

**Adults' experiences of life with Chronic Fatigue
Syndrome/ME**

Catherine Nicholl

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Declaration

I declare that this thesis is the result of my own original work and that the work included in this thesis has not been submitted to any other university for a degree, diploma, or any other qualification.

Catherine R. Nicholl

University of Sheffield

16th July 2004

Abstract

Literature Review: Studies investigating the Quality of Life (QoL) and experiences of people with CFS/ME are reviewed. A number of standardised measures of QoL have been used with people with CFS/ME. Studies have consistently shown significantly reduced QoL across all domains, compared to the general population and other chronic illness groups. The mainly qualitative literature describing the experiences of people with CFS/ME highlighted the impact of symptoms, experiences of not being believed, difficulties obtaining a diagnosis and the effects of the illness on identity. The conceptual and methodological limitations of the studies are discussed. The relevance of the findings to theoretical models of CFS/ME and chronic illness are considered and recommendations made for future research.

Research Report: A qualitative study was undertaken to explore the experiences of people with CFS/ME. Semi-structured interviews were completed with eight women. The results were analysed using Interpretative Phenomenological Analysis. Participants described initially feeling overwhelmed by their illness. Attempts to seek help and advice resulted in experiences of being let down and disbelieved. Participants reacted to this by seeking information and identifying sources of self help, this enabled them to increase their sense of control and begin to accept their illness. The relationship of the results to existing research and theoretical models of adjustment to CFS and other chronic illnesses is discussed.

Critical Appraisal: A reflective discussion of the process of the research from identifying the research aims, to writing up is presented. Resulting opportunities for personal, clinical and research learning are highlighted and discussed.

Acknowledgements

I wish to acknowledge and thank the eight women who shared their experiences with me. Without them this thesis obviously would not be possible. I also wish to thank my supervisors, Andrew Thompson and Alan Blair, for reading and commenting on drafts, pinning me down to specify aims and definitions and providing general encouragement. Finally I wish to thank my parents, for patiently listening to my moaning, and Paul Edwards for making me laugh and always being there for me.

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LITERATURE REVIEW

CFS/M.E AND QUALITY OF LIFE: A REVIEW

ABSTRACT

Purpose: Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME) is a condition with unknown aetiology and poor prognosis which has a severe impact on people's lives. This review aims to increase the insight of professionals into the lives of people with CFS/ME.

Methods: A literature review was conducted using EMBASE, PsycInfo and Web of Science databases to identify studies investigating Quality of Life (QoL) and the experience of living with CFS/ME. The mainly qualitative data describing people's experiences of CFS/ME is presented as a summary of common themes.

Results: Studies have consistently found severe impairment across all domains of QoL compared to the general population and other physical illness groups. However, difficulties exist due to lack of definition of the concept of QoL and the use of a variety of different measures, small sample sizes and different diagnostic criteria. A review of qualitative research studies addressing the experience of living with CFS/ME identified a number of common themes, including 'symptoms and their impact', 'the importance of diagnosis', 'impact on identity' and 'lack of understanding and disbelief'. The methodological limitations of such studies are examined.

Conclusions: CFS/ME is an illness with a profound effect on people's QoL. This is perceived to be compounded by a lack of understanding from professionals and the general population. Clinical and theoretical implications of the findings are discussed and recommendations are made for future research.

INTRODUCTION

There is currently a perception by people with CFS/ME that their illness and the difficulties it presents are poorly understood. This paper aims to review current knowledge about the experiences of people living with CFS/ME, in order to increase the insight of professionals into this condition. Firstly, the research on the QoL of individuals with CFS/ME will be reviewed. Secondly, the findings from a number of qualitative studies will be summarised, in order to explore current knowledge about the experiences of people living with CFS/ME. Following on from this will be a discussion of the findings in relation to current psychological theories.

CFS/ME was officially recognised as a 'real entity' in 1998 (CFS/ME Working Group, 2002), but has a long and controversial history (see Wessely, 1991; Moss-Morris & Petrie, 2000). Despite investigation of numerous hypothesised causative agents including infectious, immunological, neuroendocrine, sleep and psychiatric mechanisms, no consensus has yet emerged on the aetiology of CFS/ME (Afari & Buchwald, 2003; Komaroff, 2000). Consequently, many different names have been given to CFS over the years. Following the approach of the CFS/ME Working Group (2002), throughout this report the term CFS/ME will be used.

A number of different definitions of CFS/ME are available (e.g. Fukuda *et al.*, 1994; Holmes *et al.*, 1988; Sharpe, Archard, & Banatvala, 1991), all of which require new onset of fatigue of at least 6 month duration with disabling functional impairment and no identifiable physical or psychological cause. Additional specific symptoms vary between

definitions but commonly include; sore throat, muscle pain, headaches and post exercise malaise. Such case definitions have been criticised due to vague and subjective criteria, resulting in poor agreement between physicians (Jason, King, Taylor, & Kennedy, 2000). Perhaps unsurprisingly, prevalence rates of CFS/ME are found to vary significantly. Afari and Buchwald (2003) suggested rates vary between 0.007-2.8% in the general adult population, and 0.006-3.0% in primary care. A review of follow up studies by Joyce, Hotopf, & Wessely (1997) reported that less than 10% of adults diagnosed with CFS/ME according to full diagnostic criteria returned to pre-morbid levels of functioning at follow up. CFS/ME is also found in children (CFS/M.E. Working Group, 2002). However, this review is limited to adults with CFS/ME.

Studies have repeatedly shown rates of depression and anxiety in CFS/ME to be significantly higher than in the general population and other physical illness groups (e.g. Afari & Buchwald, 2003; Iversen & Wesseley, 2003). A review by Afari & Buchwald (2003) reported 50-75% of patients with CFS/ME to have a lifetime history of major depression, 17-25% panic disorder, 2-30% generalized anxiety disorder and up to 28% somatization disorder. However, there are difficulties with diagnosis due to overlapping symptoms. Particularly, diagnosis of somatization disorder is suggested to be of limited use in conditions where aetiology remains uncertain, due to the key role of attribution of symptoms within the diagnosis (Johnson, DeLuca, & Natelson, 1996). Discussion of the role psychiatric disorders play in CFS/ME is controversial and it remains unclear whether such disorders play a causative role in CFS/ME, are reactive to the impact of the condition, or occur alongside the illness. However, co-morbid psychiatric disorders have been suggested to predict poor CFS/ME prognosis (Bentall, Powell, Nye & Edwards,

2002; Bombardier & Buchwald, 1995; Clark *et al.*, 1995) and priority should be given to their assessment and treatment.

Both reports in the literature and anecdotal evidence suggests that people diagnosed with CFS/ME feel that they are not listened to, believed or understood (CFS/ME Working Group, 2002; Hughes, 2002; Sykes & Campion, 2002). People with CFS/ME are reported to be frequently dissatisfied with medical services (Ax, Gregg, & Jones, 1997; Deale & Wesseley, 2001) and studies of GP's and other medical professionals confirm that some professionals remain 'uncomfortable' with the concept of CFS and reluctant to diagnose (Prins, Bleijenberg, Rouweler, van Weel, & van der Meer, 2000; Stein, 2001; Woodward, Broom, & Legge, 1995). Contradictory beliefs about the cause of CFS/ME, particularly the suggestion of psychiatric causative factors, and the sense of lack of legitimacy of the condition, were suggested to affect both patients and doctors (Ax *et al.*, 1997; Deale & Wesseley, 2001; Stein, 2001; Taillefer, Kirmayer, Robbins, & Lasry, 2003). The difficulties which appear to exist between some patients and professionals are likely to be significant barriers to the effective care of this chronic and disabling condition.

Although psychological models of CFS/ME have been developed, with the exception of Fennell (1995), these have largely focused on cognitive processes hypothesised to be maintaining the illness (e.g. Friedberg, 1995; Surawy, Hackmann, Hawton, & Sharpe, 1995; Vercoulen *et al.*, 1998). This is in contrast to the general chronic illness literature within which numerous models have been proposed describing the processes of coping with, or adjusting to, chronic illness. Several stage models of chronic illness exist which identify initial phases at symptom onset of uncertainty, followed by attempts to regain

control and mastery and integrate pre and post illness identity (e.g. Calabro, 1990; Moos & Schaefer, 1984; Morse & Johnson, 1991; Taylor, 1983). Such models may have relevance to the experiences of people with CFS/ME.

METHODS

A literature search was conducted using EMBASE, PsycInfo and Web of Science Databases. The search terms 'Chronic Fatigue Syndrome', 'Myalgic Encephalomyelitis' and 'Post Viral Fatigue Syndrome' were initially entered. Articles were identified from peer reviewed journals which included these terms alongside terms of 'experience', 'subjective', 'impact', 'qualitative' and 'quality of life'. The abstracts of articles were reviewed to detect those discussing either QoL, or the experience of living with CFS/ME. For the purpose of this review, this was defined in terms of papers which asked about the experience of living with CFS/ME from the perspective of the person with the illness. Further articles were identified from the reference sections of relevant papers. As the aim of the review is to explore the experiences of people with CFS/ME, articles using QoL purely as an outcome measure were excluded. Articles relating to children, and those discussing general fatigue rather than chronic fatigue syndrome, were also excluded.

QUALITY OF LIFE

Traditionally used measures of medical outcome such as morbidity, mortality and symptom severity do not sufficiently capture the full impact of chronic diseases such as CFS/ME. Such illnesses typically impact on the entirety of people's lives, affecting

physical health and functioning, relationships, ability to work and leisure activities. The concept of QoL aims to address this by capturing a more overriding and subjective sense of how satisfied people are with their life. This could be extremely valuable to aid clinicians in understanding the impact of CFS/ME and identifying possible areas for intervention. QoL also has value as an outcome measure to ascertain the efficacy of interventions which aim to improve general wellbeing or distress, rather than attempting to 'cure'. Further, given the hypothesised role of psychosocial factors in CFS/ME, a person's QoL may have some influence on their illness course (Anderson & Estwing Ferrans, 1997)

However, assessing and investigating QoL is greatly complicated by the lack of definition of the concept, and studies investigating QoL may actually be measuring very dissimilar things. Nord, Arnesen, Menzel, & Pinto (2001) described QoL as 'reflecting individuals overall feeling of wellbeing and their view of the desirability of the life they are living'. Other researchers have defined QoL in terms of the domains covered by the concept. These have typically included physical functioning, social functioning and psychological functioning (e.g. Ferrans, 1990; Schweitzer, Kelly, Foran, Terry, & Whiting, 1995). A related concept is Health Related Quality of Life (HRQoL). This was defined as the 'implications or effects of an individual's physical state for their life opportunities and psychosocial functioning' (Weinman, Wright, & Johnston, 1995, p3). Within this review the focus will be on the literature which has aimed specifically to assess the QoL or HRQoL of people with CFS/ME, with the aim of gaining insight into the difficulties faced by people with this condition. For the purpose of this review QoL is

therefore defined as reflecting a sense of people with CFS/ME's wellbeing or subjective satisfaction with their current life.

Research Findings

Assessment of quality of life in CFS/ME: Standardised measures described as assessing QoL used to date with people with CFS/ME are the Medical Outcomes Study Short-Form General Health Survey (SF-36, Ware & Sherbourne, 1992, used by Buchwald, Pearlman, Umali, Schmaling, & Katon, 1996; Hardt *et al.*, 2001; Hyman & Wasser, 1998; Kennedy, Abbot, Spence, Underwood, & Belch, 2004; Manu, Affleck, Tennen, Morse, & Escobar, 1996; Myers & Wilks, 1999; Smits, Van Rooy, & Nagtegaal, 2002; Tiersky, Matheis, Deluca, Lange, & Natelson, 2003), the Sickness Impact Profile (SIP, Bergner, Bobbitt, Carter, & Gilson, 1981, used by De Ridder, Schreurs, & Bensing, 1998; Schweitzer *et al.*, 1995), the WHOQoL-100 (WHOQOL group, 1995, used by De Vries & Van Heck, 1997; Van Heck & De Vries, 2002), the Euroqol (The Euroqol Group, 1990, used by Myers & Wilks, 1999), the Quality of Life Index (QLI, Ferrans & Powers, 1985, used by Andersen & Estwing Ferrans, 1997; Taylor, 2004), the Manchester short assessment of quality of life (MANSA, Priebe, Huxley, Knight & Evans, 1999, used by White *et al.*, 2002) and the COOP charts (Dartmouth Primary Care COOP Project, 1992, used by Wagner-Raphael, Jason & Ferrari, 1999). All studies comparing scores of people with CFS/ME to the general population found significantly reduced QoL in people with CFS/ME. This result was found with Euroqol health value and visual analogue scale scores (VAS) and across all SF-36 and SIP subscales and all WHOQOL subscales with the exception of

spirituality¹. Studies also included samples from different countries and different recruitment sources (e.g. Hardt *et al.*, 2001; Myers & Wilks, 1999; Schweitzer *et al.*, 1995; Van Heck & De Vries, 2002).

Looking in more detail at these results, greater levels of impairment have been found on physical functioning subscales than mental health and emotional limitations of role subscales of the SF-36 (Hardt *et al.*, 2001; Myers & Wilks, 1999; Smits *et al.*, 2002, Tiersky *et al.*, 2003), and on health and functioning subscales than on social/economic and family subscales of the QLI (Andersen & Estwing Ferrans, 1997). Studies have also investigated QoL using non standardised measures. Andersen, Permin, & Albrecht, (2004) reported on changes in QoL over a five year period using a questionnaire focused on coping with daily living. Andersen *et al.* reported high levels of disability affecting social life and work situation, cognitive abilities and neuropsychological problems. At five year follow up increases in work disability, allergies and some cognitive difficulties were found, along with some improvement in emotional problems. However, as a newly developed questionnaire, limited information on reliability and validity was available and no comparison group was used. Schweitzer *et al.* (1995) and Andersen & Estwing Ferrans (1997) included qualitative methods to ascertain important aspects of QoL for people with CFS/ME. Themes to emerge included the profound impact of the illness with multiple losses impacting on identity, dissatisfaction with health and functioning,

¹ SF-36 subscales: physical functioning, role limitations due to physical problems, bodily pain, general health perceptions, vitality, social functioning, role limitations due to emotional problems, emotional wellbeing.

SIP subscales: ambulation, body care and movement, mobility, sleep and rest, eating, emotional behaviour, alertness behaviour, social interaction, communication, home management, recreation and pastimes, work.

WHOQOL subscales: physical, psychological, independence, social relationships, environment, spirituality/religion/personal beliefs

QLI subscales: health and functioning, social, psychological/spiritual, economic, family

difficulties with family and social relationships, severe disruptions to recreational activities, reduction in quantity and/or quality of work tasks and the economic implications of the illness.

Comparative research: QoL measures have also been used to make comparisons between groups. Kennedy *et al.* (2004) compared people recruited from CFS/ME self help groups, people with CFS/ME reporting exposure to organophosphates as cause of illness and Gulf War veterans with CFS/ME symptoms. Differences between the groups were found on some SF-36 subscales. CFS/ME patients from self help groups were significantly less impaired on role limitations due to emotional problems and mental health subscales than the other two groups. The Organophosphate group were found to be significantly less impaired on physical and social functioning, and the Gulf War group had significantly greater levels of bodily pain and poorer general health scores. White *et al.* (2002) found similar levels of QoL, as measured by the MANSA, in people with CFS/ME attending immunology and psychiatry outpatient clinics. Finally, Hyman and Wasser (1998) found patients with CFS/ME and functional bowel disease (FBD) scored significantly lower on general health perception and energy/fatigue on the SF-36 than patients with FBD alone.

Studies have also compared CFS/ME patient scores to previous research with other chronic illness groups. Andersen and Estwing Ferrans (1997) reported lower scores of people with CFS/ME on all domains of the QLI than found in previous research on HIV, narcolepsy, hemodialysis, long term bone marrow transplant, post chemotherapy cancer, liver transplant, post angioplasty and coronary artery disease. Van Heck and De Vries

(2002) reported considerably lower WHOQOL scores on physical health, level of independence, social relationships and environment subscales than elderly groups and patients with sarcoidosis and psoriasis. In a comparison to patients with Multiple Sclerosis (MS), Schweitzer *et al.* (1995) reported higher SIP scores in CFS/ME patients overall, but that differences were due to psychosocial functioning and other life quality measures rather than physical functioning.

Factors affecting quality of life: A limited number of studies have looked at relationships between QoL and other measures. De Vries and Van Heck (1997) found moderate correlations between the WHOQOL-100 and SIP in people with CFS/ME. Myers and Wilks (1999) found good correlations between Euroqol health value and visual analogue scale (VAS) and the SF-36, with the weakest correlations between emotional limitations of role and mental health. Research has also investigated links between illness duration and severity and QoL. Myers and Wilks found that duration of ill health was significantly negatively correlated with Euroqol health score and VAS, and SF-36 physical functioning, pain, general health and vitality. Andersen *et al.* (2004), described above, also reported increased disability at 5 year follow up. In a study using structural equation modelling, Manu *et al.* (1996) suggested that QoL in CFS/ME was predicted by physical symptoms, which were correlated with hypochondriacal beliefs and preoccupations. Additionally, Wagner-Raphael *et al.* (1999) reported fatigue severity to be predictive of scores on the QoL section of the COOP chart scales in nurses with CFS/ME. However, Schweitzer *et al.* (1995) found that demographic variables, including duration of illness, were not predictive of QoL as measured by the SIP. De Ridder *et al.*

(1998) also found participants' evaluation of adaptive tasks to be more predictive of QoL, as measured by the SIP, than illness characteristics or coping styles.

Myers and Wilks (1999) reported that participants working full time had greater physical functioning and less pain than those who were unable to work. Again, no significant differences in functioning were found between groups who were and were not working by Schweitzer *et al.* (1995). Tiersky *et al.* (2003) looked at the relationship between psychiatric illness and QoL. Contrary to expectations, Tiersky *et al.* found concurrent psychiatric illness to reduce scores on the mental health composite score of the SF-36, but not the physical health composite. Research on factors affecting QoL to date therefore appears inconclusive and further research is necessary.

Summary

The studies described above have demonstrated the severe impact of CFS/ME on people's lives, with participants reporting similar or lower levels of functioning compared to a number of other chronic illnesses. CFS/ME has also been reported to have a greater impact on physical than psychosocial functioning. However, the lack of definition of the concept of QoL has severely limited research to date in this area. Several of the measures described as assessing QoL or HRQoL are measures of health or functional status, and do not address the more overarching concept of QoL (Allison, Locker, & Feine, 1997; Hunt, 1997; Van Heck & De Vries, 2002). For example, the SIP was designed as a behaviourally based measure of perceived health status (Bergner *et al.*, 1981) and the SF-36 and Euroqol are often referred to as measures of health status or functioning (e.g.

Buchwald *et al.*, 1996, Taillefer, Kirmayer, Robbins, & Lasry, 2002). Within the general QoL literature, level of functioning has not been found to relate directly to a person's sense of wellbeing or satisfaction with their life (e.g. Allison *et al.*, 1997; Hunt, 1997). Such measures of functional abilities can therefore not be presumed to be assessing QoL, if this is to be defined in terms of a person's subjective satisfaction with their life. In contrast, the WHOQOL and QLI consider the subjective nature of QoL to be of key importance². As discussed above, recent studies using these measures have continued to show the severe impact of CFS/ME on all aspects of QoL. A key problem with research on QoL is the lack of conceptual models or theory underpinning the assumptions of QoL. This makes it extremely difficult to assess the validity of different measures or to define the concept. If a consensus cannot be reached regarding the nature of QoL it may be necessary to consider whether QoL can be measured in a meaningful way (Hunt, 1997).

In terms of methodological limitations, the QoL studies described above included people with CFS/ME based on different diagnostic criteria. Studies also varied in recruitment source with some using medical settings (Andersen *et al.*, 2004; Hardt *et al.*, 2001; Myers & Wilks, 1999; White *et al.*, 2002), whilst others recruited through support groups (Kennedy *et al.*, 2004; Van Heck & De Vries, 2002) or a combination of sources (Andersen & Estwing Ferrans, 1997; Schweitzer *et al.*, 1995). This causes difficulties when making comparisons across studies. Further, few studies have used matched comparison groups within the studies, tending to compare people with CFS/ME to population norms or previous research findings. Those studies which have used a comparison group have recruited from an undergraduate university sample (Schweitzer *et*

² The WHOQOL asks for evaluations of people's satisfaction with the different aspects of quality of life, while the QLI weights subscale scores based on ratings of the importance of the area of functioning for the individual.

al., 1995) and through friends or family of the CFS/ME participant (Van Heck & De Vries, 2002). These recruitment sources are likely to be affected by biases such as age and socioeconomic class.

The findings of the studies described above also raise some concerns about the sensitivity of the EuroQoL and SF-36. Myers and Wilks (1999) reported possible ceiling effects on mobility and self care subscales of the EuroQoL and floor effects on the role limitations due to physical problems subscale of the SF-36. Similar difficulties have also been reported with the use of the Euroqol and a disease specific version of the SF-36 in patients with MS (Nicholl, Lincoln, Francis, & Stephan, 2001). Further research is therefore necessary to investigate whether these measures are sufficiently sensitive for patient groups with severe disability. Conflicting findings were also reported regarding the relationship between illness duration and work status and QoL as measured by the Euroqol, SF-36 and SIP (Myers & Wilks, 1999; Schweitzer *et al.*, 1995). The findings of these studies were based on small sample sizes and further research is necessary to clarify this relationship.

QUALITATIVE EXPLORATORY STUDIES OF LIVING WITH CFS/ME

Qualitative research aims to give a greater depth of insight into peoples' experiences than can traditionally be gained through quantitative techniques. The studies reviewed here, although coming from a variety of perspectives, aim to "tap into" people with CFS/ME's own understandings and experiences (Cohn, 1999), and to give the point of view of the person with CFS/ME (Söderlund, Skoge, & Malterud, 2000). As a result of the rapid

expansion of qualitative research, there is an increasing demand for techniques to integrate qualitative findings across studies. McCormick, Rodney, and Varcoe (2003) and Sandelowski and Barroso (2003) have recently discussed approaches to this, the area of qualitative meta-synthesis or meta-analysis. Such methodologies are still in the early stages and no uniformly established method exists. There also remains a great deal of disagreement as to whether such an approach is possible or desirable, particularly given the difficulties combining data based on different methodologies and theoretical assumptions. For the purposes of this review, the qualitative studies were examined to identify commonalities and differences in themes. This therefore is a summary of common themes as stated by the original researchers, and does not attempt to offer a reinterpretation (cf. McCormick *et al.*, 2003; Paterson, 2001).

A total of 17 studies were identified that included a qualitative component addressing people's experiences of life with CFS/ME. Of these, three were separate reports from the same original studies. Therefore, the studies covered a total of 14 samples. In order to extract the themes, the results of the studies were read and themes noted down, alongside a brief description from the text. For studies which did not clearly state themes, the description of results was read and re-read and key areas identified by the authors were extracted and listed in a similar way. After reviewing all the individual studies, commonalities were identified in the overall list of themes, and groups of themes with similar foci were identified. These themes will be illustrated through reference to the results of relevant quantitative studies and followed by a discussion of the methodological limitations of such research techniques.

