



DOCTORATE IN CLINICAL PSYCHOLOGY

Major Research Project

Exploring the online social identities of people with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): A discourse analysis approach

Submitted by Alice Catriona Kennedy, to the University of Exeter for partial fulfilment for the degree of Doctor of Clinical Psychology. May 2014.

Word count	Literature Review:	3,992
(exc. tables and abstract)	Manuscript:	7,960

Supervisor: Dr Janet Smithson, University of Exeter

Nominated Journal: Qualitative Health Research

This thesis is available for Library use (after the embargo period) on the understanding that it is copyright material and that no quotation from the thesis may be published without proper acknowledgement.

I certify that all material in this thesis which is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.

Signature:

Contents

Literature Review: What qualitative research explores the psychological experiences of people with CFS/ME?	7
Abstract	8
Introduction	9
Rationale	9
Objectives.....	11
Methods.....	11
Information Sources.....	11
Search Strategy	12
Quality Appraisal.....	12
Organisation of the Review.....	21
Perceived Legitimacy of CFS/ME.....	21
Family and friends.....	22
Seeking Diagnosis.....	22
Stigma.....	23
Phases of experience of CFS/ME.....	23
New Identity.....	24
Role Constriction.....	24
Coping Strategies	25
Growth through experience of CFS/ME.....	25

CFS/ME EXPERIENCES

Data Collection.....	26
Data Analysis.....	26
Limitations.....	28
Sampling.....	28
Sample Size	29
Longitudinal Studies.....	29
Future Research	30
Implications for Clinical Practice	30
Conclusion.....	31
References.....	32
Appendix A: Search Strings	40
Appendix B: Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist	42
Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist.....	42
Exploring online social identities of people with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): A discourse analysis approach.....	45
Abstract	46
Introduction	47
Identity Disruption	47
Social Identity Theory	48
Discourse Analysis Methods	49
CFS/ME Illness Experiences.....	50
The Present Study	51
Research Aim	52

CFS/ME EXPERIENCES

Methods.....	53
Identifying the Online Forum.....	53
The Online Forum	53
Ethical Considerations.....	54
Sample.....	55
Analytic Approach	55
Action.	55
Construction.....	56
Variability.	56
Integrity of Data Analysis	56
Analysis.....	57
Data Overview.....	57
Symptoms	58
Healthcare.....	62
Family and Friends	63
Physical or Psychological Condition	66
Discussion.....	70
Summary of Findings.....	70
Social Identity Theory	71
Biographical Disruption.....	74

CFS/ME EXPERIENCES

Expert Patient Discourse.....	75
Limitations.....	76
Clinical Implications	76
Formulation.....	77
Healthcare professionals.....	77
Online support.	77
Future Research	78
Conclusion	79
References.....	80
Appendix A: Ethical Approval Letter	92
Appendix B: Researcher Posts to Researcher-Initiated Thread.....	93
Appendix C: Responses to the Researcher-Initiated Thread	95
Appendix D: Reflexive Analysis	98
Appendix E: Dissemination Plan	100
Appendix F: Qualitative Health Research: Instructions for authors	101

List of Tables

Table 1	Quality appraisal of all eligible articles using the CASP	16
Table A1	Search Strings	40
Table B1	Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist	42
Table 2	Frequency of topics (the ten most frequent)	58

List of Figures

Figure 1	Search and selection flow diagram	15
----------	-----------------------------------	----

CFS/ME EXPERIENCES

Literature Review: What qualitative research explores the psychological experiences of people with CFS/ME?

Submitted by Alice Kennedy, to the University of Exeter

May 2014

Supervisor: Dr Janet Smithson

Word Count: 3,992 (excluding abstract, table, figure, references and appendices)

Nominated Journal: Qualitative Health Research

This thesis is available for Library use (after embargo period) on the understanding that it is copyright material and that no quotation from the thesis may be published without proper acknowledgement.

Abstract

Chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) is a contested condition, owing to its lack of biological marker and it being a diagnosis of exclusion. This review explores qualitative literature about CFS/ME illness experiences. Keyword searches of PsychInfo and Web of Science, review of references and review of articles resulted in inclusion of 25 peer-reviewed articles.

