through another CFS/ME service, and stories I have heard about struggles with recruitment and the discontinuation of another CFS/ME service. I wonder whether this reflects differences between CFS/ME services across different areas."

Selecting examples of quotes for master table of themes: “I am very conscious of what participants might think about each quote that I am including… Most importantly, I am being careful that quotes do not identify the member of staff to the rest of their team. There is a risk that this might prevent me from including certain quotes, but I feel this is important in order to respect the participants who have been so open in sharing their experiences”.

Re-ordering themes post- IPA group feedback: “I enjoyed the experience of sharing my research and themes with the IPA group more than I expected. I feel encouraged by the positive feedback from the group and am glad people feel it is an interesting and important piece of research. The specific feedback on each theme has helped push me to think about my themes from a slightly different angle. I have used this fresh perspective to experiment with re-arranging the themes in several different ways. I have felt some frustration with this struggle to find the ‘end’ point. After lots of re-arranging, the ONLY way the data made any sense to me was to order the themes in a temporal sense – the journey BEFORE patient gets to the CFS/ME service, the starting point of providing relief, making sense of CFS, the therapeutic process, and recovery / ending. I feel that I have now reached the ‘end’ point in terms of the order of themes.”

Reflecting on audio recording of research supervision: “*Respect for Willingness* – I feel I shouldn’t have joined the previously separate themes (*Ultimate Respect* and *Patient’s Responsibility without Blame*) together. The tears and the strong sense of empathy, that kind of emotional connection, isn’t about the patients willingness to engage… It’s linked to a kind of sadness and an anger at the injustice at the patients’ experiences. That injustice is mainly about other people not believing the patients and not supporting them in the way they deserve to be supported. In a way, the limitations of the medical model in being able to help people with CFS/ME, is partly an injustice but I don’t think that’s the main thing; there are many health problems, which medicine has not been able to provide a “quick fix” for…physiotherapy, occupational therapy, and psychological therapies are all hard work, whether addressing a physical or a psychological problem. So CFS/ME isn’t different in *that* sense. CFS/ME is different in the sense that it is seen as a physical health problem but there is no well-established medical treatment. Therefore, the injustice is more about the disbelief and lack of understanding that people experience. I think that *Holding in High Regard* reflects the general respect and admiration that participants expressed towards patients with CFS/ME. The disbelief element fits within the *Damaging Experience of Being Disbelieved* subtheme and the *Emotional Connection* subtheme captures the sense of injustice expressed by some participants.”

Finalising themes: “It has taken about ten weeks from first finishing the themes, to finalising them. I have found it very, very difficult to feel that I had reached the point of getting the titles of themes ‘right’. Finding appropriate titles for each theme was more challenging than ordering the themes – I had very clear ideas in my head about what each theme meant, but finding the right words to capture this and communicate the essence of a theme to the reader has taken time. I think this reflects the level of detail and meaning that the interview data held.”

Glossary of Terms

BME – Black and Minority Ethnic group

CBT – Cognitive Behaviour Therapy

CDC – Center of Disease Control

CFS – Chronic Fatigue Syndrome

GET – Graded Exercise Therapy

GP – General Practitioner

IPA – Interpretative Phenomenological Analysis

ME – Myalgic Encephalomyelitis

NICE – National Institute for Health and Clinical Excellence

NHS – National Health Service

OT – Occupational Therapist

RCT – Randomised Controlled Trial

SMC – Standard Medical Care

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