Research findings

Symptoms: Articles described a range of symptoms of CFS/ME, the worst of which were reported to be exhaustion, or lack of energy, and pain (Cohn, 1999; Söderlund *et al.*, 2000). Additional symptoms included sleep disturbance and auditory sensitivity. Cognitive difficulties were also reported which severely affected participants' ability to communicate, think and learn (Hart & Grace, 2000; Söderlund *et al.*, 2000; Tuck & Human, 1998). Symptoms were reported to be numerous, changeable, unpredictable, hard to explain and generalised, affecting the whole body (Clarke, 1999; Cohn, 1999; Cooper, 1997; Hart & Grace, 2000). The nature of the symptoms of CFS/ME made it extremely hard to fit in with a society which is suggested to be focused on constant activity, speed and 'scheduledness' (Ware, 1999).

The range of symptoms described, generally fitted within the CFS/ME case definition (Fukuda *et al.*, 1994; Holmes *et al.*, 1988; Sharpe *et al.*, 1991), and previous quantitative studies of CFS/ME symptoms (e.g. Vercoulen *et al.*, 1994). Interestingly, despite the high rates of depression and anxiety typically reported in people with CFS/ME (e.g. Afari & Buchwald, 2003), depression was only mentioned within one study (Tuck & Human, 1998). In agreement with the findings of the qualitative studies, cognitive problems are reported to be some of the most disruptive and disabling symptoms of CFS/ME (Afari & Buchwald, 2003). A recent review by Michiels and Cluydts (2001) confirmed a modest but significant deficit in information processing, impaired working memory and poor learning of information in people with CFS/ME.

Misunderstanding and disbelief: A number of studies described participants' perception that their illness was not believed or understood. This was suggested to relate to the lack of objective or visible signs of illness. Participants reported that their symptoms were trivialised (Cooper, 1997; Lehman, Lehman, Hemphill, Mandel, & Cooper, 2002; Ware, 1992, 1999) or interpreted as psychological or psychosomatic (Åsbring & Närvänen, 2002; Lehman *et al.*, 2002; Ware, 1992, 1999; Wheeler, 1992) by friends, family and doctors. This was experienced by some as a threat to their identity or 'questioning (their) morality' (Åsbring & Närvänen, 2002). A range of responses to this are reported, varying from self doubt to anger (Ware, 1999). Lehman *et al.* (2002) found that participants reporting that their physician failed to legitimize their illness had significantly higher depression and anxiety scores than those who felt legitimized. A questionnaire based study by Green, Romei & Natelson (1999) also found that 70% of participants recruited from medical settings believed that other people attributed their symptoms to psychological causes. The finding of themes describing a sense of not being believed is in agreement with reports described earlier (CFS/M.E. Working Group, 2002; Hughes, 2002; Sykes & Campion, 2002).

The importance of a diagnosis: As a result of the failure to find legitimacy, participants began a process of 'doctor shopping' (Clarke, 1999, 2000). Participants consulted multiple doctors seeking an acceptable diagnosis. The delay in finding a diagnosis was perceived to have negative effects in terms of physical health and psychological responses such as anxiety, confusion and bitterness (Pinikahana, Holloway & Millen, 2002; Woodward *et al.*, 1995). Cooper (1997) described participants feeling at 'rock bottom' pre diagnosis with no available support. Diagnosis was frequently reported to be

a key event in the illness course (Clarke, 1999, 2000; Cooper, 1997; Lehman *et al.*, 2002; Pinikahana *et al.*, 2002; Woodward *et al.*, 1995). For example, Woodward *et al.* found that 90% of participants nominated diagnosis as the single most helpful event in the course of their illness. Obtaining a diagnosis seemed to be important to obtain legitimacy for illness and to give meaning to the suffering caused by the illness (Cooper, 1997; Woodward *et al.*, 1995). Although the diagnosis was perceived as a relief, it was also suggested to bring its own burdens in terms of the potential stigma attached to CFS/ME (Åsbring & Närvänen, 2002). In agreement with these findings, quantitative studies have also highlighted people with CFS/ME's dissatisfaction with doctors and the reluctance of some doctors to diagnose the condition (Ax *et al.*, 1997; Deale & Wesseley, 2001; Prins *et al.*, 2000; Stein, 2001).

Cooper (1997) discusses the expectation that doctors will be able to diagnose and treat health problems in terms of the 'public myth-private belief'. Doctors who fulfilled this expectation were 'idealised' while those who did not were 'demonised'. In response to difficulties obtaining a diagnosis, participants began to challenge their own beliefs in doctors' abilities and to take an active role in understanding and diagnosing their own illness and in its management (Clarke, 1999, 2000; Cooper, 1997; Hart & Grace, 2000; Ware, 1992; Wheeler, 1992). Participants also described trying a range of interventions including pharmaceutical and alternative therapies (Pinikahana *et al.*, 2002). For some participants taking an active role involved becoming the 'expert' and fighting to convince doctors of the reality of their illness, whilst for others it involved seeking out an expert doctor who was seen to understand. This was reported to be a turning point for some people with CFS/ME (Cooper, 1997).

Trying to make sense of the illness: Within several studies, references are made to participants having their own understanding or ‘theory’ about the causes of CFS/ME (Clarke, 1999; Cooper, 1997; Horton-Salway, 2001; Pinikahana *et al.*, 2002). This is in contrast to the general lack of consensus regarding the aetiology of CFS/ME (Afari & Buchwald, 2003; Komaroff, 2000). Typically participants’ ‘theories’ are based on a physical cause with a possible role for psychosocial factors such as stress. Within this description, reference is frequently made to high pre-illness activity levels and stresses, or life crises occurring around the onset of symptoms (Clarke, 1999; Cohn, 1999; Horton-Salway, 2001; Pinikahana *et al.*, 2002). In a related piece of qualitative research, Clements, Sharpe, Simkin, Borrill & Hawton (1997) discussed the development of people’s beliefs about the illness through ‘prolonged reflection on their own experiences’ and reading of media reports, self help books and patient group literature.

Social impact: CFS/ME is reported to have a severe negative effect on people’s social lives and ability to work (Pinikahana *et al.*, 2002; Söderlund *et al.*, 2000; Ware, 1998, 1999; Woodward *et al.*, 1995). Participants described withdrawing from social contact due to fatigue, symptom unpredictability, and cognitive difficulties affecting their ability to take part in activities and conversations (Hart & Grace, 2000). Moreover, the perceived lack of understanding by others was suggested to create a sense of distance or ‘unconnectedness’ within existing relationships, further increasing the feeling of social isolation and reducing potential sources of support. The strategies aiming to help cope with CFS/ME described below, may result in further withdrawal from social contact. Participants also reported friends and family to have withdrawn from them. Additionally, CFS/ME symptoms such as cognitive problems, lack of energy and chronic pain make

getting to work a daily challenge (Ware, 1998). This may cause embarrassment and shame, and place jobs in jeopardy, resulting in further social isolation. The social impact of CFS/ME may be exacerbated by financial problems related to a reduction in income, difficulties accessing benefits and increasing expenses (Asbring, 2001; Clarke, 1999; Pinikahana *et al.*, 2002; Ware, 1999; Woodward *et al.*, 1995). Green *et al.*'s (1999) questionnaire study, reported 95% of participants to feel estranged due to CFS/ME. The QoL literature described previously also showed greatly reduced social functioning in CFS/ME (e.g. Andersen & Estwing Ferrans, 1997; Schweitzer *et al.*, 1995). Despite this, relatively little research to date has investigated the social context of CFS/ME (Cordingley, Wearder, Appleby, & Fisher, 2001).

Coping strategies: Ware (1998) described strategies used by participants to enable them to continue in their work roles given the limitations of their illness. These include prioritizing work over other activities, compensating for deficits, hiding symptoms and finding flexibility in work demands. The use of such strategies allowed participants to maintain their place in the 'social world of healthy people' (Ware, 1999), but came at a cost in terms of lack of energy for social activities and distancing from potential sources of social support. Åsbring and Närvänen (2002) also discuss strategies used by participants to protect themselves from enacted stigma, and help retain their identity and position in society. Such strategies included withdrawing from friends and colleagues in order to conceal the illness and avoid unachievable demands. Conversely, some participants were reported to actively spread information in order to educate others. Some participants also chose to approach other people with CFS/ME as a source of support, whilst others chose to avoid them. Maintaining roles at work and a place within society

was suggested to be extremely important for an individual's sense of identity. Similar strategies of concealment and educating others were also reported in Green *et al.*'s (1999) questionnaire study.

Changes in identity: Studies refer to the dramatic changes forced in the lives of people with CFS/ME. This is discussed in terms of 'an earlier identity part lost' and 'a before and after story' (Asbring, 2001; Horton-Salway, 2001). Participants described very busy and active lives, which were halted by the onset of fatigue (Clarke, 1999; Cohn, 1999; Horton-Salway, 2001; Tuck & Human, 1998). Such changes also impacted on the lives of family members (Horton-Salway, 2001). CFS/ME is seen to 'crash from outside' taking away people's control over their life and 'knocking the stuffing out of them' (Cohn, 1999, Hart & Grace, 2000). The losses of social contact, work and place in society described above may further impact on people's sense of identity. Asbring (2001) described participants being at different stages of 'coming to terms with' their new identity. This was achieved through reorganising their lives, getting to know the limits of the body, and recognising the need for help from others. This may also require changes in the expectations people place upon themselves (Ware, 1999). Adhering to these personal limitations was reported to facilitate participants' recovery (Lehman *et al.*, 2002). Some participants also described gains from their illness, related to changes in priorities and relationships and personal understanding and strength (Asbring, 2001; Cohn, 1999).

Summary

The themes described above give some insight into the findings of qualitative studies investigating the experience of living with CFS/ME. It is important to consider these findings alongside their methodological limitations. Established principles for assessing the quality of qualitative research were used to evaluate the studies described above (e.g. Elliott, Fischer & Rennie, 1999; Stiles, 2003; Willig, 2001). These differ to those traditionally applied to quantitative research. However, it must be borne in mind that the majority of the studies were taken from anthropological or sociological journals. As such the studies may have had different aims and employed different methodologies. It is therefore perhaps unsurprising that the studies do not fulfil criteria set out within the disciplines of Psychology and Medicine.

Key criteria in qualitative research include the transparency of the research process. This is achieved through grounding themes in the data by providing quotes and describing the interview and analysis process. This allows the reader to understand how the themes emerged, and therefore to ascertain the validity and reliability of this process (Mayes & Popes, 2000). Research reflexivity is also stressed, as it is acknowledged within qualitative research that the researcher cannot remain fully objective. Through reporting on researchers' perspectives and possible biases, the reader has additional information on which to judge the validity of the findings. Finally it is necessary to fully describe the context of the study and the sample, to enable appropriate comparisons to be made to other samples and clinical populations. The extent to which researchers attempted to fulfil these criteria is presented in Table 1.

Table 1: Methodological limitations of qualitative research studies

	Sample ¹	Data Collection method	Analysis method	Quality control
Ware (1992) USA	50 individuals. 80% women, 92% white, Age 23-66. ID: 1 __ - 25 years. PR: 50 out of 350 referred DC: 80% met US, British or Australian CFS case definitions. Recruitment: M	Interviews covering life history and illness experience Questions NS	NS	NS
Wheeler (1992) USA	10 women.	Open ended interview format. Questions given	NS	Reflexivity: discussion of authors perspective
Woodward (1995) Australia	40 women. Aged 13-64 10 men Aged 25-53 DC: Diagnosed by doctors, criteria stated	3 indepth interviews over 2 years. Questions stated	Analysis helped by NUDIST computer program.	NS
Cooper (1997) UK	7 women 3 men. Varying degree of disability. Recruitment: SH	Life history interviews. Areas covered stated.	NS	Reflexivity: states opinion on ME concept
Tuck & Human (1998) USA	22 participants Age 19-74. 86% female. PR: 22/49 Recruitment: SH	Postal questionnaires Open ended questions (questions specified)	NS	Reflexivity: States view on CFS Validity checks: transcripts read by two researchers

¹PR= participation rates

DC= diagnostic criteria

Recruitment source (M = medical, SH = Self Help Groups, I = informal network)

ID= illness duration

NS = not stated

	Sample	Data Collection method	Analysis method	Quality control
Ware (1998, 1999) USA	66 participants. 53 women. 94% Caucasian. Age range 27-72. ID: 2 _ - 36 years. PR: 80 contacted. DC: CDC criteria Recruitment: M	4 contacts per year over 3 year period. Semi structured interview + questionnaires (3 months and 9 months) + telephone interview.	Identification of content themes and the elaboration and interpretation of their larger meaning as social processes mediating illness experience in CFS	Reflexivity: Ware (1998) description of anthropological perspective
Cohn (1999) UK	25 in depth interviews with a cross section of sufferers. Recruitment: I	In depth interviews. Questions NS	NS	Reflexivity: discussion of perspective on illness
Clarke (1999, 2000) Canada	60 participants. 41 women age 18-80 ID: 8% >10 years, 30% 5-10 years, 51.6% 1-5 years. DC: All diagnosed by a doctor, criteria unspecified. Recruitment: SH	Telephone interview Open ended focussed interview schedule. Topics stated	1999 study: Constant comparative method. Referenced & described. 2000 study: Cross-Case analysis. Referenced & described	NS
Söderlund et al (2000) Norway	10 men, 2 women. ID: 1-20 years. PR: 40 invited to take part DC: Diagnosed by doctor. Criteria NS Recruitment: SH	Group Interview (90mins). Questions stated.	Giorgi's phenomenological approach. Referenced	Reflexivity: states approach to CFS and theoretical beliefs
Hart & Grace (2000) New Zealand	11 female non-Maori New Zealanders aged mid 20s – late 60s At various points in illness. Recruitment: SH, M & I	Interviews: Asked very general questions to fit individual interviews. Questions NS	Sections in which word fatigue or synonym or describing experiences of fatigue scanned for key words and phrases which were grouped according to themes.	NS

	Sample	Data Collection method	Analysis method	Quality control
Horton-Salway (2001) UK	1 female ME sufferer and partner	Interview, questions NS	Discursive psychology approach. Analysis unclear.	Reflexivity: describes theoretical approach
Asbring (2001), Åsbring & Närvänen (2002) Sweden	12 women with CFS, 13 women with fibromyalgia Age range 32-65. ID: 1-23 years (mean =10) PR: 2 women with CFS declined, 1 withdrew. DC: All diagnosed, criteria not specified Recruitment: M	Semi structured interviews following an interview guide. Topics stated	Grounded theory & Constant Comparison methods. Described & referenced	Reflexivity: Asbring & Närvänen state perspective re: causes of CFS/ME Asbring states theoretical framework
Lehman et al (2002) Canada	105 participants. 96% white, 88% women. Mean duration of symptoms 8 years (1-22) number of years since diagnosis mean = 5 (1-18). Mean age 47. PR: 62% of ME society responded. Recruitment: SH & M	Questionnaire measures and interviews. Topics stated	Codes, i.e. categories for responses grouped according to common themes, were developed by examining a random sample of responses.	Reflexivity: NS Validity checks: Two independent raters
Pinikahana et al (2002) Australia	90 questionnaires returned. 52 women. Ages stated. Average ID: 9 years PR: Initial response rate estimated 75%-85%. 45 interviewed. 25 transcribed and analysed Recruitment: SH	Open ended interviews, questionnaires, semi-structured interviews. Questions NS	NS	NS

All 17 studies provided examples of quotes, but in several accounts it was difficult to ascertain exactly what participants had been asked. This made it difficult to establish whether themes emerged naturally as important to participants or were prompted by the researcher. It is also unclear whether some studies focused on particular aspects of the experience of living with CFS/ME, or whether the reported results represent only a proportion of the findings. Additionally, only five of the studies used established analysis methods, although a further three gave some description of the techniques used for analysis, and few reported any credibility checks for their findings. There was also a great deal of variability in terms of reflexivity or owning one's perspective. Although some researchers described their theoretical or philosophical perspective, few discussed their beliefs regarding CFS/ME. A further difficulty relates to setting the context for the research, not all the studies reported fully described their sample, participation rates or recruitment source. Factors which may be important to be aware of when reading such research include gender, ethnicity, recruitment source and stage or severity of illness. For example, Cooper (1997) suggested that people contact self help groups because they have not received satisfactory advice and help elsewhere, thus representing a specific section of the CFS/ME population.

DISCUSSION

Despite the limitations of research to date, it seems that the devastating impact of CFS/ME is in no doubt. CFS/ME substantially reduces QoL across all domains, and has further implications for sufferers including the difficulties obtaining a diagnosis, and facing misunderstanding and disbelief. QoL seems to be a valuable concept to measure in

chronic conditions, however, a great deal more research needs to be done to arrive at a consensual definition and assessment techniques. It may be necessary to design a CFS/ME specific QoL measure including additional areas of particular importance to people with this illness. This has previously been done for several conditions such as MS (Cella, Dineen, & Arnason, 1996) and Cancer (Ferrans, 1990), and a need for add on modules to cover aspects of QoL specific to chronic illness was suggested by the WHOQOL Group (1995). Considering the two qualitative QoL investigations and the discussion of the experience of living with CFS/ME confirms the importance of existing QoL domains of physical and social functioning and suggests some additional areas which may be particularly important for people with CFS/ME. However, despite the evidence of increased rates of psychiatric diagnoses in CFS/ME, the relevance people with CFS/ME attach to psychological functioning for QoL appears less clear. Themes which seem to have emerged frequently within the literature include the impact of not being believed, difficulties obtaining a diagnosis, and financial implications. The development of more sensitive measures which are representative of the experiences of people with CFS/ME may be valuable both within clinical practice and as a research outcome measures.

Theoretical implications

A number of the themes identified from the qualitative literature have similarities to aspects of the models of adjustment to chronic illness described earlier (Taylor, 1983, Moos & Schaefer, 1984, Calabro, 1990, Morse & Johnson, 1991), although further research is necessary to explore this fully. Particularly, Taylor's (1983) discussion of the

need to find meaning in illness in order to regain a sense of control and mastery, and enhance self esteem, appears similar to the themes describing participants' need to make sense of their illness. Leventhal *et al.* (1980) also discuss the importance of illness representations in their self regulatory model of illness behaviour. The area of illness representations has received a great deal of research attention in CFS/ME. The illness beliefs of people with CFS/ME have been found to be notably consistent and to remain constant over time (Moss-Morris & Petrie, 2000), and research has suggested that illness representations, particularly strong illness identity, can predict poorer outcome (Edwards, Suresh, Lynch, Clarkson, & Stanley, 2001; Moss-Morris, Petrie, & Weinman, 1996). Illness beliefs and symptom interpretations are also suggested to be involved in the maintenance of the illness (Friedberg, 1995; Surawy *et al.*, 1995; Vercoulen *et al.*, 1998) and as such are explored within CBT approaches (Moss-Morris & Petrie, 2000; Prins *et al.*, 2001; Sharpe *et al.*, 1996). Within the qualitative studies described above, finding meaning for illness was perceived to be a helpful process, assisting participants to cope in the face of little support. Further research is therefore necessary to clarify the relationship between illness representations, coping and outcome.

Alongside coping with the numerous physical symptoms, people with CFS/ME also described difficulties with relationships, and experiences of not being understood and believed. The discussion of misunderstanding and disbelief and the search for diagnosis can be related to two main bodies of literature. Firstly, to the discussion of the importance of illness legitimation and the sick role (Bury, 1982; Stewart & Sullivan, 1982), and secondly to the area of stigma (Goffman, 1976). Bury (1982) suggested that the availability of medical knowledge and a diagnosis is important to allow people to

distance themselves from illness and legitimately relinquish responsibility. The lack of belief in CFS/ME prevents legitimate access to the sick role and participants were therefore not able to receive the support or understanding they wished for. This resulted in feelings of anger, depression and anxiety. Instead of the illness being legitimatised, participants were faced with potential stigma related to the suggestion of psychological illness and the diagnosis of CFS/ME itself. This further added to the burden of the illness. Similar difficulties and the necessity for role negotiation to gain illness legitimation have also been described in relation to MS (Stewart & Sullivan, 1982).

Goffman's (1976) discussion of stigma highlights the potential threat posed by the experience of stigma to identity. A number of coping strategies, such as information control and managing the visibility of the stigmatising characteristic are described, as reported by Åsbring and Närvänen (2002). The importance of identity in living with CFS/ME was also highlighted within other common themes, and has been discussed frequently in relation to chronic illness (e.g. Charmaz, 1983; Wright & Kirby, 1999). Charmaz (1983) considered the impact of chronic illness in terms of 'loss of self'. Major sources of loss of self were identified as living a restricted life, social isolation, experiencing discredited definitions of self and becoming a burden. Again, all these challenges are experienced by people with CFS/ME.

Clinical Implications

For clinicians coming into contact with people with CFS/ME, the extreme and overwhelming impact of the condition highlighted both by the QoL and qualitative

literature may help give some insight into the difficulties faced by clients. Particularly important to consider are the experiences of disbelief and stigma in relation to professionals 'psychologising' symptoms. This is likely to impact on people's reaction to referral to psychology and may need to be addressed carefully. The strength of feeling against psychologising symptoms is also in concordance with suggested explanations for high drop out rates from CBT, related to rejection of non medical explanations of illness (Prins *et al.*, 2001). As discussed by Sykes and Campion (2002), the suggestion that CFS/ME is purely psychological and the reaction to this seems to have resulted in a negative opinion of the role of psychology and psychiatry. This is unhelpful and it is important for professionals and patients to maintain a collaborative relationship.

The QoL and qualitative literature also highlights additional stresses faced by people with CFS/ME related to socioeconomic impact, social isolation, illness delegitimation and stigma. These are important to consider given the hypothesised role of psychological factors and psychosocial stress in the maintenance of the condition (Prins *et al.*, 2001; Sharpe *et al.*, 1996). As stated previously, the social context of CFS/ME has received little research attention to date (Cordingley *et al.*, 2001). However, this seems an important area for future research and preliminary research and theoretical models have suggested a key role for family and friends in aiding coping with CFS/ME (Butler, Chadler, & Wessely, 2001; Fennell, 1995; Schmaling, Smith, & Buchwald, 2000).

Conclusions and Recommendations for future research.

The research described above gives some insight into important aspects of the experience of living with CFS/ME. The findings are also broadly in line with recent reports by the CFS/ME Working Group (2002) and Action for ME (Sykes & Campion, 1992).

However, methodological difficulties make it difficult to ascertain the validity and reliability of the findings. It therefore is important that further research is conducted to confirm the validity of these findings using explicit analysis techniques and verifying the validity of the findings as much as is possible within the domain of qualitative research.

Particularly useful would be research addressing the process of living with CFS/ME.

Further exploration of the course of the illness may help to shed light on the processes people go through in adjusting to CFS/ME, and begin to identify ways in which clinicians can help with this process. Such research may also involve consideration of the importance of illness beliefs.

Considering the samples used within existing research also highlights important areas for further investigation. Particularly under-represented are men and people from ethnic minorities. The reliance on interview techniques may also exclude people who are severely ill and may be unable to participate in such a research process. This group of people are less visible but substantially impaired and it is important to find ways of investigating their experiences. Further, this review has highlighted the need for more sensitive and comprehensive measures of QoL. Such measures should cover the range of issues of importance to people with CFS/ME, addressing people's subjective satisfaction

with their lives, rather than purely their level of functioning. However, care should also be taken to address the conceptual difficulties involved in investigating QoL.

In conclusion, the current review has emphasised the severe impact of CFS/ME on peoples QoL, affecting social, occupational and physical functioning. People with this condition perceive that their illness is not understood or believed in, and battles for legitimization result in an increased illness burden. Some commonalities are drawn to existing models of adjustment to chronic research. Further research is necessary to explore this further and to develop sensitive and comprehensive measures of QoL in CFS/ME.

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RESEARCH REPORT

**AN 'OVERWHELMING ILLNESS': WOMEN'S
EXPERIENCES OF LEARNING TO LIVE WITH CFS/ME**

ABSTRACT

Objectives: CFS/ME is an illness which has a significant impact on the lives of sufferers.

A qualitative study was undertaken to gain insight into the experiences of people living with CFS/ME.

Design: The qualitative method Interpretative Phenomenological Analysis was used.

Methods: Semi structured interviews were conducted with eight women from an ME self help group. All participants reported having been diagnosed by a medical professional.

Results: Participants described CFS/ME as ‘an overwhelming illness’, resulting in distressing symptoms, multiple losses and affecting family and relationships. Attempts to seek support and advice were thwarted by the ‘invisible’ nature of the illness. The illness was frequently not believed and participants reported being let down by medical professionals, family and friends. The majority of participants reacted to this by seeking ‘knowledge’ about their illness. This enabled them to develop their own understanding of their illness and identify appropriate types of ‘self help’. This included alternative treatments, ‘pacing’ and having a positive ‘mindset’. The availability of practical and social support was also reported to be extremely important. Through these processes participants were able to regain a sense of control over their illness and reduce their sense of being overwhelmed. Alongside this, participants described moving away from fighting or denying their illness and towards acceptance.

Conclusions: The relevance of the themes to existing research on CFS/ME and other chronic illnesses is discussed. Similarities can be drawn to existing models of adjustment to chronic illness. Recommendations are made for clinical practice and future research.

Keywords

Chronic Fatigue Syndrome, Myalgic Encephalomyelitis, Acceptance, Qualitative, Experience

INTRODUCTION

What is CFS/ME?

Chronic Fatigue Syndrome (CFS) was officially recognised as ‘a real entity’ in 1998 (CFS/ME Working Group, 2002). The condition is characterized by a wide array of symptoms with different sufferers experiencing different symptom ‘profiles’. Several terms exist which describe the disorder including Post-Viral Fatigue Syndrome (PVFS) and Myalgic Encephalomyelitis (ME). Following on from the majority of research, within this report CFS, PVFS and ME will be presumed to refer to the same syndrome and referred to using the term CFS/ME.

There are currently several diagnostic criteria available for CFS/ME (e.g. Fukuda *et al.*, 1994; Holmes, 1988; Sharpe *et al.*, 1991). All criteria require onset of disabling fatigue of 6 months duration which has a substantial impact on functioning. A recent Department of Health report (CFS/ME Working Group, 2002), while acknowledging the difficulties of

lack of sufficient studies, suggested a population prevalence for CFS of at least 0.2% - 0.4%. Although the aetiology of CFS continues to be debated (see Afari & Buchwald, 2003; Komaroff, 2000), studies clearly demonstrate the reality of the distressing and debilitating constellation of symptoms experienced by sufferers. The prognosis of CFS/ME is reported to be extremely variable and although many sufferers improve, few return to pre-illness levels of functioning (Joyce *et al.*, 1997). The CFS/ME Working Group agreed that 'there is no cure for CFS/ME'. Suggested therapeutic strategies to aid management of the illness are, graded exercise/activity programmes, cognitive behavioral therapy and pacing (CFS/ME Working Group, 2002). There is some evidence for the effectiveness of these approaches (Whiting *et al.*, 2001), but further research is necessary. There is also concern that, while such techniques can be helpful for some, they may be detrimental for others (CFS/ME Working Group, 2002).

The psychosocial impact of CFS/ME

CFS/ME symptoms commonly reported include exhaustion, muscle weakness and pain, headaches, problems with memory and concentration and sleep disturbances (Söderlund *et al.*, 2000; Vercoulen *et al.*, 1998). These symptoms have been shown to have a significant impact on sufferers' quality of life, affecting family and social relationships, recreation and work and often resulting in social isolation and loss of valued roles (e.g. Andersen & Estwing Ferrans, 1997; De Ridder *et al.*, 1998; Hardt *et al.*, 2001; Van Heck & De Vries, 2002; Ware, 1998). Perhaps unsurprisingly, studies have found high rates of depression and other psychiatric disorders in CFS/ME, in comparison to both the general

population and other chronic illness groups (Abbey, 1995; Afari & Buchwald, 2003; Iversen & Wesseley, 2003; Moss-Morris & Petrie, 2000).

People with CFS/ME also describe additional stresses related to lack of belief and understanding both from the medical profession and the wider population (CFS/M.E. Working Group, 2002; Hughes, 2002; Sykes and Campion, 2002). Similarly, several qualitative studies to date have described specific aspects of the experience of living with CFS/ME as being problematic, such as experiences of stigma (Åsbring & Närvänen, 2002), illness delegitimation (Ware, 1992), role constriction in employment (Ware, 1999) and the difficulties involved in getting a diagnosis (Clarke, 2000; Woodward *et al.*, 1995). Studies have also explored people's experiences of CFS/ME symptoms (Hart & Grace, 2000; Söderlund *et al.*, 2000). These findings have highlighted the distressing nature of the symptoms of CFS/ME and indicated processes people with CFS/ME may go through in learning to live with their illness (e.g. Clarke, 1999; Cooper, 1997; Hart & Grace, 2000; Horton-Salway, 2001; Pinikahana *et al.*, 2002; Ware, 1992; Wheeler, 1992). However, the majority of the qualitative studies conducted to date are restricted by poorly defined methodologies or analysis techniques, thus limiting conclusions about the validity of their findings.

Adapting to life with CFS/ME

Although research has considered coping strategies used by people with CFS/ME (see Ax *et al.*, 2001, for a review), limited research to date has specifically investigated the processes by which people adapt to life with CFS/ME. De Ridder *et al.* (1998) carried out

a qualitative study asking participants to identify the adaptive tasks of living with CFS/ME. These were; adapting to the social identity of being an ill person, being creative in defining new challenges, learning to be dependent on others, finding a new way of maintaining social relationships, having to give up ordinary activities, dealing with physical impediments and being able to recognize their own needs. Similarly, Fennell (1995) described the CFS/ME experience as a series of adaptations or adjustments that begin at the onset of symptoms. Comparable findings have been reported with other chronic illness groups (e.g. Wright & Kirby, 1999).

Various models of adjustment to chronic illness exist, few of which have been discussed in relation to CFS/ME. Several researchers have described the process of adjusting or adapting to chronic illness in relation to coping with a stressful event (e.g. Moos & Schaefer, 1984; Taylor, 1983). The strategies used for dealing with the stressors are suggested to have an effect on health and wellbeing. For example, Taylor (1983) described a process of adjustment to threatening events through searching for meaning in the experience, gaining a sense of mastery and enhancing self esteem. Other researchers have focused on the use of a range of coping strategies to adapt to the challenges presented by the illness, in order to regain equilibrium (Moos & Schaefer, 1984). Some of the identified challenges of adjusting to physical illnesses are very relevant to CFS/ME, for example, dealing with pain, incapacitation and other symptoms, preserving a satisfactory self image, maintaining a sense of competence and mastery, sustaining relationships with family and friends, and preparing for an uncertain future (Moos & Schaefer, 1984).

Leventhal *et al.*'s (1980) illness regulation model has also been applied to CFS/ME. Leventhal *et al.* discussed the role of illness representations in guiding coping and reactions to illness. This has been investigated in CFS/ME through examining relationships between people's beliefs about their illness, coping, and outcome (see Ax *et al.*, 2001; Moss-Morris & Petrie, 2000). Models of CFS/ME have also been developed based on cognitive therapy concepts (e.g. Friedberg, 1995; Surawy *et al.*, 1995; Vercoulen *et al.*, 1998). Such models are generally focused on factors involved in the maintenance of CFS/ME and, similar to Leventhal *et al.*'s model, stress the importance of people with CFS/ME's reactions to, and interpretation of, their symptoms and the impact this has on their lives. However, the models vary in terms of which cognitions are seen as key. Cognitive Behavioural Therapy (CBT) for CFS/ME is also based on the premise of the role of beliefs about the cause of illness, ineffective coping and negative mood states in perpetuating the condition (e.g. Sharpe *et al.*, 1996). Such treatment approaches focus on gradually increasing activity levels alongside challenging unhelpful thoughts and symptom attributions (Prins *et al.*, 2001).

The present study

CFS/ME is an illness with currently no cure, which has serious effects on physical functioning, social functioning, psychological wellbeing and quality of life. To date, research has investigated the impact of CFS/ME, and started to consider the tasks with which people with this condition are faced in learning to live with their illness. The Fennell model has also suggested the utility of seeing this as a process of moving through phases of learning to cope, as has been described in other chronic illnesses. Although the

qualitative research conducted to date has shed some light on particular aspects of this process, existing research has not fully considered the experiences of people living with CFS/ME.

Gaining a greater understanding of the process of adapting to life with CFS/ME has both clinical and theoretical value. Clinically, this can increase the insight of professionals into the difficulties facing people with CFS/ME and their experiences of life with this condition. Theoretically, the themes which emerge from this study will provide information about what people with CFS/ME actually experience when they first suffer symptoms and how this experience might change over time. As there are few theoretical models specifically related to adjustment to CFS/ME, this will add to the literature in this area.

Research Aims

To investigate people's experiences of living with CFS/ME and help increase insight into the experiences of and difficulties faced by people with this condition. Alongside this to start to explore some of the experiences people go through in learning to live with their condition and to identify whether models of adjustment are useful in relation to this illness.

METHODS

Why use a qualitative methodology?

Qualitative research aims to ‘understand and represent the experiences of people as they encounter, engage and live through situations’ (Elliott *et al.*, 1999, p216). Through this, the methodology aims to capture, as much as possible, the perspectives of the people being interviewed. Clearly this fits closely to the aim of this research, to increase insight into what it is like to live with CFS/ME. This depth of information is more achievable through qualitative methodologies than quantitative techniques such as questionnaire based studies.

Although previous research has looked at experiences of living with CFS/ME, this study aims to do this in a more methodologically rigorous way using the established analysis technique of Interpretative Phenomenological Analysis (IPA). This technique aims to ‘unravel the meanings contained in...accounts through a process of interpretative engagement with the texts’ (Smith *et al.*, 1997) and focuses on the experiences of individuals and the meaning they ascribe to these experiences, trying to gain an ‘insider perspective’ (Conrad, 1987). The aims of IPA seem more appropriate for this research project than alternative methodologies such as Grounded Theory, which aims to ‘identify and explicate contextualized social processes which account for phenomena’ (Willig, 2001, p69). IPA has also been applied to similar research questions in other areas of health psychology (e.g. Smith, 1996; Thompson *et al.*, 2002).

Participants

Participants were recruited from a local ME self help group through posters at meetings and an e-mail sent to support group members on an e-mail network (see Appendix 4).

The following inclusion criteria were used:

- All participants were aged 18 or above and spoke English as their first language.
- All participants stated that they had been diagnosed with CFS/ME by a medical professional
- Participants reported suffering from CFS/ME for a minimum of 1 year (not necessarily diagnosed for 1 year). There was no maximum length of illness.
- Participants considered CFS/ME to be their main health problem at the current time.
- Participants were currently experiencing symptoms of at least moderate severity as described by the CFS/ME Working Party (2002).
 - Reduced mobility
 - Restricted in all activities of daily living
 - Require rest periods during the day
 - Sleep quality generally poor and disturbed

The ME self help group offers support and information for people with CFS/ME, their family and carers. The group arranges monthly meetings and members can also be part of an e-mail network. It is estimated that information about the study was made available to approximately 50 of the 200 members of the ME group. A total of 10 people agreed to

participate, all of whom were women. This was unsurprising given the higher proportion of women than men diagnosed with CFS/ME (CFS/ME Working Group, 2002). Smith and Osborn (2003) suggest five or six participants to be a reasonable sample size for IPA, enabling examination of similarities and differences without becoming overwhelmed by the data. For the purpose of this study eight participants were interviewed. This number was felt to maximise the information available whilst maintaining a manageable data size.

The women interviewed were between 37 and 55 years of age (mean age 42.5) and had experienced the symptoms of CFS/ME for between 20 months and 12 years (mean duration 6 years). In terms of ethnic group, six women described themselves as White British, one as Chinese and one as mixed race (white British and Pakistani). Following inclusion criteria, all women had been diagnosed with CFS/ME by a medical professional; four women were diagnosed by hospital consultants; two by GP's; one by a private doctor specialising in CFS/ME and one person was diagnosed by a consultant psychologist. Five of the women heard about the research through group meetings and three through the group e-mail network. No demographic information is available about the two volunteers who were not interviewed.

Procedure

All participants were given an information sheet and signed a consent form (see Appendix 5) prior to being interviewed. Interviews took place in participants' own homes and lasted between 45 minutes and 1 1/2 hours. For one participant the interview was

conducted in two sections due to fatigue. Immediately before completing the interview participants were asked for their age, ethnic group and preferred label for their condition. A semi-structured interview schedule was used following Smith and Osborn (2003). Such an interview schedule aims to use questions related to the area of interest which are as general as possible and to encourage the interviewee to tell their story. This is to ensure that, as far as is possible, the interview will reflect the opinions and beliefs of the interviewee, rather than the interviewer. The questions asked were;

- Could you tell me what happened when you first started experiencing the symptoms of CFS/ME?
- What were things like after that time?
- Can you tell me what life is like now?
- How did you get from where you were then to where you are now?
- Where do you think you are currently in terms of living with CFS/ME?
- How do you see your future?

Further prompts were used to encourage participants to elaborate on their responses (see Appendix 6 for interview schedule). Interviews were tape recorded and transcribed. The first interview was transcribed by the first author in order to familiarise herself with the transcribing process and its impact on the data. Subsequent interviews were transcribed by a professional transcriber. The transcriber was experienced at transcribing research interviews and was aware of the importance of confidentiality. Prior to receiving interview tapes the transcriber also signed a confidentiality form (see Appendix 7).

Data Analysis

Interview transcripts were analysed using IPA. Willig (2001) and Smith *et al.* (1999) describe the process of the analysis in detail. The analysis includes a series of steps through which the researcher identifies themes and integrates them into meaningful clusters. This is done first within, then across cases and each level of the analysis is therefore informed and enhanced by the other levels. A summary of the method of analysis is given below.

Analysis of an individual case

- Stage 1: The transcript is read and re-read, general unfocused notes are made recording initial thoughts and observations in the left hand margin.
- Stage 2: The transcript is re-read and preliminary themes are identified for each section of the text and noted in the right hand margin.
- Stage 3: Sections of text accompanying each initial theme are copied and pasted into initial theme tables. These are then read and re-read to ascertain whether the quotes represent a homogenous theme or fit more closely elsewhere.
- Stage 4: Initial themes are examined to look for connections, in order to identify clusters of themes or hierarchical relationships between themes. At this stage some initial themes may be subsumed within larger superordinate themes. Labels are given to theme clusters.

Stage 5: A summary is produced for each participant including the structured themes and quotations which illustrate each theme. At this stage themes that do not relate to the phenomenon under investigation can be excluded.

Integration of cases

Stage 6: Summary tables for all participants are examined to look for similar themes and connections between themes.

Stage 7: A summary table is produced listing master themes and relevant quotes for each individual case.

For a more detailed description of the analysis with examples from a transcript see Appendix 8.

Validity and reliability

The research was conducted in such a way as to maximise the reliability and validity of findings, through following guidelines for ensuring quality in qualitative research (e.g. Elliott *et al.*, 1999; Mays & Popes, 2000; Stiles, 2003; Willig, 2001).

Transparency: Within qualitative methodologies it is important to give sufficient information to allow the reader to follow the analysis process and ascertain whether the resulting themes are justifiable (Mays & Popes, 2000). In order for the research process to be as transparent as possible, detailed descriptions of data collection and analysis techniques were given. Throughout the results section quotations were also given to

illustrate themes. This enables the reader to gain greater insight into the relationship between themes and quotes.

Reflexivity: Considering the perspectives of the researcher is necessary to ascertain possible implications of this on the interviews and the analysis. The principal researcher, who conducted the interviews and the analysis, was a white, middle class, female, trainee clinical psychologist with an interest in adjustment to chronic illness. The research was completed as part of a doctoral thesis. In terms of CFS/ME, the researcher believed the illness to be caused by multiple factors. The researcher also had both clinical and personal experience of the impact of this condition on the lives of sufferers.

Validity audit: The analysis was conducted in such a way as to allow for audit, as recommended by Smith (2003). A clear progression of the development of themes can be followed throughout the analysis process, through the completion of a reflexive diary and saving copies of theme tables from each stage of the analysis. Anonymised interview transcripts and individual participant theme summaries were also read by colleagues for half the interviews, to ensure that themes were justifiable based on the data (peers, clinician with experience of CFS/ME, researcher with experience of IPA). Within the analysis process described above, the researcher also frequently reviewed and re-reviewed the relationship between quotes and themes to ensure that themes were representative of the quotes.

Member validation: Throughout the interviews the interviewer summarised and reflected back the points discussed by the interviewee to check that she had an accurate

understanding of the interviewees meaning and to give participants an opportunity to correct any misunderstandings. Copies of individual participant themes and quotes were also sent to participants for member validation (see Appendix 9), in order to verify that the themes provide an accurate account of their experience, thus checking the validity of the conclusions drawn for those individuals (Mays & Popes, 1995). Two participants returned comments on the themes. These comments mainly consisted of elaborations of the summary themes and were used to inform the final stage of integration of themes across cases. One participant suggested a slightly different interpretation of a theme and another emphasised one aspect of the theme as being more important than suggested by the summary. Following these comments, individual summary tables were re-reviewed to verify whether the data supported these comments. For one participant this was felt to be the case and the emphasis of a sub-theme was changed slightly. The suggestion of the other participant was not felt to be justified by the data available. At this stage, the initial theme tables were also reviewed for the other six participants.

Ethical Considerations

The study was reviewed by the North Sheffield Ethics Committee (see Appendix 3). The committee was satisfied that the research was ethically sound. When designing the study, particular attention was given to interviewer safety when conducting home visits and verifying the procedure to follow should participants become distressed. Throughout the research process care was also taken to ensure participants interviews remained anonymous, for example through careful storage of tapes and transcripts and use of a transcriber confidentiality form.

RESULTS

A summary of the five main themes is given in Table 1. Themes were included if they were expressed by the majority of participants or were theoretically relevant. Themes are illustrated by quotes given in italics, and participants are identified by letters given in brackets. In order to clearly relate the emerging themes to existing theory and research, discussion of this will be presented within the results section. This procedure is an alternative format for presenting the results of qualitative research (Smith & Osborn, 2003) and has been commonly used within qualitative research (e.g. Charmaz, 1983; Schur *et al.*, 1999).

Table 1: Summary of Master Themes

	Theme name	Description
1	An ‘overwhelming illness’	Participants describe initially feeling overwhelmed by their illness.
1.1	A ‘really awful time’	Severe and disabling symptoms affect the whole body
1.2	‘I wasn’t able to do anything’ ‘I just was not me’	Numerous losses occur due to CFS/ME. For some this results in a sense of loss of self.
1.3	‘It’s hard on your family and on your carer’	CFS/ME also impacts on the lives of other people
2	‘An invisible illness’	CFS/ME is hard to define and explain, the reactions of others are extremely distressing
2.1	‘It’s genuine what I’ve got, they’re genuine symptoms’	CFS/ME is often not understood or believed by both professionals and family and friends
2.2	‘How was I going to get any help?’	Participants describe being let down by the medical profession
2.3	‘And then there was nothing, no-one, nothing’	Experiences of isolation and lack of support
3	‘Gaining insight’	Increasing understanding of the illness.
3.1	‘Knowledge was, I guess the first step’	Seeking knowledge and information about CFS/ME.
4	‘Self help’	Actively searching for things that help
4.1	‘Finding what’s right for you’	Trying alternative therapy approaches
4.2	‘Pacing’	Learning to listen to your body and pacing activities.
4.3	‘Mindset’	Thinking positively
4.4	‘I’m able to handle it with the help I’ve got’	Role of practical help in coping
5	‘Acceptance’	Ongoing process of accepting illness
5.1	‘Pushing and pushing and pushing myself’	Period of trying to battle on, failing to recognise illness
5.2	‘It’s been a very hard slog mentally to accept what I’ve got’	Gradual and difficult process of acceptance
5.3	‘I’ve lost a lot but I’ve gained something’	Recognition of positives from illness, sense of regaining identity.

Theme 1: An ‘overwhelming illness’

1.1 ‘A really awful time’

Five of the eight participants described experiences within the initial stages of the illness of feeling overwhelmed and extremely distressed by the huge range of debilitating symptoms they were experiencing. *‘I could have laid down in the road and gone to sleep’* (B). Severe symptoms were described which affected the whole body, for some this resulted in a sense of being overwhelmed and frightened.

‘I was really frightened because at one stage I was just lying down constantly sleeping day and night, and because I was so lethargic and exhausted, I was scared because I thought I was dying.’ (C)

The overwhelming nature of the illness was compounded by the difficulty explaining and defining the illness. CFS/ME was seen to be *‘an illness that you couldn’t really explain’* (G). For some participants this resulted in fear and difficulties knowing how to cope.

‘I think I was really getting so desperate to find out perhaps what was the matter’ (E)

The large range of severe and debilitating symptoms experienced by people with CFS/ME has been well documented (e.g. CFS/ME Working party, 2002; Söderlund *et al.*, 2000; Tuck & Human, 1998), as has the impact of these symptoms on quality of life (e.g.

Andersen & Estwing Ferrans, 1997; Van Heck & De Vries, 2002). Previous qualitative studies have reported such symptoms to be experienced as overwhelming and affecting the whole body (Cohn, 1999; Hart & Grace, 2000). The uncertainty accompanying initial symptoms has also been recognised in relation to other chronic illnesses (Conrad, 1987; Radley, 1994), including rheumatoid arthritis and chronic pain (Bury, 1982; Savidge *et al.*, 1998). In this initial stage participants appeared unable to make sense of their symptoms or to cope with them. This initial reaction to onset of symptoms can be compared to the early stages of models of adjustment to chronic illness, for example, the pre-encounter phase in Calabro's (1990) cognitive model of adjustment to chronic illness, Morse and Johnson's (1991) initial stage of uncertainty and the Crisis phase of Fennell's (1995) model of stages of CFS. These stages are characterised by severe disruption to patients' lives and feelings of uncertainty, shock and depression.

1.2: 'I wasn't able to do anything' 'I just was not me'

All participants spoke about the numerous losses which occurred due to CFS/ME. They described no longer being able to pursue previously valued activities, losing physical fitness and both physical and cognitive abilities, losses of friends and valued roles in the workplace and at home, and financial losses. The importance of specific losses varied according to pre-illness expectations and lifestyles. For example, for some participants loss of career was particularly important, while for others difficulties fulfilling roles within the family were particularly painful.

'I realised I couldn't do sport I mustn't much, had to sort of sit down and watch telly which was difficult for me because I was hardly ever in my house.' (A)

'I clung on to the mother thing, and then when I couldn't do that I was so distressed. I mean really really really distressed cos it was like the very important thing that I was hanging on to' (B)

The experience of losses was described as extremely painful and depressing by some participants, and as similar to bereavement by one participant. The cumulative effect of multiple losses was expressed by three participants in terms of a loss of sense of self. Faced with the limitations of the illness it was hard to find activities and roles to replace those which were lost.

'it's almost like grief and the pain and the loss' (B).

'all the things that I like to do that were me, and that .. made me feel OK ...those things you have lost.....but I've not got anything that I can find to make, to put it back together in a different thing which is OK. So I'm just like this blob of, it's not even a blob it's more of a, it's a tangle of upset and nothing can replace them' (B)

However, this was not experienced by all participants with one participant stating that;

'I think I'm pretty much the same person I was before' (F).

The loss of previously valued activities in CFS/ME has also been reported by several researchers (Asbring, 2001; Clark, 1999; Cohn, 1999; De Ridder *et al.*, 1998; Horton-Salway, 2001; Tuck & Human, 1998; Ware, 1998, 1999). As people begin to recognise losses, emotions of depression and anger become more prevalent. The experiences of participants in this study are reminiscent of Charmaz's (1983) discussion of loss of self in chronic illness. Charmaz described this as 'a crumbling away of former self images without simultaneous development of equally valued new ones'. Fennell (1995) also described this process in CFS. People's inability to continue to fulfil valued roles results in feelings of guilt, shame, anger, depression and worthlessness. As was expressed by one participant, this is similar to a process of grief or bereavement.

1.4 'It's hard on your family and on your carer'

The majority of participants described the severe impact of CFS/ME on the lives of other people. The losses described above impact on other people in terms of losses of joint activities, financial and practical implications. Participants experienced feelings of guilt at letting people down which impacted back on their own ability to cope. Some participants described a need for other people to accept and learn to cope with the illness in the same way they had had to.

'he lost his mother at that time, and he had no other adult, he'd to do it all on his own really'. (B)

'When I first became ill I was very guilty that I was letting everybody down' (C)

The impact of CFS/ME on the lives of others has been less well documented. Fennell (1995) stressed the importance of involving the social network in helping people to cope with CFS/ME. The role of other people in adjusting to physical illness has also been stressed within general adjustment models such as Morse and Johnson (1991).

Theme 2: 'An invisible illness'

The lack of clear diagnosis and recognition of CFS/ME has severe implications for sufferers.

2.1 'It's genuine what I've got, they're genuine symptoms'

All participants described experiences of their illness not being understood or believed in by others. *'I think there was disbelief off the people close to me' (G)*. This was suggested to compound the problems of the illness. The lack of visible signs of the illness and historical factors or 'bad publicity' attached to the diagnosis of CFS/ME were suggested to contribute to this problem.

'I think the...the plights of people with M.E, the difficulties that are sort of added through the fights with the benefit system and the health service' (G).

'I mean one of the problems was it was, when it was first brought out as such, M.E. was known as Yuppie Flu. So it was just these high fliers who burnt themselves out, and it wasn't your ordinary pleb like me who contracted it' (D)

Participants described feeling angry and let down by both professionals and family and friends. Not being believed also led people to push themselves or to feel they had to prove themselves. Experiences of disbelief related to insurance and benefits claims were suggested to be particularly damaging.

'you feel in some way you have to justify your illness, and explain your illness' (E)

'people who assess you for illnesses whether its DLA or insurance companies, it is horrendously stressful, very very negative.' (A)

The stigma and lack of belief related to CFS/ME has been discussed in numerous studies (e.g. Äsbring & Narvanen, 2002; CFS/ME Working Party, 2002; Cooper, 1997; Fennell, 1995; Hughes, 2002; Lehman *et al.*, 2002; Sykes & Campion, 2002; Ware, 1992, 1999; Wheeler, 1992). Similar experiences of not feeling believed or validated have also been reported in people with chronic pain (Savidge *et al.*, 1998). Although the term stigma was not used by any participants within this study, their statements suggested that CFS/ME was experienced as stigmatising, as defined by Goffman (1976, p13) as 'an attribute that is deeply discrediting'. People were perceived not to understand the illness and to hold

negative beliefs about it. These negative reactions to illness present a significant threat to identity (Charmaz, 1983). Research on stigma has suggested that the perception of a condition as stigmatising may result in attempts to conceal the illness to prevent discreditation and maintain a well identity (Goffman, 1976). The discussion of participants' initial reactions of battling on (theme 4.1) could be interpreted as an example of this.

For the participants in this study, the 'invisible' nature of the illness was suggested to contribute to the difficulties gaining understanding and belief. Interestingly, in a study by Schur *et al.* (1999) of adolescents with diabetes, the invisible nature of diabetes was seen as enabling participants to maintain a 'healthy' or 'normal' identity. This suggests that for this adolescent sample concealing the illness and avoiding stigma was more important than gaining recognition for this illness. Reasons for this difference may include the specific age group in Schur *et al.*'s study and the different degrees of legitimacy given to diabetes and CFS/ME.

2.2 'How was I going to get any help?'

All participants described feeling let down in some way by the health profession. Participants went through a process of trying to find out what was wrong and to get a diagnosis, hoping that this would lead to some kind of treatment. For most, this included multiple medical investigations and referral to different professionals.

'there was no way I was going to give in to whatever was the matter with me, you know, it was something that needed diagnosing and presumably there'd be some kind of treatment for it, and then I'd be bouncing back again' (E).

Instead, they found that even post diagnosis there was a lack of understanding and advice from the medical profession. Participants generally found that they had to '*muddle through*' and felt that had they received advice on how to manage their illness in the early stages, they would not have become as ill.

'The doctors couldn't give any treatment' 'they just discharged me and that was that' (D)

'I think I had to find a lot of it out for myself, how to deal with it, how to handle it.' (F)

For some participants health professionals were seen as trying their best but lacking in knowledge and understanding. For others, experiences with health professionals were extremely negative. This resulted in participants feeling disempowered, helpless and hopeless. One participant had a different experience and was diagnosed and treated by a consultant psychologist. However, she was very aware that her experience was not the norm.

'I mean, with all fairness to the doctors, I mean M.E. 's a pain in the arse illness that, you know, they don't really understand a lot about.'

(D)

'I'd been rejected here there and everywhere and made to feel like an idiot'. 'I think it's disgraceful to be a GP treating me the way that he's treated me.' *(B)*

'I think that's been tremendous and I consider it that I'm very very lucky' *(E)*

Studies have previously found people with CFS/ME to be dissatisfied with medical support (Ax *et al.*, 1997; Deale & Wesseley, 2001), and stressed the importance patients attach to obtaining a diagnosis (Clarke, 1999, 2000; Cooper, 1997, Lehman *et al.*, 2002; Pinikahana *et al.*, 2002; Woodward *et al.*, 1995). A similar process of searching for a diagnosis and not receiving appropriate illness recognition and support has also been described in people with chronic pelvic pain and Multiple Sclerosis (MS, Savidge *et al.*, 1998; Stewart & Sullivan, 1982).

The availability of medical knowledge and a diagnosis may be important to enable people to distance themselves from their illness and legitimately relinquish responsibility (Bury, 1982). During the early stages of chronic illness, patients are suggested to feel powerless and out of control (Bates & Rankin-Hill, 1994; Morse & Johnson, 1991). This results from their apparent lack of authority to affect an outcome, the unpredictability of

symptoms and lack of resources and support (Fitzgerald-Miller, 1992). A reaction to this may be to attempt to relinquish control to the family or medical professionals. The experiences of participants in this study, suggest this initial phase of becoming overwhelmed, but that nobody appeared to be willing or able to take over control. Participants therefore either remained overwhelmed, or turned to their own resources and knowledge.

2.3 'And then there was nothing, no one, nothing'

Three participants described not receiving support from family and friends, feeling lonely, isolated and abandoned. *'I felt like I was on a desert island, no way of getting anywhere or reaching anyone else'* (D). They described being shocked to find that other people weren't there for them and a sense of being greatly let down. Participants without support also saw this as contributing to their struggle to cope with their illness.

'I didn't know what to do, what are you meant to do if you don't have anybody to help?' (A).

'I think if I had some help with like, even with the housework, it might give me a bit more energy to do something to keep my spirits up'. 'I haven't had anyone to help me grieve for those things or to put them somewhere and find something else.' (B)

Experiences of social isolation in CFS/ME have been reported elsewhere (Green *et al.*, 1999; Pinikahana *et al.*, 2002; Söderlund, 2000; Ware, 1999; Woodward *et al.*, 1995). As

discussed above, social support in chronic illness can enable sufferers to temporarily relinquish control and responsibility. Several researchers have also discussed the role of significant others in protecting the person with chronic illness from undue stressors (Morse & Johnston, 1991), normalizing and depersonalising the illness (Schur *et al.*, 1999), and reducing the stigmatising potential of chronic illness, through providing sources of positive self esteem (Charmaz, 1983). The lack of this support can leave people extremely vulnerable to discrediting events and attacks on the sense of self. This seems to be an experience of some participants, resulting in an increasing sense of being overwhelmed and lacking in value and self worth.

Theme 3: 'gaining insight'

3.1 'Knowledge was, I guess the first step'

As discussed above, participants were generally unable to find the support and the answers they needed from the health services. Participants therefore began to seek out information and develop their own understanding of the illness. Having this increased understanding was believed to be extremely important.

'if I had the knowledge I could be more in control of it' (G)

'you need to learn the lessons 'why you got ill' in order to get better' (H)

This information was gained from speaking with other sufferers and experts, from reading and the internet. Within the interviews all but one of the participants described their own understanding about the cause and nature of their illness. Most understood the illness as having a physical, typically viral, cause with an influence of psychological factors such as stress. Conversely, one woman attributed the start of her illness to a period of depression. Participant's pre-illness beliefs and philosophical ideas influenced their understanding of their illness. This understanding guided attempts at coping

'I've always had a virus, I've had parasites, I've had various other bits and pieces found as well and the thyroid, you know, makes your immune system worse if you're low in thyroid, so of course if you've got all these bugs you just go right down even more.' (A)

'my feeling and again my own research, I think it was triggered by a depressive illness that I had' (E)

A process of trying to make sense and understand the illness has been reported in previous qualitative studies (Clarke, 1999; Cooper, 1997; Horton-Salway, 2001; Pinikahana *et al.*, 2002). Similarly, people with CFS/ME have been described as reaching a point of challenging their own beliefs in doctors' abilities and taking a more active role in illness and its management (Clarke, 2000; Cooper, 1997; Hart & Grace, 2000; Ware, 1992; Wheeler, 1992). In agreement with the findings of this study, Clements *et al.* (1997) reported that patients arrived at their beliefs following 'prolonged reflection on their own experiences' and reading of media reports, self help books and patient group

literature. The views of health professionals were reported to play a relatively small role in this process. Comparable processes of searching for meaning have been described in the general adjustment literature by Taylor (1983) and Morse and Johnson (1991) and in research with people with vitiligo and MS (Stewart & Sullivan, 1982; Thompson *et al.*, 2002). The process of gaining insight into CFS/ME can be hypothesised to be an initial stage of regaining control, with the formation of illness representations having an impact on patients' perceived powerlessness (Fitzgerald-Miller, 1992).

Although no consensus has yet been reached regarding the aetiology of CFS/ME (see Evangard & Klimas, 2002), a body of research has investigated the role of illness beliefs in people with CFS/ME, drawing on Leventhal *et al.*'s (1980) model of illness representations. Illness perceptions are reported to be associated with variations in disability and psychological adjustment (Edwards *et al.*, 2001). For example, Moss-Morris *et al.* (1996) found belief of control over CFS/ME to relate to use of 'positive coping strategies'. Edwards *et al.* (2001) found strong illness identity, belief in severe consequences, low perceived control, and belief in a psychological cause, to be predictors of anxiety and depression. Satisfaction with medical support has also been found to relate to illness perceptions, with sufferers believing in a physical cause of CFS/ME being less satisfied with medical care (Ax *et al.*, 1997). Research to date therefore suggests a relationship between belief in a physical cause of CFS/ME and poor outcome or coping. This is in contrast to general chronic illness research which has suggested that forming a causal explanation for illness relates to more positive physical and emotional outcomes (Turnquist *et al.*, 1988).

Theme 4: 'Self Help'

All but one of the participants described searching for things which could help them to recover from CFS/ME. This is very much an active process.

'all the time that I've had the illness I've been trying to do something to improve the situation or make it better' (G)

Participants began to take on some responsibility for their illness and tried to identify ways of coping with it. This can be compared to discussions of the need to gain mastery and control over illness (Taylor, 1983). As discussed above, previous qualitative research has highlighted the importance of sense of control in coping with chronic illness. Schur *et al.* (1999) found gaining a sense of control over diabetes to be extremely important, allowing participants to protect themselves from the possible negative impact of the illness. In a study of people with chronic pain, Bates and Rankin-Hill (1994) reported that patients' locus of control had an impact on intensity of pain and distress. An internal locus of control was suggested to relate to more positive adaptation, less interference of pain in activities and lower emotional distress.

Three key types of self help emerged across the interviews.

4.1 'Finding what's right for you'

Five of the participants described trying a range of alternative techniques. Therapies tried included, acupuncture, homeopathy, dietary supplements, kinaesiology, osteopathy, reiki and visiting a spiritual healer. Trying such techniques had financial implications. Yoga, meditation and relaxation were also practiced by several of the participants. Participants described both positive and negative experiences of such approaches. For some this started as a process of searching for a cure, but this opinion was revised over time. For other participants, this hope was maintained.

'now I don't see anything as a cure, I just think it's gonna alleviate my symptoms and it's gonna help me on the way to recovery, but it's only a small part of the big picture' (H)

'it's like a jigsaw puzzle and you've got to get a lot of the pieces there before you get better.' (A)

Previous research has suggested a process of moving away from relying on expert help in order to regain self esteem and mastery (e.g. Bates & Rankin-Hill, 1994). In contrast, participants in the present study described trying different treatments, but this process appeared to be generally under their control. Although some participants recognised an earlier unhelpful stage of searching for a cure few still felt they were aiming for this. Instead, participants appeared to use their own understanding and knowledge to organise

and choose which treatments they tried. They therefore retained the responsibility and control over their illness rather than passing this over to ‘experts’.

4.2 ‘Pacing’

All the participants spoke about recognising a need to learn to live within their bodies’ limitations. Some described this as ‘pacing’ and one participant differentiated this from graded exercise. Other participants described this as *‘ride with it’* and *‘do a bit, rest a bit’*. Within these limits participants described feeling more in control of their illness.

‘pacing myself, but in the right sense of pacing, not this graded exercise thing which I think is a bit daft’. (D)

‘your body needs rest, but you need a regime and you need to be working towards something and pacing yourself, and nobody tells you how to pace yourself.’ (H)

‘as long as I’m controlling it and controlling what things I do physically, I can feel relatively normal’ (F)

Pacing is learnt gradually through *‘trial and error’* and by *‘listening to your body’*.

Overstepping the limits leads to *‘payback’*. For one participant it seemed that the process of learning to live within her limitations was only just beginning. Despite an understanding of the importance of pacing, participants described finding it extremely

hard to stay within their limits. Four of the participants described at times ignoring their limitations or '*kicking against it*'. Some participants also found that the demands of their daily life meant they were forced to exceed their limits.

'if I do something I really shouldn't and I suffer for it, by bloody hell I suffer for it but I'm gonna do it anyway because I, essentially I'm bloody minded' (E)

'As I get a bit better it's going to be much easier to pace myself and try and increase. Because you've got to be able to do certain basic things in a day before you can start increasing your activity levels. So many people with ME are forced to do more, ... its just impossible for them to do less than what they've got to do. So you really need help and support from outside.' (A)

The descriptions of pacing given by participants suggest that this term was used in different ways. For some participants pacing consists of living within their limitations and not pushing themselves, whilst for others pacing was about finding a comfortable level and then trying to gradually build up activity levels. Similarities can be drawn between this strategy and the recommendations of ME self help groups (Shepherd, 2001) and the pacing component of CBT (Prins *et al.*, 2001). One participant specifically differentiated pacing from 'graded exercise'. Graded exercise is described as a form of 'structured and supervised activity management which aims for gradual but progressive increases in aerobic activity such as walking and swimming' (CFS/ME Working Group,

2002). The graded exercise approach is based on the theory that CFS/ME is maintained by inactivity and subsequent physical deconditioning. However, evidence for this theory is conflicting (e.g. Bazelmans *et al.*, 2001; Wagenmakers, 1999). In agreement with the comments of the participant in this study, Shepherd (2001) describes the results of a treatment audit of ME Self Help groups reporting that around 50% of respondents stated that graded exercise had made their condition worse.

4.3 'Mindset'

Six of the participants spoke about the importance of thinking positively. This optimism was seen to keep them going. Participants focused on the things they could do and maintained a hope for future improvement. One participant described that in order to do this she needed to '*sort out all the crap, before I could even think about getting better and accepting my illness*' (H). For other participants a further source of optimism was through downward social comparison;

'I think generally just having a positive attitude, is one of the best ways of recovery'. (G)

'I'm still quite ill but I'm not as ill as I should be my brain isn't nearly as bad as other peoples with ME that's because I've been able to afford things to help.' (A)

Generally participants felt it was important not to dwell on the negatives and to focus on trying to get better by ‘switching off’ from thoughts on bad days. One participant differentiated this from positive thinking as recommended by CBT.

‘I still try not to think about it, I suppose I try not to think about these things. I just keep myself going and trying to do things which help myself get better.’ (A)

‘not just this CBT ‘you’ve got to think positive’ stuff, that it’s just you’re not thinking positively enough rubbish, that I think is a bit rubbish.’ (D)

The theme ‘mindset’ includes the use of positive thinking, avoiding negative thinking, optimism and hope. Such strategies fall within the dimension of emotion focused coping techniques, which reduce distress through cognitively avoiding or reappraising situations (Lazarus, 1993). Similarly, research has suggested the frequent use of emotion focused coping in people with CFS/ME (Blakely *et al.*, 1991). Schur *et al.* (1999) discuss similar coping strategies in terms of ‘adaptive denial’. This was suggested to enable participants to feel positive and confident in the present and have hope about an uncertain and unchangeable future. In a review of denial in physical illness, Goldbeck (1997) concluded that denial can be adaptive in terms of preventing psychological distress, if it does not block action. For example, denial can be helpful to deal with fear and uncertainty, but if sustained may prevent appropriate adaptation. It may also be important to differentiate between levels of denial, some of which may be more helpful than others. Ax *et al.*

(2001) reported preliminary evidence that strategies such as disengagement and denial were associated with greater perceived illness burden and poorer psychological health, while positive reinterpretation was associated with psychological wellbeing.

The findings from this study suggest that, similarly to Schur *et al.*'s sample, participants positive 'mindset' served an adaptive function preventing them becoming overwhelmed by their symptoms, losses and fears. The coping strategies described by the participants in this study appeared to fall generally at the level of positive reinterpretation, although for some participants there appeared to be some denial of the negative impact of their illness. Although these participants did talk about having accepted their illness it is uncertain whether the extent of their positive mindset actually prevented full acceptance. It seems that denial may be adaptive and maladaptive at different stages of illness. The mindset of the participants in this study seemed to play a role in enabling them to become less overwhelmed by their illness and start to begin to actively cope with it. However, the impact that mindset has on participants' level of acceptance is less clear.

4.4 'I'm able to handle it with the help I've got'

As mentioned within themes 4.2 and 2.3, participants spoke about the need for practical and social support to help them cope with their illness. Four participants either had access to support from others or used practical aids to help them cope with the limitations of their illness. This included hiring a home help, adapting the house and getting a wheelchair. Such physical aids were seen as extremely important to enable participants to

conserve their energy for other tasks. Participants felt that their health noticeably suffered at times when this support was not available.

'using the wheelchair gives me the mental, because I'm not taxing myself physically I can keep myself alert mentally, and that's been a big boon.' *'I can get between two floors without a lot of fighting, cos the housing association's put me a stair lift in, I've had the path widened for the wheelchair so I can get the chair down. I've got a shower, up in the bathroom instead of just a bath, so. It's very positive.'* (D)

'At the moment they're on holiday and I will dip this week, towards the end of the week,' (F)

As discussed previously, for some participants the availability of support may serve a buffering function, helping to maintain self esteem in the face of extreme difficulties and losses (Charmaz, 1983; Morse & Johnson, 1991). The impact of lack of resources on participants' ability to cope with their symptoms poses a difficult challenge for clinicians.

Theme 5: Acceptance

From seven of the accounts a theme of acceptance emerged. For some participants there appeared to be an initial period of 'battling on' or 'non acceptance' followed by recognition of the reality of illness and a gradual acceptance.

5.1 'Pushing and pushing and pushing myself'

Six participants described an initial reaction to their illness of trying to '*fight it*'. During this phase participants '*tried to keep up*' with the normal demands of their life. Some participants identified external pressure from work pushing them to continue. Participants also identified internal pressure to keep going, due to beliefs about the importance of work or in order to fight against the loss of valued roles. Experiences of not being believed further added to the pressure to keep going. Two participants also described a lack of realisation that they were ill, '*it didn't quite register*' (B).

'I had a conflict in my head because I've always had this really strong work ethic ... that you must turn up to work even if you're poorly' (H)

'because they doubted me, I doubted myself, therefore pushing myself to doing things that maybe I shouldn't have.' (C)

Following a period of battling on, participants typically either came to recognise that they were ill, or became exhausted and unable to carry on;

'I realised what was happening and just stopped because I'd heard of Post viral fatigue conditions' (A)

'I just thought 'I can not carry on.' (E)

Previous research with chronic illness groups has suggested that, following initial illness onset, the awareness of being chronically ill develops gradually (e.g. Stewart & Sullivan, 1982; Thompson *et al.*, 2002). Patients may initially normalise or rationalise symptoms, rather than attributing them to a chronic illness. Some participants also seemed to be utilising a more extreme form of denial, as discussed within theme 4.3. This encourages patients to ‘push on’ and keep going as they may have done previously in response to mild acute illnesses. The processes of gaining insight and self help described above may be an important part of the gradual realisation of being chronically ill. It was also noted by Thompson *et al.* that this process is not an individual process, but is affected by the social context. Given the difficulties gaining understanding and support experienced by the majority of participants, this seems likely to have increased the difficulties some participants experienced in recognising and accepting their illness.

5.2 ‘It’s been a very hard slog mentally to accept what I’ve got’

Seven of the participants described reaching some level of acceptance of their illness. To achieve this it was necessary to accept the illness with its ups and downs, as gaining full control of the illness remained impossible. Reaching a stage of acceptance was described as a very difficult and painful process but once achieved life is described as being ‘easier’

‘I do think it’s easier to cope with the ME once you kind of accept all those things.’ (E)

'I don't feel frightened now. I just know, you come to realise that you are ill after a while. It took a long time to accept that you'll be ill for a long time' (A)

However, despite this there is a suggestion that complete acceptance is a bad thing and that it is important to continue to fight.

'there's a certain level of acceptance, maybe I need a little bit more, but at the moment I'm not sure I want to totally accept' (G)

'I won't let it beat me' 'I'm not gonna let it get the better of me, but I think the only way to kind of win with it is to come to terms with it.' (E)

Previous qualitative studies in CFS/ME have highlighted themes relating to coming to terms with or accepting the illness (Asbring, 2001; Hart & Grace, 2000). Participants begin to listen to and learn from their bodies enabling them to feel more in control and able to get on with life. Schur *et al.* (1999) also highlighted the importance of reaching a position of acceptance, getting a balance between diabetes taking over and lifestyle impacting on diabetes. With acceptance participants recognise that their illness is chronic and begin to adapt life to it. However, as described by the participants in this study, this can be an extremely challenging and painful process. Similarly, the difficulties in fulfilling the tasks suggested to be important to adapt to life with CFS/ME (De Ridder *et al.*, 1998) are reflected in several of the themes which have emerged from this research. For example, participants described the impact of being forced to give up activities, and

the difficulties adapting to a changed identity, defining new challenges and maintaining social relationships.

Rather than being a linear process, adjustment has been suggested to be a dynamic problem solving process with much variation over time (e.g. Thompson *et al.*, 2002; Yoshida, 1993). It seems likely that variations in levels of acceptance will occur in chronic illnesses such as CFS/ME, related both to illness relapses and external life events. This is reflected by participants continuing to fight against their limitations and feeling complete acceptance is unhelpful. The idea that living with chronic illness is an ongoing, constantly changing process, has recently been conceptualised within the ‘shifting perspectives model’ of chronic illness (Paterson, 2001). This model suggests that people with chronic illness shift between living with illness and wellness in the foreground. Similar to the findings of this study, shifts to a focus on illness are suggested to occur related to perceptions of threats to control, while shifts to perceptions of wellness relate to the use of strategies such as those described as ‘mindset’.

5.3 ‘I’ve lost a lot but I’ve gained something’

Five of the participants discussed positive changes in themselves brought about through their illness. There is a sense that through living with and accepting the illness there can be some positive gains. For some participants this resulted in a change in their view of world and their priorities.

'you're a stronger person for it as well, and you know yourself better as well, you know what you want.....and you value the people around you more' 'I suppose as well you change your outlook on life cos, I'm not as career orientated now. I'm not as motivated in terms of, umm, I am a motivated person but I'm not as motivated by things that I used to be, like career and money and, they're not my priorities now, my priorities are sort of my health and my family and my friends' (H)

'the ME has got me here, made me think about my own life, and, I have no regrets.' (E)

Participants also felt that as their health, coping and acceptance improved they were able to re-gain some of themselves which resulted in further improvements in health and quality of life.

'because I now use the power chair I can be an active granny' 'I'm more me' (D)

'actually starting doing things then brought me back to being my normal self' (H)

Two previous qualitative studies reported that participants identified positive gains from their illness experience (Asbring, 2001; Cohn, 1999). The ability to integrate pre and post illness identity and recognise positive aspects of illness is also the end point of models of

adjustment to chronic illness (e.g. Morse & Johnson, 1991; Taylor, 1983). Charmaz (1983) found that people who had recovered or improved were more likely to see their illness as a journey with positive experiences, compared to people who were still suffering. It may be that the participants identifying positive gains in this study were those who had experienced significant improvements.

DISCUSSION

The findings of this qualitative study confirm the devastating and overwhelming impact of CFS/ME. Participants described a stage of initial uncertainty at onset of symptoms, for some this was more overwhelming than others. The theme 'an invisible illness' describes how participants tried to gain support and understanding from both the medical profession and family and friends, but were frequently let down or disbelieved. This added to the sense of being overwhelmed, powerless and out of control. It is hypothesised that the majority of participants reacted to this by trying to 'gain insight' and identify sources of 'self help'. Through making sense of the illness and seeking out ways to actively cope with it, the sense of being overwhelmed became decreased and perceptions of control increased. This is reflected in the emphasis on 'coping by doing' in several accounts, with participants remaining focused on actively coping with their illness, rather than becoming overwhelmed by its impact. In contrast, one participant seemed to be unable to make sense of her illness, and was struggling to identify ways to cope with it. This participant appeared to remain overwhelmed, focused on the losses caused by her illness, and extremely depressed. Attempts to understand her illness or cope with it failed, resulting in a spiralling sense of desperation and hopelessness. This could be understood

as a kind of learned helplessness, with her repeated negative experiences of attempting to access help or support, further reinforcing feelings of powerlessness and hopelessness.

Alongside the process described above, participants also spoke about a gradually developing sense of acceptance. In the early stages of illness, participants described trying to keep going or not recognising the severity of their illness. Within this stage participants were typically overwhelmed by their illness and seeking support from others, while possibly denying the severity of their symptoms. Participants gradually increased their understanding of the illness, whilst using strategies such as 'mindset' to prevent them from becoming overwhelmed. Similarities can be drawn to Calabro's (1990) cognitive model of adjustment, which suggests a process of varying degrees of approach and avoidance as people gradually accept the reality of their illness. Acceptance of the illness thus occurs slowly, with participants achieving some level of acceptance, but still having periods of fighting their illness. This is reflected within the theme of pacing, despite accepting a need to live within limitations, participants still at times 'kicked against it'. Having achieved a level of acceptance, participants became more able to identify illness gains, as their pre and post illness identities became more integrated. Interestingly, within this study length of illness did not appear to relate to acceptance or style of coping.

The findings of this study are in agreement with previous quantitative and qualitative research in this area. As discussed within the results section, a number of parallels can be seen between the themes which emerged from the interview, and existing research and theories of adjustment of chronic illness in general (Calabro, 1990; Morse & Johnson,

1991; Taylor, 1983), and CFS/ME specifically (Fennell, 1995). Such models describe an initial period of 'crisis' or 'disequilibrium' followed by attempts to make sense of the illness and re-gain mastery and self esteem. Through achieving control of symptoms and adapting life to their impact, it becomes possible to integrate pre and post illness aspects of identity. The results presented here suggest a similar process of becoming overwhelmed by the illness and trying to understand it, learn to cope with it, and accept it. Paterson's (2001) shifting perspectives model is also helpful in understanding variations in participants coping and acceptance levels over time. The findings of the present study stress the potential negative role played in this process by other people, in terms of the impact of other people's reactions to the illness and the difficulty gaining support, treatment and advice. The discussion of these findings also highlights the role of participants' perceptions of control over their illness in aiding coping.

Clinical implications

This qualitative study aimed to increase insight into the experiences of people with CFS/ME. The results reiterate the difficulties faced by this population, and draw attention to specific findings of relevance to the clinician. Firstly, all the participants in this study felt they had been let down by the NHS. Clearly current service provision is not meeting the needs of this population. This has recently been addressed by the NHS's pledge to commit more funds to the treatment of CFS/ME (Department of Health, 2003). Hopefully in the future, people with CFS/ME will be able to receive support and advice at an early stage of their illness rather than being left to 'muddle through'.

Secondly, the experiences of some participants in this study have resulted in a negative and distrustful opinion of the health profession in general, and psychiatry and psychology specifically. Awareness of this will be important for clinicians working with this population, and it may be necessary to address this early on within therapy. The participants in this study also showed a great deal of expertise and understanding about their illness, and motivation and determination to make the most of their lives. Within therapy, clients strengths should be drawn upon and utilised in forming a joint understanding of illness and exploring strategies to aid coping. Further, the similarities of participants reported coping strategies to techniques used within CBT approaches, adds weight to the utility of this approach. However, one point of disagreement seems likely to remain the role of illness beliefs. Further research is necessary to clarify their role in aiding or hindering coping with CFS/ME.

The results of this study also highlighted the role of acceptance in aiding coping. For the majority of participants this was seen as a key step in enabling them to adjust to live with CFS/ME. Again, clinicians should be aware of people's stage of acceptance and take this into account when formulating and planning interventions. The social context of CFS/ME was also confirmed as extremely important, impacting on levels of distress, acceptance and coping. However, to date relatively little research has addressed this (Cordingley *et al.*, 2001). Preliminary research has suggested that the reactions of family members may impact on recovery in CFS/ME (Butler *et al.*, 2001; Schmaling *et al.*, 2000). Including family members within assessment and therapy may be an important step, as has been found for other chronic illness groups (e.g. Chohanec & Binik, 1982; Radley & Green, 1986). Finally, participants in this study highlighted the importance of social, emotional

and practical support and the financial implications of their illness. Again clinicians need to take this into account when completing an assessment. An awareness of sources of support and advice on benefits claims may be beneficial.

Limitations of the research

The similarity of the themes identified for these participants to previous quantitative and qualitative research adds weight to their validity. The researcher has also addressed the recommendations for quality in qualitative research in order to ensure that the results are as valid and reliable as possible. However, despite this, there are obviously limitations to the study. Firstly, the interview relied on retrospective data, such information may be susceptible to memory biases (Brewin, 1998). This may be more problematic due to the length of time that some participants had experienced their illness, and the cognitive problems reported by people with CFS/ME (Michiels & Cluydts, 2001). This could be addressed within future research through the use of longitudinal research designs. The information for this study was also generally gathered from one interview, thus limiting opportunities for the interviewer to build rapport. However, the interviewer did not feel this had impacted on the interviews as participants were generally keen to tell their stories.

Due to small sample sizes it is not possible to generalise from the findings described.

However, the presentation of a clear description of sample and methods may allow comparison with similar groups. Although all participants in this study met the criteria for moderate impairment, they exhibited a range of levels of impairment and duration of

illness, which may have impacted on the findings. Further, information about the study was only available to a quarter of the ME group, and only a fifth of those aware of the study volunteered. These participants are likely to differ in terms of their level of impairment and in their interest in, and opinion of, research and psychology. A possible bias related to recruitment of participants from ME groups has been mentioned in several previous studies. For example, *Ax et al.* (1997) reported self help groups to typically downplay the role of psychosocial factors, and *Bentall et al.* (2002) reported membership of self help groups to predict poorer treatment outcomes following an education based intervention. It may be that people in self help groups have stronger opinions about the medical profession and treatment options. Such a population may also be more likely to have spent time researching their illness and identifying alternative sources of help. A further concern is that through attending the same self help group the participants may have some kind of 'joint understanding' of the nature of CFS/ME. However, although all participants had access to ME group information not all attended regular meetings and some variation can be seen in their individual stories. Despite this, it remains possible that the recruitment source did affect the emerging themes and this should be considered when assessing their validity.

It is also important to consider reflexivity and the impact of the interviewer on the research process. As mentioned within the results section, the majority of participants had experienced lack of understanding of their condition. Some participants also described negative experiences of their symptoms being attributed to psychological causes.

Although the nature of the interview meant that the interviewer did not impose her beliefs or opinions in any way upon the interviewee, it does seem likely that the psychology

background of the interviewer may have affected the interviews. Two participants specifically mentioned the interviewer's profession either during or after the interview, one of whom inquired after the interview about the interviewer's beliefs about the illness. However, the discussions that took place regarding poor treatment by the medical profession suggest that participants felt able to openly express their opinions.

Recommendations for future research

The results described above have given a significant amount of information about the experiences of people with CFS/ME. The discussion of these findings has also highlighted several potential areas for further research, these are listed below.

- Current research on the relationship between illness representations, coping and outcomes remains unclear. Further research is required to clarify the role of people's understanding about the cause of their illness.
- Longitudinal studies addressing participants' coping, understanding of illness and levels of acceptance using both quantitative and qualitative techniques.
- Further research investigating the impact of CFS/ME on families and relationships
- Further investigation of the relationship between emotion focused coping strategies, disability, acceptance and outcome.
- Further research investigating experience of illness in poorly represented groups of people with CFS/ME, particularly men, people with severe impairment and ethnic minorities.

CONCLUSIONS

The themes emerging from interviews with eight women diagnosed with CFS/ME suggest commonalities in their experience of the illness. Participants described an initial stage of being overwhelmed by their illness. Symptoms were numerous and distressing and resulted in losses of valued roles and activities. This also impacted on family members and relationships. Participants tried to seek help and advice but experienced lack of understanding and disbelief. This resulted in them feeling let down and isolated. Typically participants then began a process of searching for knowledge and insight into their condition. Through this they were able to identify sources of self help, such as alternative treatments. Participants also described the value of pacing activity levels and learning to listen to their body and its limitations. Further, the ability to think positively was reported to be important, as was the availability of emotional, practical and social support. In addition, the majority of participants described a process of struggling to accept their illness. Achieving this enabled them to adapt to life with CFS/ME and, for some, begin to identify illness gains. Similarities between these findings and existing research and models of adjustment to chronic illness suggest implications both for future research and clinical practice.

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CRITICAL APPRAISAL

Introduction

A reflective discussion will be presented describing the process of the research and my own resulting personal and professional development. Completing this was aided through consulting my reflexive diary in which I noted key meetings, thoughts and reactions throughout the process of identifying the research focus, interviewing, analysis and writing up.

Origins of the project

As the majority of my pre-course experience is in research, I approached the research with a great deal of enthusiasm. I believed it was extremely important to find an area to research that I was really engaged with, in order to maintain my enthusiasm and interest over the next two years. My interest in Chronic Fatigue Syndrome (CFS/ME) arose primarily through the experience of a close friend who was diagnosed with the condition. I had seen the painful struggle she had gone through, first to have her illness recognised and then to come to terms with the impact it had on her life. Her experiences of people's reactions to the condition, family, friends, employers and the medical profession, had fuelled my interest in undertaking a piece of research aiming to increase people's insight into this condition. I also had the impression that this was an area with relatively little research. Given my personal investment in CFS/ME, and a general interest from my pre-course research experience in applications of psychology to physical health, research on CFS/ME seemed to be an obvious choice. I also planned to complete a third year

placement in health psychology and therefore felt my choice of placement and research would complement each other.

The research process: Making decisions - going round in circles

Research report: My ideal choice of topic was in the area of adjustment to CFS/ME, as this appeared to have been a significant battle for my friend and I was also aware of existing models of adjustment to chronic illness. I felt that gaining insight into what people have found helpful within this process would be extremely beneficial for aiding others going through similar difficulties. A literature search found very little research specifically on adjustment to CFS/ME. As I was interested in exploring people's experiences, I decided that qualitative exploratory research would be the optimum approach. Although I had no previous experience of qualitative research I was keen to learn more and felt it would complement my existing quantitative research experience.

However, in discussion with my University and Field supervisors, difficulties soon arose related mainly to my lack of knowledge about qualitative techniques. As adjustment is a poorly defined term, focusing a piece of research on this was not felt to be appropriate, as within qualitative research the existence of such a process could not be presumed but would have to emerge naturally from the data. I could not ask participants directly about their experiences of adjustment as this would be presuming that a process of adjustment existed for them and that they were aware of this. I continued to explore the literature further in order to identify an appropriate and useful topic to research. I began to realise

that much more research had been completed on CFS/ME than I first thought, and was struggling to identify a research question which was both novel and useful.

Eventually my thoughts returned to my initial aim and I began to explore the idea of investigating the experiences of people with CFS/ME without specifically focusing on adjustment. It was therefore decided to focus more broadly on the experience of living with CFS/ME, asking questions about peoples experiences, from onset of symptoms through to the current time. Through doing this I hoped to capture a sense of the processes people went through in learning to live with their condition. Similarly to my original aim, I hoped this would give insight into the experiences of people with CFS/ME and into what they perceived to help them to learn to live with their illness.

Literature Review: Despite some minor difficulties, my choice of research area felt relatively straightforward. However, this was definitely not the case for my literature review. As mentioned above, on exploring the literature I found a great deal more research had been completed than I initially realised. Again I had a choice of topic in my head, of reviewing what is known currently about adjustment to CFS/ME, drawing on models of adjustment to chronic illness. Again this was impossible due to the lack of definition of the concept and again I started a circular process of identifying a topic to review, then finding either that far too much research had been completed to realistically review the topic within the limitations of the thesis, or finding that the literature had already been reviewed.

Having completed a literature review in the first year I was extremely keen to find an area which I was interested in. Without this I felt the slow process of completing the review would be a nightmare. The topics which had not been reviewed fully or comprehensively did not interest me whatsoever, and the topics I was interested in were vague and poorly defined. Through endless literature searching I began to realise that there was a body of research, mainly from sociological and anthropological journals, that had begun to investigate the experiences of people with CFS/ME. After overcoming my initial panic that these studies might invalidate my choice of research topic, I decided a useful and interesting literature review topic would be to draw together the findings of these previous studies, alongside relevant quantitative research. However, identifying what to include as related areas proved difficult to ascertain. I found I was in danger of trying to review a vast amount of literature. Eventually after a few more weeks of going round in circles I decided to review the literature on the subjective experience of living with CFS/ME and the related body of literature on the Quality of Life (QoL) of people with CFS/ME.

Getting going

Interview schedule design: I found discussions of interview schedule design by Smith and Osborn (2003) a useful guide in this process. Key issues to cover were identified as initial symptom onset, the impact of this on the participant, how this has changed over time, and what the participant has learnt. I then identified brief, neutral questions and prompts to explore these areas. The interview schedule was discussed within a peer protocol review, and some questions were reworded to ensure that they were as open and neutral as

possible. For example, prompts asking how people felt or what they did in reaction to symptoms were too leading and needed to be removed. Following approval of the interview schedule and protocol by the University, the research was submitted to the ethics committee and approved with some minor revisions.

It is necessary to ask very open questions within qualitative research to prevent imposing the views of the researcher (Smith & Osborn, 2003). However, this also felt quite risky, as I was concerned about ensuring the interviews accessed the depth of material I was interested in. The schedule was further reviewed through piloting it with peers to ensure that questions were experienced as clear and open. Following this some further revisions were made to the interview schedule, which were approved by the ethics committee. These revisions aimed to ensure that the schedule was able to identify changes over time, and to ask participants opinion on how this has happened.

Recruitment and Interviewing: It was decided to recruit from the local ME self help group as there was currently no CFS/ME specific NHS service, thus making recruitment through medical services problematic. Quite broad inclusion criteria were set with a requirement sufficient to ensure participants had been experiencing a significant level of disability for at least a year. At this stage I met with the Chairperson of the Sheffield ME group and outlined my research proposal. She was extremely enthusiastic about the research and was confident I would be able to recruit sufficient participants. Her enthusiasm was encouraging and increased my determination to produce a valuable piece of research offering useful information.

I was extremely lucky with recruitment and this made the whole of my research much less stressful and much more under my control. Following an e-mail round the ME e-mail network and a brief presentation of my research at the Sheffield ME Group Annual General Meeting, 10 women volunteered. I was therefore able to quickly get started on my research. Although I had practiced the interview schedule with peers, I found the process of interviewing much harder than I expected. Keeping track of the interview and things to follow up required a great deal of concentration. I found that I was drawing on my clinical skills to encourage rapport, using sensitivity, empathy, warmth and engagement (as discussed by Grafanaki, 1996), but also felt some tension between the roles of a clinician and a researcher.

After my first interview my enthusiasm was somewhat dampened. My first participant described her experiences in a very matter of fact way and was very focused on medical explanations and interventions. I felt that throughout the interview I failed to gain any insight into the personal impact of her illness. I also began to feel concerned again that I would not gain anything of value from the interviews. After this initial interview I had time to listen to the interview, transcribe it and discuss it with my supervisor. I found this extremely helpful in terms of developing my own interview technique. I was able to identify which prompts were more or less helpful and identify statements that with hindsight I should have followed up. I also discussed with my supervisor the nature of the interview. I felt that the participant focused by coping and ignoring the impact of the illness (as discussed within the research report). Given this, I felt that to probe too much into the psychological impact of the illness would have been unethical.

I found subsequent interviews continued to be very draining, and quickly learnt my mistake in arranging two interviews a day. Interviews were particularly hard when participants became distressed, as happened in three of the interviews. Although no participants expressed any regret at taking part, I felt a certain amount of responsibility for triggering their distress. When participants did become distressed I found my clinical experience both a help and a hindrance. I was able to empathise and talk with participants after the interviews and in one case complete a risk assessment due to my level of concern. However, my clinical knowledge also made it hard to leave people knowing they were not getting potentially beneficial support. This was particularly difficult for one participant who appeared to be extremely depressed. Although I fulfilled my research responsibility by checking that there were no risk issues and discussed with her the possibility of her contacting her GP, I felt as a clinician I could do much more.

The difficulties maintaining boundaries between researcher and clinician are discussed by Grafanaki (1996) and Hadjistavropoulos and Smythe (2001). As I discovered, research questions have the potential to traumatise participants, especially if they are related to unresolved or painful issues. Similar to my experience with my first interview participant, Grafanaki (1996) discusses 'ethical decision making' and the importance of monitoring the amount of pressure (direct and indirect) placed on participants to respond to questions. Although I had considered the ethics of interviewing participants in terms of identifying procedures to follow should participants become distressed, I had not given as much consideration to the personal impact of this. I found that regular meetings with supervisors and peers to debrief were helpful in dealing with this. I also felt that although I was gaining a lot from the interviews, I was unsure how much participants were

gaining. However, all the people I interviewed were enthusiastic about the research and keen to increase the knowledge about CFS/ME. This encouraged me and increased my resolve to find some useful publishable results yet further.

Analysis: As mentioned above, prior to starting my research I had no experience of qualitative analysis. Introductory teaching on the course helped to familiarise me with different methodological options. Through further reading and discussion I identified Interpretative Phenomenological Analysis (IPA) as the most suitable method for the aims of this particular research project. The aims of this methodology were therefore borne in mind when designing the interview schedule. Through some further reading and specific IPA teaching on the course I felt I was beginning to gain a better idea of what this method of analysis involved. However, I was also extremely daunted by the task ahead and envisaged my house becoming overrun with pieces of paper. Attending the IPA conference in summer 2003 was a key learning opportunity. Through a combination of lectures and workshops I gained an understanding of the reality and practicalities of using IPA.

One of the main things I took away from the IPA conference was a sense that although IPA provides a model of how to analyse data, there is no one correct way of actually doing this (also discussed by Smith & Osborn, 2003). Bearing this in mind was invaluable through the at times frustrating process of the analysis. Although methodology descriptions were useful, I found that it was more important to find my own specific analysis technique. Identifying this and trying out different techniques helped to improve my confidence in my ability to complete a qualitative analysis.

After the initial phase of reading and rereading transcripts I began the daunting task of separating out transcripts into themes. I initially attempted this by physically cutting up transcripts and placing them into clear pocket files. However, I quickly realised this method wasn't for me. Surrounded by bits of paper I felt overwhelmed by chaos and was unable to make sense of the groups of themes. I decided to change approach and instead compiled tables of quotes by cutting and pasting on the computer. This process immediately felt easier. I found that the method also had the added bonus of helping to produce an audit trail. As I revised and re-revised theme tables I saved each version separately, thus producing an audit trail I could check back through as the analysis progressed. This technique also allowed easier checking of the relationship between quotes and themes. The data felt more manageable thus allowing me to make sense of the emerging themes.

After analysing the first interview I had a slight crisis of confidence. Having previously been used to statistical analysis I found the level of subjectivity involved in qualitative analysis to be very unsettling. I realised that although I was sure the themes which had emerged were accurate representations of the data from the interview, I was also aware that I could have interpreted the quotes in many different ways. Having the theme tables checked by my supervisor as part of the audit trail was extremely reassuring at this point. I was further reminded of discussions at the IPA conference regarding different levels of interpretation. I felt that I had stayed quite close to the data in interpreting themes. This made it easier to establish the validity of themes than if I had taken a more interpretative approach bringing in my own theoretical knowledge. Throughout the analysis I was also aware that I was completing my literature review simultaneously, and was cautious of

this contaminating or biasing the analysis process. Repeatedly reviewing the relationships between themes and quotes and verifying this with peers and supervisors was helpful to clarify that themes were representative of the interviews, rather than being biased by my own knowledge and beliefs.

After completing the analysis process I sent copies of individual master themes back to participants asking for any comments. I originally had some concerns about sending copies of the themes back to the participant who had appeared very depressed. However, following discussions with my supervisor it was decided that this was appropriate. I was very interested to hear what participants made of the themes and was disappointed that only two participants responded. The comments made did not contradict the themes and were taken into account during the final stage of the research. I was unsure what the lack of response meant. It could be that the themes were fine, that participants were too fatigued to comment or that there was a lack of interest or opinion. Unfortunately I am unable to find the answer to this.

Following receipt of individual participant feedback I moved on to integrating the master themes. Again this initially felt overwhelming, as if this stage of the analysis could go on for ever. Eventually I returned to a cutting and sticking approach, as the volume of data at this stage felt more manageable. Printing out individual master themes on coloured paper and cutting and sticking similar quotes on a large sheet of paper proved initially to be a relatively lighthearted diversion, though later finalising themes was more intensive.

Throughout interviewing and analysis I had found potential themes or models emerged, I found that it was useful to bear these in mind when trying to organise the data but was

wary of imposing them on the data prematurely. As master themes emerged, seeing the similarities between the interviews enhanced my confidence that I was drawing out something clinically useful. Throughout this process I used a circular analysis technique, checking back to initial themes and quotes for each participant, as recommended by Stiles (2003). Although this was both taxing and time consuming I found the process satisfying as it increased my confidence in the validity of my analysis across levels.

Writing up

Research report: I felt very fortunate having previous research experience, as writing up the research report did feel too daunting. In fact I found that I was looking forward to bringing the findings together. Having completed the analysis I felt like the report was almost starting to write itself, although tracking down and linking in appropriate theory was quite time consuming. Throughout the research project I had been determined to write my research report in the journal format. However, as I started to draw in theory the report grew longer and longer and this determination began to fail. Having put in so much work and identified what I saw as useful links to theory I was reluctant to cut it out. I therefore eventually decided to change to option A and write a longer research report. Once I had finished analysing the themes I felt the research had produced interesting findings and was pleased with the outcome.

Literature review: Again, writing up the literature review proved to be a more stressful and frustrating process. Every paper I found seemed to reference several more and the number of papers I was aiming to review began to spiral out of control. I also repeatedly

felt that I had lost the aim of the review and had to frequently refocus myself. I found reviewing qualitative papers much more interesting but also more challenging than reviewing quantitative papers. I felt that I was completing a parallel process analysing the themes of papers, to that of pulling together the individual themes to identify the master themes in my research. Drawing on my IPA skills therefore proved helpful in this process. However, this was complicated by incomplete information and understanding about the individual study themes and their different methods of reporting. I came to the conclusion that, as with my research analysis, some level of subjectivity was inevitable in this process, but that as long as I was clear about my aims and the methods I had used, the findings would still be valuable. Throughout this process, I was also very aware that what I was doing was not a straight forward traditional literature review. Although I felt this was not a reason not to do it, this did make completing the review more stressful and at times I wished I had never chosen the topic. Reviewing QoL also proved difficult due to the lack of definition of the concept. Again, I found being very clear about my aims and the information I was hoping to gain to be the key. This helped to draw the two aspects of the review together.

Looking back: Learning opportunities

Use of supervision: Throughout the process of the research I met regularly with both my supervisors. I found that supervision on the research differed to supervision I had received previously. As neither supervisor had specific research experience in CFS/ME, I found that I was the expert on this area. Although being in this position was a useful process in terms of my development as a clinician and a researcher, it was extremely

daunting at times. As described earlier, nobody was able to give me definite answers I ended up going round in circles. I feel that I adapted to this over the course of the research and began to use supervision as an opportunity to bounce around ideas, clarify my own conclusions and receive encouragement. This enabled me to use supervision more efficiently, rather than becoming frustrated by lack of specific answers. I believe that this model of supervision is likely to be closer to that which I will experience in the future as a qualified clinical psychologist.

Personal Learning: Throughout the clinical course trainees are warned by their peers of the stressful nature of the third year and are very aware of the drawn, agitated faces of those currently going through this. I was determined that this would not happen to me and worked steadily on my research to prevent it becoming too overwhelming. However, this did seem to be something of a self fulfilling prophecy and trainee stress levels proved extremely contagious. Completing both clinical and research work simultaneously was extremely hard to manage at times and there felt to be no emotional reserves left if anything else went wrong, personally or professionally. However, through this process I have learnt a lot about myself. Looking back over the past two years has also proved to be an interesting process in itself, especially noticing the time and stress involved in going round in circles prior to making decisions.

Throughout the process of the thesis, I found that maintaining boundaries between clinical and research work and personal space were vital. Without these I struggled to devote my full attention to anything and ended up wasting time. Given multiple competing demands, I also fell back to the use of lists to keep track of where I was at and

where to go next. Organisation and planning were vital as my study began to fill with research papers, interview transcripts and themes. Thinking back to my experiences of completing the thesis reminds me of the discussion of the usefulness of different types of coping discussed within my research themes (Lazarus, 1993). I found that I was very good at problem focused coping, tackling the job in hand by planning, prioritising and breaking things down into small steps. However, at the times when there was nothing more to be done but to contain the anxiety about the level of work and it's quality, my emotion focused coping strategies proved less successful!

The experience of completing interviews was also a learning process for me personally. Many participants spoke about manic, stressful lifestyles preceding their illness and reinterpreting values and priorities. This led me to frequently question my own lifestyle, expectations and priorities and to think about relaxation and prioritising life outside of work. I believe all of these skills and insights will be important for me in the future, remembering to prioritise yourself and your health alongside work and dealing with inevitable ongoing and uncontrollable sources of stress.

Clinical learning: The experience of conducting the interviews was also a learning opportunity in terms of my clinical skills, particularly through the need to rapidly build rapport, show empathy and asking open questions. These are obviously very useful skills, especially within the early stages of therapy. Once I had completed the interviewing and initial analysis I began to see clients with CFS/ME on my health psychology placement. I found the experience I had gained from the interviews invaluable within this process, in terms of increasing my empathy and understanding. Through the background reading for

my research I also gained a lot of understanding about theories and research on adjustment and coping with other chronic illness groups. Being aware of ideas both from my own research and previous research, and applying these within client work proved helpful, both with clients with CFS/ME and other chronically ill clients. As discussed within the report I also believe the findings of both the literature review and the research provide suggestions for clinicians working in this area. In the near future I will be presenting the results of this research back to the Sheffield ME group. I will be extremely interested to hear their reactions and comments.

Research learning: I found completing a qualitative research project interesting and thought provoking. I feel that I have gained a good understanding of the IPA methodology and the benefits and advantages of this, and would feel confident in applying such a technique in the future. I was also able to apply a similar technique in an innovative way within the literature review. Further, completing this research confirmed my desire to incorporate research and clinical work in my future career. Through this experience I found that it is relatively easy to apply the findings of qualitative research directly to my clinical work. However, such research would be likely to have much less impact at an organisational level. Identifying the purpose of research and what the findings hope to achieve will clearly be very important in future research projects.

Although I enjoy working independently, I found the involvement of other people to be crucial in qualitative research. Reviewing the analysis with supervisors and peers ensured a balance between being immersed in the data and becoming stuck in a rut. Frequently, getting an external opinion was helpful to ensure that themes identified were valid and

based on the data. I have also come to realise the importance of involvement of others in ensuring dissemination of findings. I plan to feed back the results of my research to the Sheffield ME Group and aim to get them published in a peer reviewed journal. However, if the research was situated directly within a CFS/ME service it may be easier to ensure the results were integrated within clinical practice and that clinical recommendations were considered. I would definitely bear this in mind when planning future research. Finally, completing this research has confirmed for me yet again the importance of comprehensive literature searching and identifying specific aims at as early a stage as possible. Achieving this would prevent unnecessary time and energy being spent going round in circles!

Conclusions

Despite the inevitable stresses, I have enjoyed completing the thesis and, contrary to predictions, it has not put me off completing research in the future. I have learnt a lot from the process, about myself personally, as a researcher and as a clinician and believe it has helped me on my path to becoming a clinical psychologist. Although I have identified things I would do differently in the future, even with the power of hindsight I am happy with my choice of topic and the progress of the research. My only remaining goal is for the findings to provide something useful for people with CFS/ME.

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APPENDICES

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Appendix 1: Notes for Contributors to the British Journal of Health Psychology.

British Journal of Health Psychology

Notes for Contributors

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The following types of paper are invited:

- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology;
- methodological papers dealing with methodological issues of particular relevance to health psychology.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5,000 words, although the Editor retains discretion to publish papers beyond this length.

3. Reviewing

The journal operates a policy of anonymous peer review. Papers will normally be scrutinised and commented on by at least two independent expert referees (in addition to the Editor) although the Editor may process a paper at his or her discretion. The referees will not be aware of the identity of the author. All information about authorship including personal acknowledgements and institutional affiliations should be confined to the title page (and the text should be free of such clues as identifiable self-citations e.g. 'In our earlier work...').

4. Online submission process

- 1) All manuscripts must be submitted online at <http://bjhp.edmgr.com>.

First-time users: click the REGISTER button from the menu and enter in your details as instructed. On successful registration, an email will be sent informing you of your user name and password. Please keep this email for future reference and proceed to LOGIN. (You do not need to re-register if your status changes e.g. author, reviewer or editor).

Registered users: click the LOGIN button from the menu and enter your

user name and password for immediate access. Click 'Author Login'.

- 2) Follow the step-by-step instructions to submit your manuscript.
- 3) The submission must include the following as separate files:
 - Title page consisting of manuscript title, authors' full names and affiliations, name and address for corresponding author.
 - Abstract
 - Full manuscript omitting authors' names and affiliations. Figures and tables can be attached separately if necessary.
- 4) If you require further help in submitting your manuscript, please consult 'Tutorial for Authors' (PDF, 130Kb).

Authors can log on at any time to check the status of the manuscript.

5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate page. The resolution of digital images must be at least 300 dpi.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions. (See BJHP Structured Abstracts)
- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the Imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations etc for which they do not own copyright.

For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association, Washington DC, USA (<http://www.apastyle.org>).

6. Publication ethics

Code of Conduct

Principles of Publishing

7. Supplementary data

Supplementary data too extensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

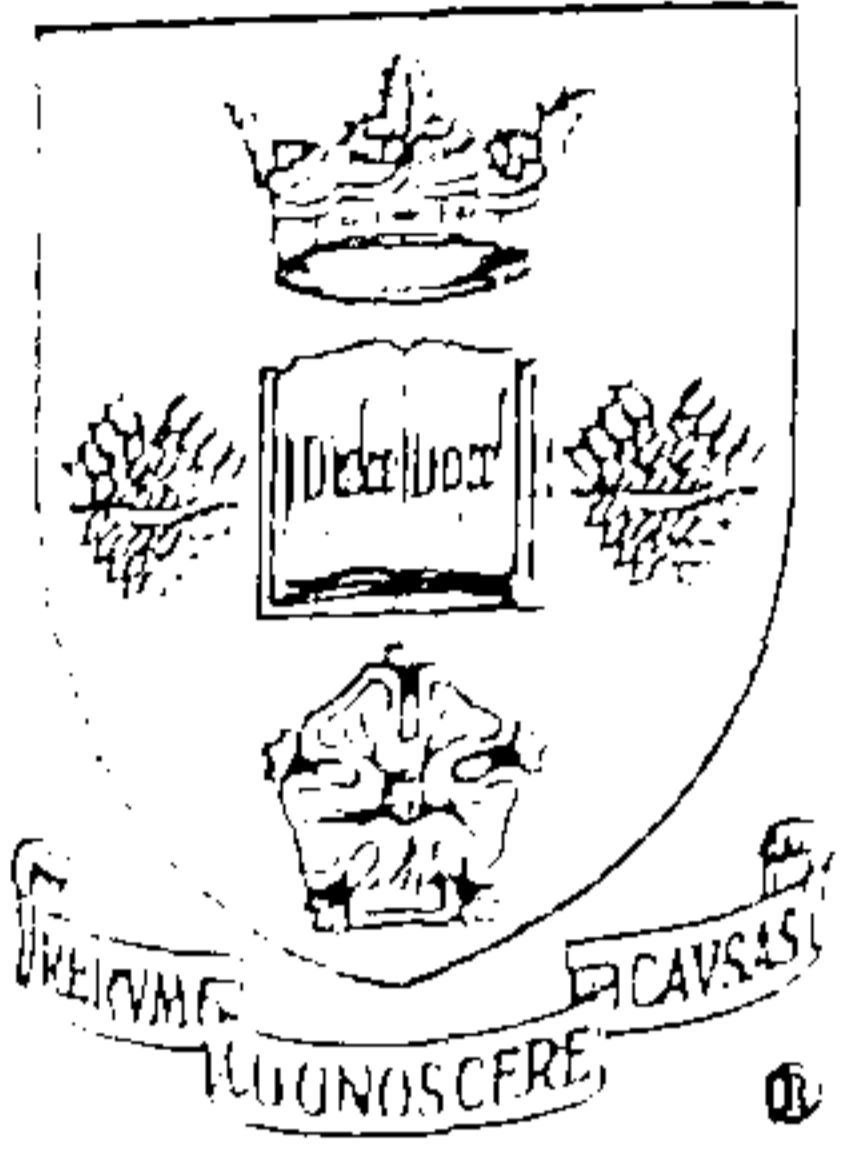
8. Post acceptance

PDF page proofs are sent to authors via email for correction of print but not for rewriting or the introduction of new material. Authors will be provided with a PDF file of their article prior to publication for easy and cost-effective dissemination to colleagues.

9. Copyright

To protect authors and journals against unauthorised reproduction of articles, The British Psychological Society requires copyright to be assigned to itself as publisher, on the express condition that authors may use their own material at any time without permission. On acceptance of a paper submitted to a journal, authors will be requested to sign an appropriate assignment of copyright form.

Appendix 2: Letter of approval from the chair of the research subcommittee



THE UNIVERSITY OF SHEFFIELD
Clinical Psychology Unit
Department of Psychology

Doctor of Clinical Psychology (DClin Psy) Programmes (Pre-registration and post-qualification)
Clinical supervision training and NHS research training and consultancy

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TP UK

Unit Director: Prof Graham Turpin
Assistant Director : Prof Pauline Slade
Prof Gillian Hardy

Telephone: 0114 2226570
Fax: 0114 2226610
Email: dclinpsy@sheffield.ac.uk

Clinical Practice Director: Ms Joyce Scaife
Course Administrator: Carole Gillespie
Prof Nigel Beail

12th July 2004

Catherine Nicholl
Third year trainee
Clinical Psychology Unit
University of Sheffield

Dear Catherine


I am writing to indicate our approval of the journal(s) you have nominated for publishing work contained in your research thesis.

Literature Review: British Journal of Health Psychology

Research Report: Option A

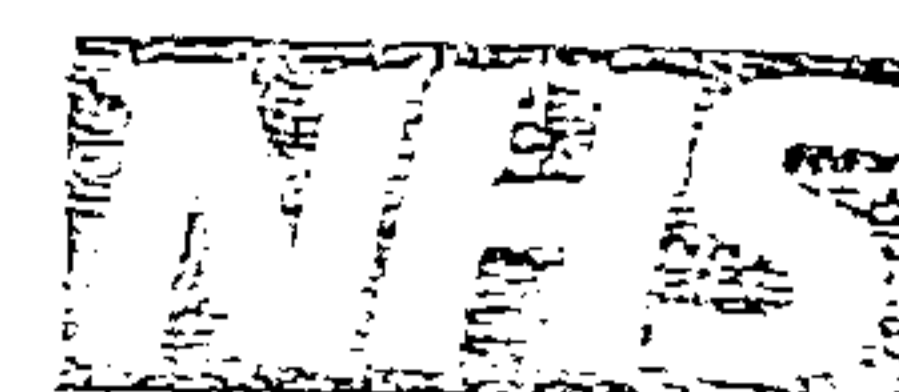
Please remember to bind in this letter and copies of the relevant Instructions to Authors with your thesis.

Yours sincerely


Andrew Thompson
Chair, Research Sub-Committee

Appendix 3: Letter of Approval from Research Ethics Committee

Sheffield Teaching Hospitals
NHS Trust



North Sheffield Ethics Office
1st Floor Vickers Corridor

Direct Line: 0114 271 4894/or 271 4011
Fax: 0114 256 2469

Email: Sue.Rose@sth.nhs.uk

Northern General Hospital
Herries Road
Sheffield
S5 7AU

CMHN/AD/02/06/03

Thompson/NS2003 6 1681

Please quote this number on all correspondence

24th July 2003

Dear Ms Nicholl

The experience of living with chronic fatigue syndrome.
NS2003 6 1681

The Chair/Honorary Secretary of the North Sheffield Research Ethics Committee has considered the modifications submitted in response to the Committee's earlier review of your application on 2nd June 2003 as set out in our letter dated 5th June 2003. The documents considered were as follows:

- Protocol dated 3rd July 2003.
- Transcriber confidentiality form version 2 dated 3rd July 2003.
- Recruitment poster version 1 dated 3rd July 2003.
- Letter to volunteers not being interviewed version 2 dated 3rd July 2003.
- Recruitment e-mail version 1 dated 3rd July 2003.
- Interview schedule version 1 dated 2nd May 2003.
- Initial letter to participants version 1 dated 3rd July 2003.
- Consent form version 2 dated 3rd July 2003.
- Participant information sheet version 2 dated 3rd July 2003.
- Certificate of insurances from the University of Sheffield dated 26th June 2003.
- Fully signed signatory page.
- Covering letter dated 2nd July 2003.

The Chair/Honorary Secretary, acting under delegated authority, is satisfied that these accord
sion of the Committee and has agreed that there is no objection on ethical grounds
sed study. I am, therefore, happy to give you the favourable opinion of the
1 the understanding that you will follow the conditions set out below.

Thompson/NS2003 6 1681/24-07-03

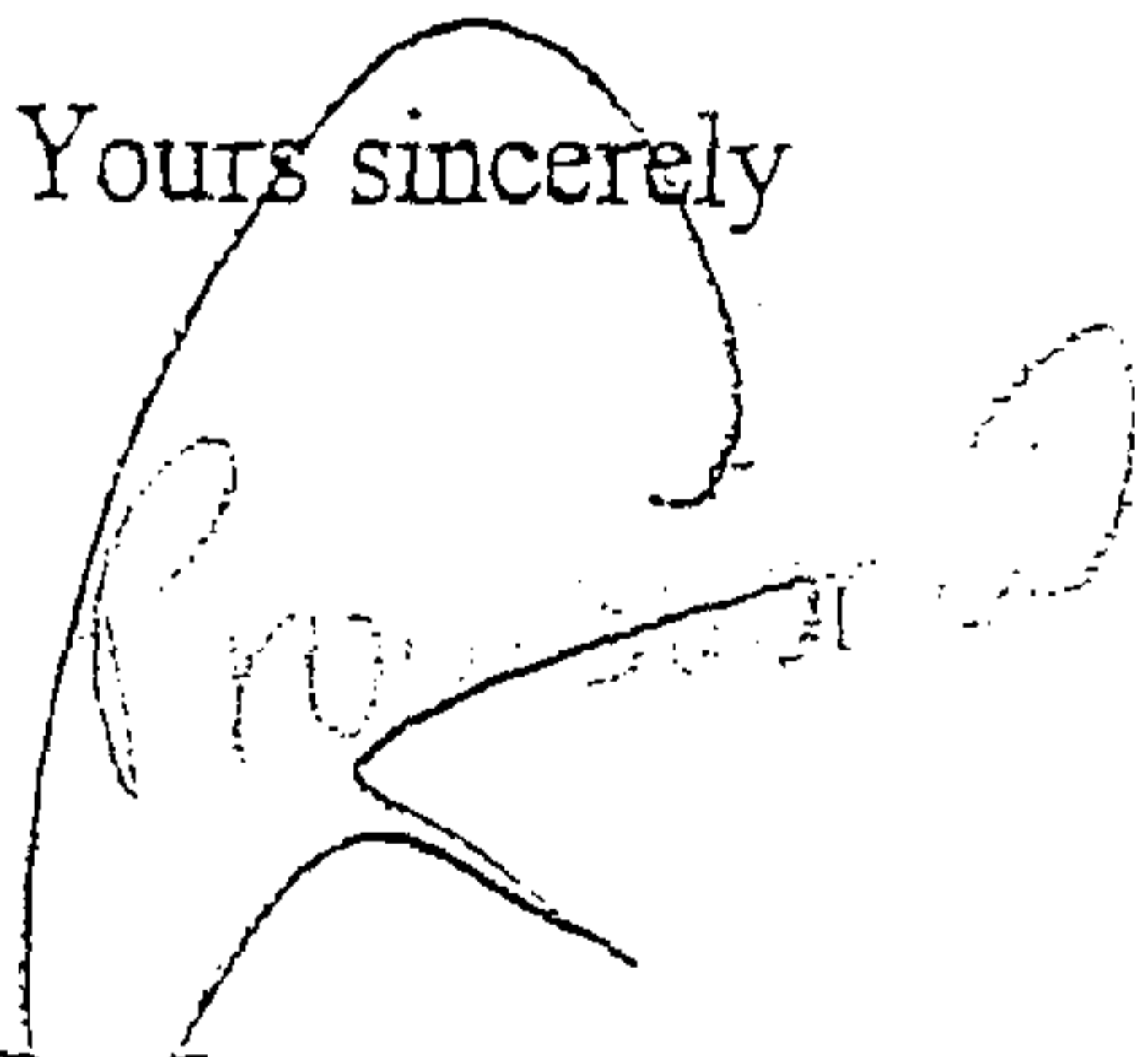
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Conditions

- You do not recruit any research subjects within a research site unless favourable opinion has been obtained from the relevant REC.
- You do not undertake this research in an NHS organisation until the relevant NHS management approval has been gained as set out in the *Framework for Research Governance in Health and Social Care*.
- You do not deviate from, or make changes to, the protocol without prior written approval of the REC, except where this is necessary to eliminate immediate hazards to research participants or when the change involves only logistical or administrative aspects of the research. In such cases the REC should be informed within seven days of the implementation of the change.
- You complete and return the standard progress report form to the REC one-year from the date on this letter and thereafter on an annual basis. This form should also be used to notify the REC when your research is completed and in this case should be sent to this REC within three months of completion.
- If you decided to terminate this research prematurely you send a report to this REC within 15 days, indicating the reason for the early termination.
- You advise the REC of any unusual or unexpected results that raise questions about the safety of the research.
- *Please provide a copy of the Sheffield Care Trust indemnity when available.*

A full record of the review undertaken by the REC is contained in the attached REC Response Form. The project must be started within three years of the date on which REC approval is given.

Yours sincerely

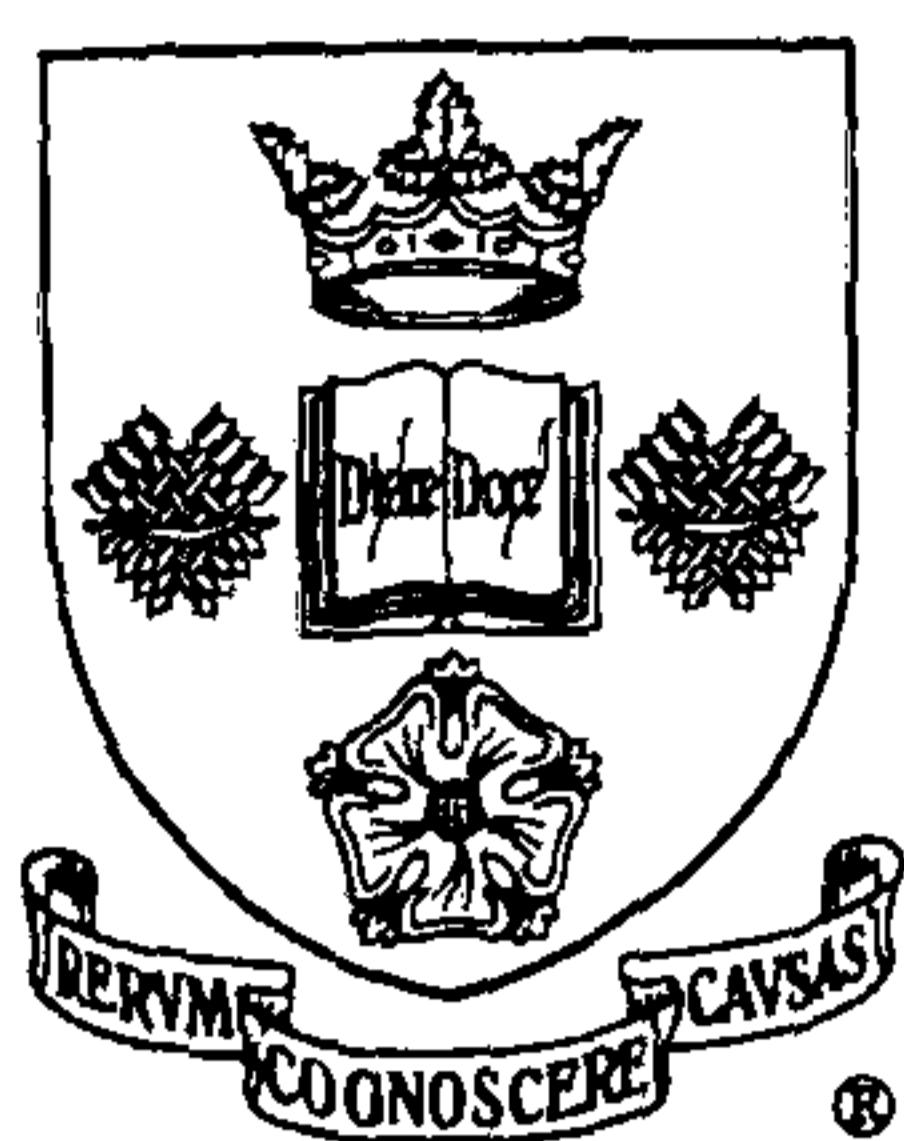


Dr C M H Newman
 HONORARY SECRETARY - NORTH SHEFFIELD RESEARCH ETHICS COMMITTEE
 Senior Lecturer in Cardiology/Honorary Consultant Physician

Cc Dr A Thompson, Dr A Blair, R & D Consortium

Encs

**Appendix 4: Recruitment information for the Sheffield ME Group.
Recruitment poster.**



THE UNIVERSITY OF SHEFFIELD
Clinical Psychology Unit
Department of Psychology
Doctor of Clinical Psychology (DClin Psy) Programmes (Pre-registration and post-qualification)
Clinical supervision training and NHS research training and consultancy

Are you suffering from the symptoms of CFS/M.E.?

Have you had these symptoms over a year?

Have you received a diagnosis of CFS/M.E. from a medical professional?

Is CFS/M.E. currently your main health problem?

Would you be interested in speaking with somebody about your experiences as part of a research project?

I am currently recruiting participants through the Sheffield M.E. Group for a research project looking at the experience of living with CFS/M.E. The aim of the project is to get a better understanding of what it is like to live with CFS/M.E. It is hoped that the findings will give professionals greater insight into what CFS/M.E. sufferers are going through.

If you are interested in more information about this project please contact Catherine Nicholl on ---- or by e-mail at ---

Recruitment e-mail



THE UNIVERSITY OF SHEFFIELD
Clinical Psychology Unit
Department of Psychology

Doctor of Clinical Psychology (DClin Psy) Programmes (Pre-registration and post-qualification)
Clinical supervision training and NHS research training and consultancy

Dear Members of the Sheffield M.E. Group,

I am writing to invite you to take part in a research project I am currently conducting. The research is being carried out in order to get a better understanding of what it is like to live with CFS/ME. It is hoped that the findings will give professionals greater insight into what CFS/ME sufferers are experiencing. I am planning to interview people aged over 18 who speak English as their first language.

Participation in the research is completely voluntary. Please read the information sheet accompanying this letter for further information about the study.

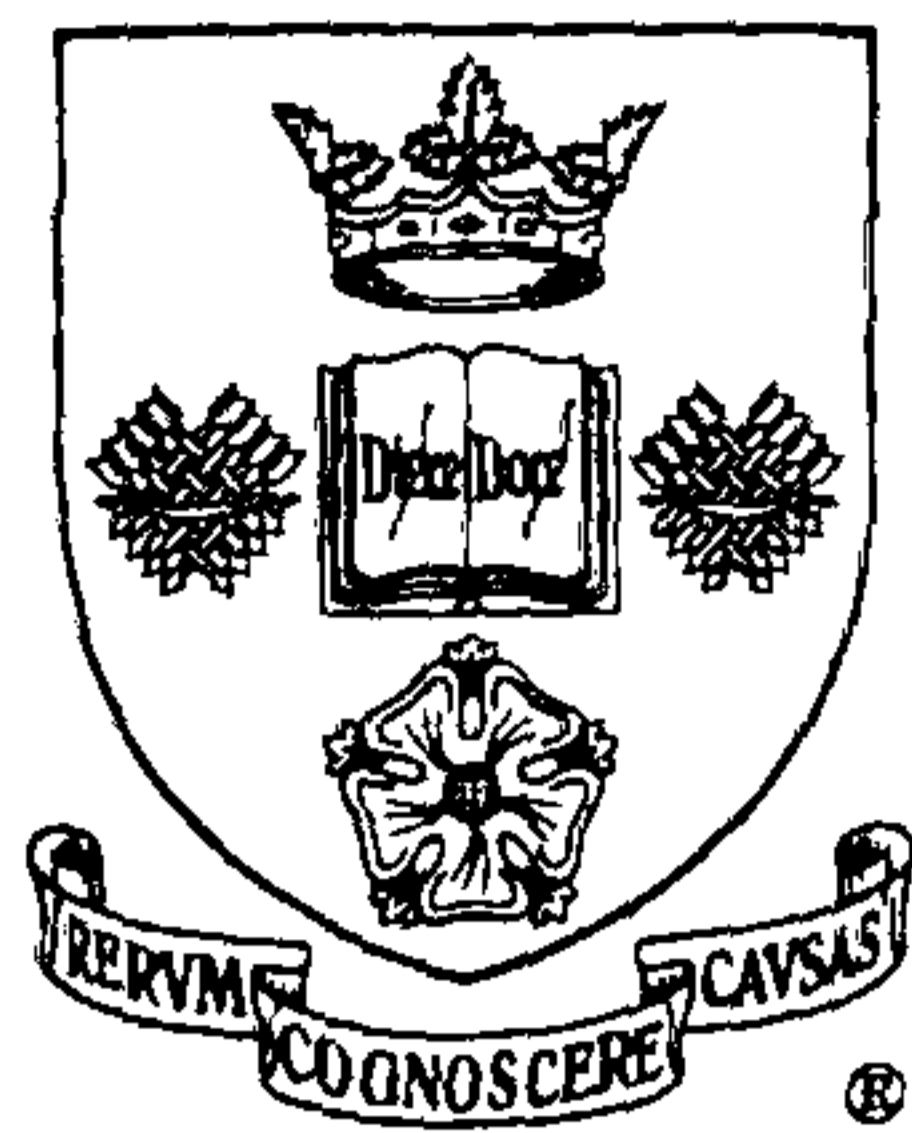
If you are happy to take part in the research or would like further information, please either leave me a message on ..., send your name, address and telephone number to (e-mail address) or let one of the M.E group committee members know who will pass your name on to me.

Thank you very much for your time

Yours Sincerely

Catherine Nicholl
Trainee Clinical Psychologist

Appendix 5: Information sheet and consent form



THE UNIVERSITY OF SHEFFIELD

Clinical Psychology Unit

Department of Psychology

Doctor of Clinical Psychology (DClin Psy) Programmes (Pre-registration and post-qualification)
Clinical supervision training and NHS research training and consultancy

An exploratory study of the experience of living with CFS/M.E.

Participant Information Sheet

You are invited to take part in a research study investigating the experiences of people living with Chronic Fatigue Syndrome/ME. Before you decide whether to take part it is important that you understand why the research is taking place and what it will involve. Please take time to read the following information carefully and discuss it with your friends, relatives and other members of the Sheffield ME group if you wish. Please ask if there is anything you are not clear about or if you would like any further information.

What is the purpose of the study?

The research is being carried out in order to get a better understanding of what it is like to live with CFS/ME. It is hoped that the findings will give professionals greater insight into what CFS/ME sufferers are going through, what helps them and what is unhelpful.

Am I suitable to take part?

We are hoping to interview 8 people aged over 18 who speak English as their first language. We would like to interview individuals who have been suffering the symptoms of CFS/ME for at least a year and who have been diagnosed with CFS or ME by a medical professional. We would like to talk to people who feel that CFS/ME is currently their main health problem, have generally poor and disturbed sleep quality and who are currently experiencing symptoms that reduce their mobility and activities of daily living and require them to have rest periods during the day.

What will be involved if I agree to take part in the study?

If you are willing to take part you will be asked to sign a consent form and to give your contact details to the researcher. If more people volunteer to take part than can be interviewed, the first 8 people will be contacted by telephone to arrange a convenient time for the interview. Any other volunteers will be contacted by letter once sufficient interviews have been completed and thanked for their interest. The full interview will take approximately 1 1/2 hours, but could be conducted in two parts or with several breaks if this would be easier for you. During the interview you will be asked about your initial experience of the symptoms of CFS/ME, how it affected you then and how it affects you now. The interviews will be tape recorded and transcribed. I will also contact you a few months after the interview asking you to read through a summary of the interview to check that I have an accurate account of your experiences.

Who will be conducting the interview?

The interview will be conducted by Catherine Nicholl, who is currently training to be a clinical psychologist.

Where and when will the interview take place?

The interview will take place at a time that suits you. Some people may prefer to be seen at home while others may find it easier to talk away from home where there are fewer distractions. The interview can be arranged either at your own home or the Sheffield Carers Centre, whichever is most convenient for you.

Do I have to take part?

You are under no obligation to take part.

Can I withdraw from the study at any time?

Even if you agree to take part now you are still free to withdraw from the research at any time. During the interview you also have the right to refuse to answer any questions you are not happy with, and to ask to take a break or terminate the interview at any time.

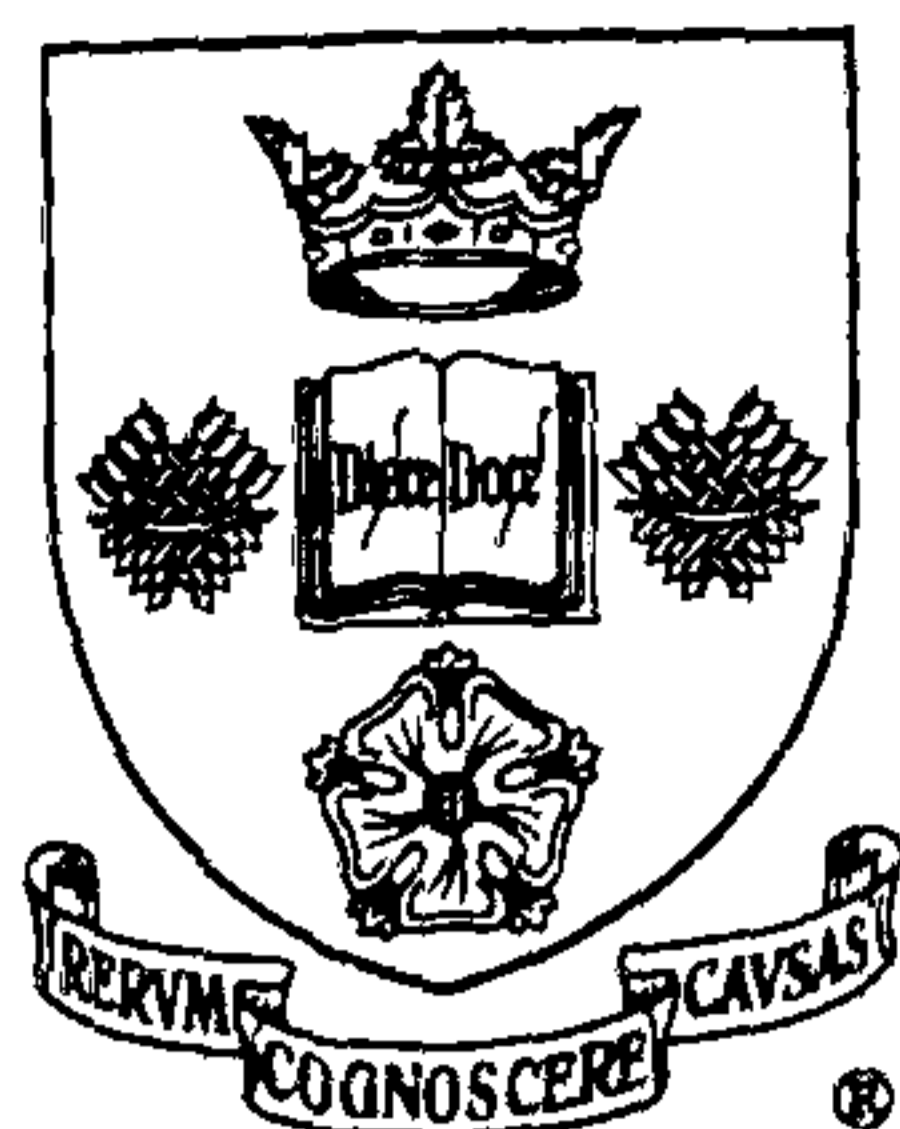
Will information be kept confidential?

All the information we gain will be kept confidential, within the professional limits of confidentiality. All transcriptions will be fully anonymised and tape recordings will be stored securely throughout the analysis and destroyed after the project is completed. Any quotes which are used in the final report will be fully anonymised to ensure that no individuals are identifiable.

What do I do if I have any complaints about this research?

If you have any cause to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available to you, and are not compromised in any way because you have taken part in a research study. If you have any complaints or concerns please contact the project co-ordinator, Dr. Andrew Thompson on 0114 2226632, in the first instance. If this is not satisfactory, you can also use the normal hospital complaints procedure through Dr. Chris Welsh, Medical Director, on 0114 271 2178.

If you have any queries or require any further information please do not hesitate to contact Catherine Nicholl on ----



THE UNIVERSITY OF SHEFFIELD
Clinical Psychology Unit
Department of Psychology

Doctor of Clinical Psychology (DClin Psy) Programmes (Pre-registration and post-qualification)
 Clinical supervision training and NHS research training and consultancy

An exploratory study of the experience of living with CFS/M.E.

Consent form

Please cross out as necessary

Have you read the Information sheet? YES / NO

Have you had an opportunity to ask questions and discuss the study? YES / NO

Have you received enough information about the study? YES / NO

Do you understand that you are free to withdraw from the study

- at any time
- without having to give a reason for withdrawing

YES / NO

Do you understand that all information will be kept confidential, and that you will not be identified by name? YES / NO

Do you agree to take part in this study? YES / NO

Do you agree for the interview to be tape recorded? YES / NO

Do you agree for fully anonymised quotes to be used in the final research report, if required? YES / NO

Signed Date

Name (in block letters)

Address:

Daytime telephone number:

Appendix 6: Interview Schedule

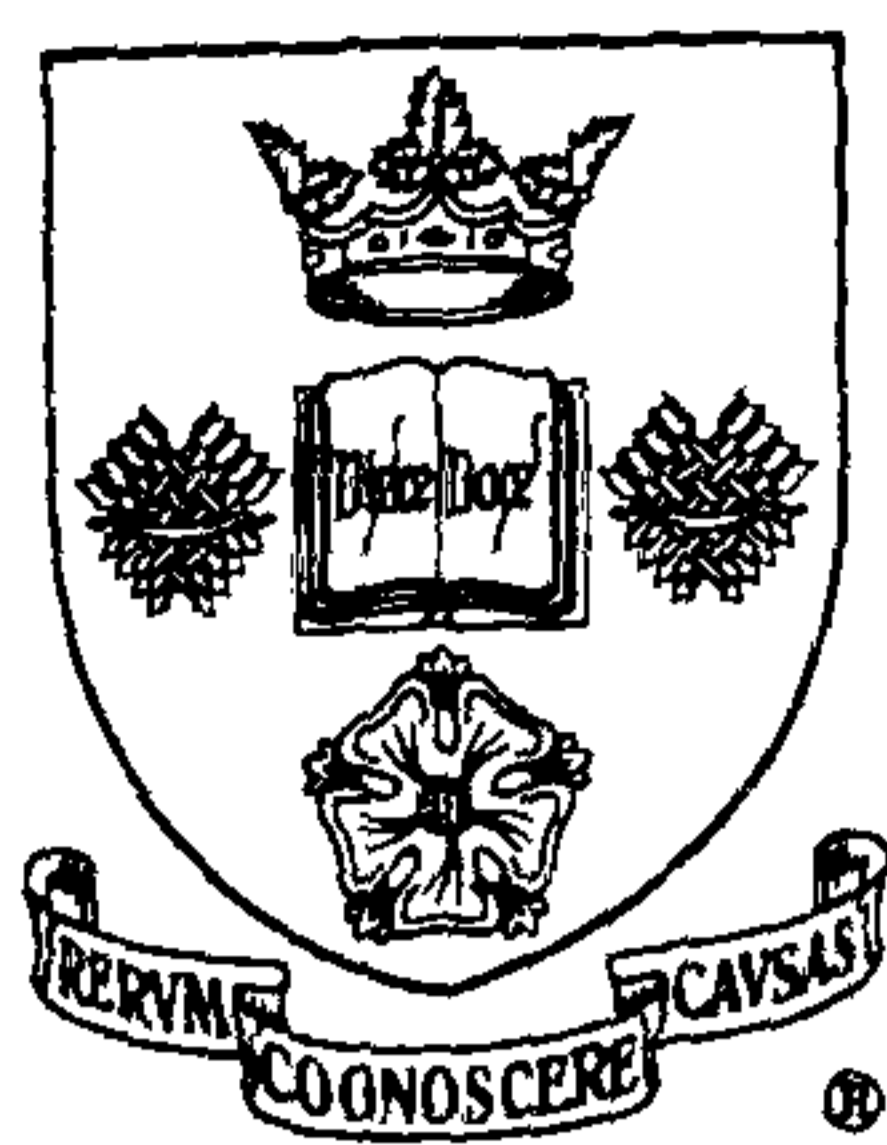
I've come to see you today to talk with you about your experience of living with Chronic Fatigue Syndrome/ M.E. I only have a few questions. I'm interested in finding out, from your perspective, how things were when you first started experiencing symptoms and how things are now. We have about one and a half hours today, but we can take some breaks within this time or can split this into two sessions if that would be easier for you. Please let me know if you want to stop at any point, I'll check out with you how things are as we go along.

- **What name do you give to your condition?**
 - *Chronic fatigue syndrome / M.E.*
- **Could you tell me what happened when you first started experiencing the symptoms of CFS/ME?**
 - *What was that like?*
 - *How did you feel?*
- **What were things like after that time?**
 - *What was that like?*
 - *How did you feel?*
 - *Could you tell me a bit more about that?*
- **Can you tell me what life is like now?**
 - *What's that like?*
 - *How do you feel?*
- **How did you get from where you were then to where you are now?**
 - *How has that been able to happen?*
 - *What has that been like for you?*
 - *How do you feel about that?*
- **Where do you think you are currently in terms of living with CFS/ME?**
- **What will happen next?**
 - *What do you think about the future?*
 - *How do you feel about that?*

General prompts

- *Is there anything else you'd like to tell me about that?*
- *Summarising + have I got that right?*
- *Could you elaborate on that?*

Appendix 7: Transcriber Confidentiality form



THE UNIVERSITY OF SHEFFIELD
Clinical Psychology Unit
Department of Psychology

Doctor of Clinical Psychology (DClin Psy) Programmes (Pre-registration and post-quali
 Clinical supervision training and NHS research training and consultancy

University of Sheffield, Doctorate in Clinical Psychology

Confidentiality Form

Type of Project: Research Thesis

Project Title: An exploratory study of the experience of living with Chronic Fatigue Syndrome/ME

Researcher's name: Catherine Nicholl

The tape you are transcribing has been collected as part of a research project. Tapes may contain information of a very personal nature, which should be kept confidential and not disclosed to others. Maintaining this confidentiality is of utmost importance to the University

We would like you to agree not to disclose any of the information you hear on the tape to others, to keep the tape in a secure place where it cannot be heard by other people, and to show your transcription only to the relevant individual who is involved in the research project. If you find that anyone speaking on a tape is known to you, we would like you to stop transcription work on that tape immediately.

Declaration

I understand that:

1. I will discuss the content of the tape only with the individual involved in the research project.
2. I will keep the tape in a secure place where it cannot be heard by others
3. I will treat the transcription of the tape as confidential information
4. If the person being interviewed is known to me I will undertake no further transcription work on the tape.

I agree to act according to the above constraints

Your name: _____

Signature: _____

Date: _____

Occasionally, the conversations on tapes can be distressing to hear. If you should find it upsetting please speak to the researcher.

Appendix 8: An example of the process of Interpretative Phenomenological Analysis

Stage 1: Initial review of transcript

On starting the analysis the researcher listened to the tape of the interview alongside the transcript to check for errors and add any additional comments related to intonation or emphasis. The transcript was then re-read and initial preliminary notes were made in the left hand margin. These notes summarised aspects of the text, noted questions or thoughts which occurred to the researcher and identified which sections of the text appeared to be particularly pertinent.

Example from participant B

Extreme symptoms

I was in agony, I could hardly walk a lot of the time or lift my legs.

Overwhelming

I was so tired, I was absolutely exhausted, I could have laid down in the road and gone to sleep. Umm, I'd a lot of numbness and trickling and sort of nerve, umm, weirdness (quiet laugh).

Desperation. Devastating symptoms, cumulative effects

OK.

Varied symptoms, affecting various body systems. Multiple investigations. Neverending and frustrating.

Umm, I got checked up gynaecologically because of stabbing and stuff down in that region and down my legs. There was nothing. Umm, I got X-rayed for my arm not working properly, stuff like that. Umm, this went on and on, all different things adding. I got terrible diarrhoea that lasted two years and it was called irritable bowel, and I was told to go away and don't darken my doors again basically (laugh). Umm, I have had a horrible time at that point, up, you know, during this time the GP was not listening or taking me seriously. It was just awful and I was very worried. I went through all those tests you get for bowel problems. I mean when I say serious diarrhoea, like ten times in the morning before I left to take my child to school. Umm, and trying to walk I was really struggling, but it didn't really compute that I was so ill because I'm the kind of person who, a single parent, 'you have to keep on,' and I was still working as a childminder.

Getting worse and worse

Rejected and deserted.

'horrible time'

Not being listened to, no support. Trivialised results in anxiety. Multiple tests.

Quantifying severe. Need to prove self?

Impact on life and roles?

Lack of realisation that ill.

Previous personality type impact on way react.

Battling on

Battled on for 3 years

Why is work so important?

Right

But it got to the point where I had to stop working because I was in so much pain and I was so tired and I'd such diarrhoea (quiet laugh) Umm, but I think I worked a very small amount for about a year and then I stopped completely in September 2000.

Stage 2: Identifying Preliminary sub-themes

The transcript was then read through a further two times and suggestions for initial themes were noted in the right hand margin.

I was in agony, I could hardly walk a lot of the time or lift my legs. I was so tired, I was absolutely exhausted, I could have laid down in the road and gone to sleep. Umm, I'd a lot of numbness and trickling and sort of nerve, umm, weirdness (quiet laugh).

Severe and devastating symptoms leading to desperation

OK.

Umm, I got checked up gynaecologically because of stabbing and stuff down in that region and down my legs. There was nothing. Umm, I got Xrayed for my arm not working properly, stuff like that. Umm, this went on and on, all different things adding. I got terrible diarrhoea that lasted two years and it was called irritable bowel, and I was told to go away and don't darken my doors again basically (laugh). Umm, I have had a horrible time at that point, up, you know, during this time the GP was not listening or taking me seriously. It was just awful and I was very worried. I went through all those tests you get for bowel problems. I mean when I say serious diarrhoea, like ten times in the morning before I left to take my child to school. Umm, and trying to walk I was really struggling, but it didn't really compute that I was so ill because I'm the kind of person who, a single parent, 'you have to keep on,' and I was still working as a childminder.

NHS treatments and investigations are symptom specific and unhelpful
Severe and devastating symptoms

Lack of support
Not being believed/ taken seriously
=> fear

Severe symptoms

Impact on abilities
Not realising that ill
Battling on

Right.

But it got to the point where I had to stop working because I was in so much pain and I was so tired and I'd such diarrhoea (quiet laugh) Umm, but I think I worked a very small amount for about a year and then I stopped completely in September 2000.

Severe symptoms,
overwhelming
Battling on

Stage 3: Initial theme tables

Theme tables were created for each of the sub-themes identified. For participant B a total of 20 sub-themes were initially identified:

Uncertainty	Need for support
Severity of symptoms	Hope for recovery
Desperation, anger and depression	Abandoned by friends, isolation
Feeling let down and unsupported by NHS and SS	Seeking out people who understand
Not being believed/taken seriously	Limits on energy
Initial lack of realisation of illness, euphoria, gradual realisation	Chance is responsible for positives
Battling on	Trying to understand and make sense of symptoms
Impact on identity	Impact on family
Disempowered, hopeless and helpless	Living within limitations
Multiple losses	Unable to accept limitations
	People don't understand

Theme tables were created for each sub-theme containing quotes, comments and line numbers. The example below shows a section of the table for participant B for the sub-theme 'not being believed/taken seriously';

Line no.	Quote	Comment
34	I have had a horrible time at that point, up, you know, during this time the GP was not listening or taking me seriously. It was just awful and I was very worried.	By GP
56	I've had to in the end take people with me (to see GP), I took several people before he'd send me to the umm	Lack of value to own report
89	I was so angry with him because a couple of years before that I'd drawn in everything, put it all together and taken my friend who'd asked her...her father who was a doctor, who thought I should maybe see a neurologist then because of all the symptoms, and he pooh poohed me and sent me away.	
98	he always made stupid jokes and was flippant. I took another friend who could not believe his attitude. But I hadn't been able to be strong enough to sort him out because I was in such a weakened position.	disempowered
111	the solicitor told me that they thought that I was less ill than I was making out which was so hurtful and stupid.	
130	And then of course I got rejected for DLA the first time, umm, the first June, even though I really really fitted the criteria (quiet laugh), and it took a whole year to get, silly appeal, a whole year. ..., there was no guarantee I was going to get this. The solicitor thought it was highly unlikely because of her experience, and because there's nothing, no medical, not really any medical stuff, evidence.	Can't prove that ill

Sub-theme tables were then repeatedly read and re-read to identify whether the quotes chosen fitted within the sub-theme or would fit better elsewhere. For example, some quotes within the initial theme of 'limits on energy' fitted closer within the theme of 'severity of symptoms' while others fitted under the coping theme of trying to live within limits. At this stage theme tables were also given to a peer as part of the audit process to check their agreement with the validity of the themes. Particular consideration was given to the theme of 'severity of symptoms' due to concern that this may have arisen directly from the questions asked within the interview (i.e. 'tell me what happened when you first started experiencing the symptoms of CFS/ME'). However, it was decided that the quotes reflected more than just a summary of symptoms but were highlighting their extreme and devastating nature.

Stage 4: Identification of relationships between themes

Consideration was also given to the relationships between sub-themes and whether some themes could be subsumed under other themes. For example, the sub-theme 'identity' was suggested to fit closely alongside 'multiple losses' as it seemed to be the cumulative effect of these losses that result in a sense of loss of identity. Themes of 'hope for recovery', 'chance is responsible for positives' and 'disempowered, helpless and hopeless' were also combined due to their mutual sense of losing hope and lack of control. Themes were clustered together in terms of master themes and sub-themes. The themes for participant B are shown below:

<u>Master themes</u>	<u>Subthemes</u>
'Initial unreality of illness'	'not knowing what was going on' (uncertainty) 'I could have laid down in the road and gone to sleep' (Severity of symptoms) 'it didn't quite register' (lack of realisation of illness).
'How was I going to get any help'	Trying to understand and make sense of symptoms Not being taken seriously/believed 'I'd been rejected here there and everywhere and made to feel like an idiot' (Let down by services) searching for people who understand
'I'm just like this blob'	Multiple losses (including impact on identity)

	Helplessness and Hopelessness (including hope and chance is responsible for positives)
Isolation	People don't understand 'and then there was nothing, no one, nothing' (abandoned by friends, isolation) Need for support
Starting to learn about limits	'if I do something I have to pay for it' (limits on energy, living within limitations) unable to accept limitations
Impact on family	

After completing all individual participant analyses this process was repeated to clarify whether the identified themes and sub-themes were representative of the individual participant quotes. The themes and accompanying quotes were checked by the research supervisor as part of the audit process, in order to verify that the theme labels were justified by the quotes within them.

Stage 5: Individual participant master theme summary.

Key quotes were identified for each theme and a descriptive list of themes consisting of the key quotes alongside a brief summary was prepared. Again this process was repeated after all individual participant master theme tables had been completed. A copy of the descriptive list of themes was sent to participants for member validation. For example, for participant B

B1 THEME 1: 'YOU JUST CAN'T BELIEVE IT'S GOING ON'

Onset of symptoms which have a severe impact on life but are difficult to understand or make sense of. Initial phase of lack of recognition or acceptance of the reality of these symptoms.

- **B1a Onset of vague and unclear symptoms:** 'Not knowing what was going on'
- **B1b 'I could have laid down in the road and gone to sleep':** Very severe and overwhelming symptoms affecting whole body.
- **B1c Initially not recognising/being aware of the severity of the illness:** 'it didn't quite register'. Seeming switched off from reality of illness, in a state of almost 'euphoria'.

B2 THEME 2: 'A TANGLE OF UPSET'

As awareness of illness increases so does awareness of its impact.

- **B2a Increased awareness of losses:** After initial stage of illness the euphoria lifts resulting in awareness of multiple losses of pleasurable activities, friends, job, money, cognitive abilities, role as a mum. ‘All the things that I used to do I can’t do and I don’t know how to cope with it’
- **B2b ‘I’ve got no identity’:** Multiple losses result in a sense of loss of self. ‘all the things that I like to do that were me, and that .. made me feel OK ...those things you have lost.....but I’ve not got anything that I can find to make, to put it back together in a different thing which is OK. So I’m just like this blob of, it’s not even a blob it’s more of a, it’s a tangle of upset and nothing can replace them’
- **B2c This is accompanied by feelings of anger, desperation, helplessness and hopelessness:**
‘It is almost like grief, everything’s like grief, and the pain and the loss, you know.’
‘it’s hard to find value in **this life**’

B3 THEME 3: ‘HOW WAS I GOING TO GET ANY HELP?’

Trying to find medical help and support, being let down and experiencing disbelief. This resulted in feeling extremely disempowered and hopeless about recovery.

- **B3a Seeking answers:** Trying to find out what was wrong. Seeking medical advice and having numerous tests, not receiving any answers, delay in receiving CFS diagnosis. ‘I was in such agony I wouldn’t believe that they couldn’t find anything’.
‘why have they put me through all that when it was so clear looking at the list what I’d had.’
- **B3b Not being taken seriously/believed:** by doctors and benefits agencies, feeling disempowered.
‘he always made stupid jokes and was flippant.... but I hadn’t been able to be strong enough to sort him out because I was in such a weakened position.’
- **B3c Let down by NHS and SS:** ‘I’d been rejected here there and everywhere and made to feel like an idiot’. No appropriate support available for ME, given symptom specific treatments which don’t get to bottom of things. Feeling let down, angry, disempowered, scared and hopeless.
- **B3d Search for alternative support, people whom listen and understand:** ‘it was important to get somebody on my side’

B4 THEME 4: ISOLATION

Alongside sense of being let down by medical profession also feeling let down by friends and family. This lack of emotional and practical support has made it extremely difficult to cope with M.E.

- **B4a People don’t understand what its like to have ME:** ‘I would never have understood that if someone told me.’
- **B4b ‘And then there was nothing, no one, nothing’:** Loss of social support, feeling isolated and abandoned, this resulted in anger and a changed view of the world. ‘I’ve been like so shocked to find that you get dumped, cos I didn’t think the world was like that, you know.’
- **B4c Need for practical and emotional support to aid recovery:** ‘I think if I had some help with like, even with the housework, it might give me a bit more energy to do something to

keep my spirits up'. 'I haven't had anyone to help me grieve for those things or to put them somewhere and find something else.'

B5 THEME 5: STARTING TO LEARN ABOUT LIMITS

Gradually starting to recognise the importance of pacing and living within limitations, this is very difficult to come to terms with.

- **B5a Pacing:** Growing awareness of importance of pacing but unable to accept limits leading to pushing self too far and being 'paid back'. 'I still haven't worked this out properly right, but I think what happens is that if I haven't..... if I do something then I have to pay for it'
- **B5b Unable to accept limitations:** 'I can't live within that amount, and I can't live, I still don't feel like I'm living, and I disregard it but it's better than sticking down here.'

B6 THEME 6: IMPACT ON FAMILY

Feeling unable to look after children, nobody else to step in and help. Has impacted on relationships and behaviour.

'he lost his mother at that time, and he had no other adult, he'd to do it all on his own really'.

Stage 6: Integrating themes

The descriptive list of themes for each participant was printed on different coloured paper. Master and sub-themes were then cut out and combined for all participants on a large sheet of paper and similar individual themes were grouped together. Using different colours of paper enabled a rapid visual scan to identify whether themes were representative of a range of participants or only applied to a few. A similar process was then conducted. Overall themes were reviewed to verify whether the individual themes and quotes seemed to fit together. Initial overall themes identified were;

A mystery illness	I could have laid down in the road and gone to sleep
Non acceptance	Battling on
Realisation of illness	Losses
Impact of losses	Seeking answers
Seeking knowledge	Importance of being understood and believed
Trying to make sense	Let down by NHS
Active coping	Trying to find people who understand
Pacing	Mindset
Self Help	Need for social, practical and emotional support
Acceptance	Making the most of life
Impact on others	Isolation and lack of support

A similar process was then repeated to that described above for individual participants. The overall set of themes was reviewed to look for relationships among themes. Initial master and sub-themes were identified as;

<u>Master theme</u>	<u>Subtheme</u>
Overwhelmed and out of control	A mystery illness I could have laid down in the road
Loss	Multiple losses Impact of losses
Trying to make sense	Seeking answers Trying to make sense
Reactions of others	Not being understood or believed Let down by NHS Isolation Seeking people who understand Importance of social support
Coping	Active coping Self Help Pacing Mindset Importance of support
Acceptance	Non acceptance Battling on Gradual acceptance Making the most of life
Impact on others	

The contents of these themes were then re-reviewed through consulting individual master theme tables. Further consideration of the meaning of the themes and sub-themes resulted in reorganisation and revision of these themes. For example loss was subsumed with the theme of ‘an overwhelming illness’ and seeking people who understand subsumed under searching for understanding. The two sub-themes of the importance of support were merged and placed within the theme of coping. Some aspects of seeking answers were felt to fit better within the theme ‘let down by NHS’, reflecting difficulties gaining a diagnosis. Other aspects were covered within the sub-theme trying to make sense.

Stage 7: Overall master theme summary table

After a conclusion was reached regarding the organisation of master themes, key quotes were identified to use as theme labels, in order to keep the themes as close to the data as possible. The final master theme headings were; **‘an overwhelming illness’** containing ‘overwhelmed and out of control’, ‘loss’ and ‘impact on others’ as sub-themes; **‘an invisible illness’** containing ‘reactions of others’, with sub-themes relating to disbelief, lack of medical support and isolation; **‘gaining insight’** containing ‘trying to make sense’ and the seeking information component of ‘coping’; **‘self help’** containing ‘coping’ and the sub-themes within it; and finally the unchanged theme of **‘acceptance’**. The table below shows the relationship between initial and final master and sub themes.

<u>Final Master and sub themes</u>	<u>Corresponding initial theme labels</u>
‘an overwhelming illness’ ‘a really awful time’ ‘I wasn’t able to do anything, I just was not me’ ‘It’s hard on your family and on your carer’	Overwhelmed and out of control, a mystery illness, ‘I could have laid down in the road’ Loss, multiple loss, impact on loss Impact on others
‘An invisible illness’ ‘It’s genuine what I’ve got’ ‘How was I going to get any help’ ‘And then there was nothing, no-one’	Not being understood or believed Let down by NHS Isolation
‘Gaining insight’ ‘Knowledge was, I guess, the first step’	Seeking answers, trying to make sense, seeking people who understand
‘Self help’ ‘Finding what works for you’ ‘pacing’ ‘mindset’ ‘I’m able to handle it with the help I’ve got’	Active coping Self Help Pacing Mindset Importance of support
‘Acceptance’ ‘pushing and pushing and pushing myself’ ‘it’s been a hard slog mentally to accept...’ ‘I’ve lost a lot but I’ve gained something’	Non acceptance, battling on Gradual acceptance Making the most of life

An example of the individual participant quotes making up the sub-theme of ‘a really awful time’ is shown below.

Subtheme: 'A really awful time'

B1b: 'I could have laid down in the road and gone to sleep'

D1a: 'It was a really awful time' 'everything was piling on top of me'

E1: 'Who would want ME?'

F1b: 'too ill to care'

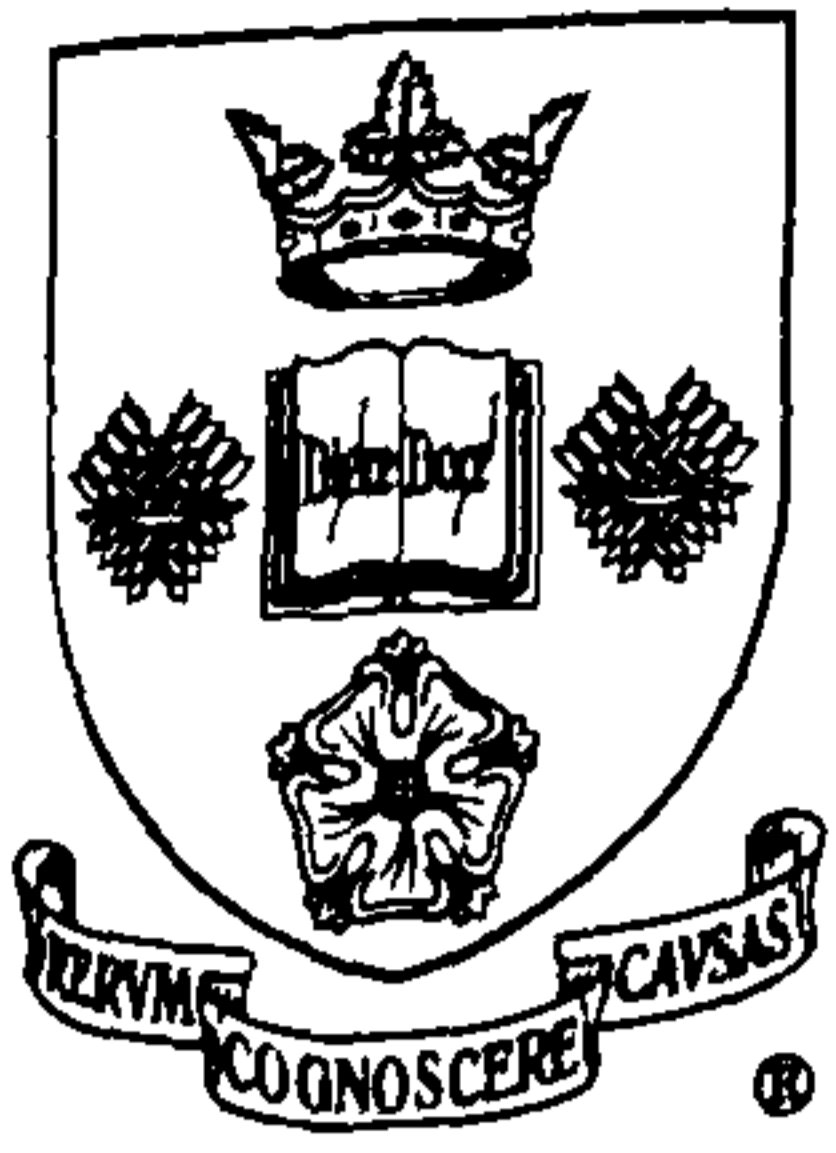
G1d: 'an overwhelming illness' 'I've not known difficulties like it before'

H3: 'it just seemed like it couldn't be true, but unfortunately it was'

Presenting the findings

Having completed the analysis, the themes and the accompanying quotes then formed the basis of the results section.

Appendix 9: Covering letter for member validation



THE UNIVERSITY OF SHEFFIELD
Clinical Psychology Unit
Department of Psychology

Doctor of Clinical Psychology (DClin Psy) Programmes (Pre-registration and post-qualification)
Clinical supervision training and NHS research training and consultancy

6th April 2004

Dear

Re: An exploratory study of the experience of living with CFS/M.E.

You may remember that when we met to discuss your experiences of living with CFS/ME on the 25th September 2003, I offered to send you a copy of the themes that I identified from our discussion. I am sorry that quite a long time has elapsed since this date. I am aware that it may be hard to remember the detail of the interview.

The themes I have drawn out from your account aim to provide a summary of important aspects of your experience. The themes are divided into smaller sub themes. These are illustrated by quotes taken from the interview. I would like your comments on the themes in order to check that they fit with your experience. Your comments will be used within the next stage of the analysis. This stage involves drawing together the themes from all the participants to create an overall set of master themes.

I would be very grateful if you could have a look at the attached themes and let me know any comments you may have. You could either write comments on the themes themselves or fill in the reply slip attached. I have enclosed a pre-paid envelope. Alternatively please contact me by telephone on ----- or by e-mail on (e-mail address). If I do not hear from you by the 3rd May I will presume that you do not have any comments. If you find reading the themes distressing in any way and wish to discuss this with somebody, please either contact myself on the above telephone number or the Sheffield ME Group Helpline on ----.

Thank you very much for your help and cooperation with the research. When the research is completed I will pass a copy of the findings to the Sheffield M.E group.

Yours Sincerely

Catherine Nicholl
Trainee Clinical Psychologist