People with CFS/ME experience delay and disbelief when seeking diagnosis, linked to perceived illegitimacy of the condition. In response, people with CFS/ME frame the experience as serious and genuine. Illness onset often leads to loss of friends and work and, with that, a loss of meaning and purpose. People often develop a new identity, moving from being healthy to having an unpredictable and chronic condition. Limitations were the small sample sizes of most studies and that participants tended to be people already in contact with services or support groups.

Keywords: families; health care professionals; illness & disease, chronic; illness & disease, experiences; research, qualitative

Introduction

Rationale

The aim of the review is to explore the qualitative literature about experiences of people with CFS/ME in order to identify areas for future research. Both terms, CFS and ME, are used. While CFS is more commonly used in health services, ME is used by many patient associations. Initially CFS was used in the United States and ME was used in the United Kingdom (Cohn, 1999). CFS and ME are recently coined terms defined as comprising two criteria: new onset of persistent or relapsing, debilitating fatigue that impairs daily functioning for at least six months and absence of other clinical conditions which could produce similar symptoms (Holmes et al, 1988). CFS/ME is not defined in DSM-5 (APA, 2013), although post-viral fatigue syndrome (PVS) and benign myalgic encephalomyelitis are defined as neurological disorders in the World Health Organization's International Classification of Diseases (ICD-10, WHO, 1992).

CFS/ME may be an older condition, neurasthenia, identified by the neurologist George Beard (Beard, 1869), although this term fell out of favour in the early twentieth century (Cohn, 1999). CFS/ME is now defined as an illness with variable symptoms that include "fatigue, malaise, headaches, sleep disturbance, difficulties with concentration and muscle pain", and, most recognisably, extreme fatigue (National Institute for Clinical Excellence, NICE, 2007, p.4). There is no biological marker or definitive way to diagnose CFS/ME; it remains a diagnosis of exclusion (Chew-Graham, Cahill, Dowrick, Wearden & Peters, 2008). Consensus is still sought about what constitutes or defines CFS/ME; recently specialists developed the International Consensus Criteria for ME (Carruthers et al, 2011). It defined ME as "an acquired neurological disease with complex dysfunction" (p. 329) and outlined criteria of pathological inability to produce sufficient energy,

CFS/ME EXPERIENCES

characterised by flu-like symptoms, long recovery periods and physical or mental fatigue. The other criteria were neurological impairments characterised by some of the following: difficulty processing information, short-term memory loss, headaches, significant pain and sleep disturbance, including disturbed sleep patterns and unrefreshing sleep. CFS/ME varies in its severity, with between 10% and 25% of sufferers experiencing severe CFS/ME (NICE, 2007a).

In addition to causing considerable distress, CFS/ME has social and economic consequences. CFS/ME is relatively common, affecting between 0.2% and 0.4% of the UK population (Department of Health, 2002). NICE stated that “CFS/ME can cause profound, often prolonged, illness and disability, which has a significant impact on patients and their families” (NICE, 2007a, p.6). Long-term conditions (LTCs), such as CFS/ME, are estimated to account for 52% of all GP appointments, 65% of all outpatient appointments and 72% of all inpatient bed days (Department of Health, 2005). This provides a financial incentive for government intervention.

Much research has examined aetiology and treatment of CFS/ME. Current treatment recommendations are that cognitive behavioural therapy (CBT) and graded exercise therapy (GET) should be offered to those with mild to moderate CFS/ME (NICE, 2007).

Previous research has explored experiences of people with LTCs (Charmaz, 1983; Kleinman, 1988; Robinson, 1990; Ware, 1992) and, specifically, CFS/ME. Qualitative research into CFS/ME was reviewed in meta-analyses (Anderson, Jason, Hlavaty, Porter & Cudia, 2012; Larun & Malterud, 2007). These concluded that CFS/ME symptoms led to disruption of life and curtailment of activities and social interactions. People with CFS/ME faced disbelief owing to the contested nature and consequent questioning of legitimacy of

CFS/ME EXPERIENCES

CFS/ME.

This review offers an update of Larun and Malterud's (2007) review based on a literature search carried out in February 2006. This review includes 13 articles published since Larun and Malterud's search was conducted. Owing both to the narrower focus of this review and this search being carried out in April 2014, approximately 4 years after Anderson et al.'s search of May 2010, it identified more recently published articles. The focus of Anderson et al.'s search was different from that of this review, which focusses solely on the experiences of people with CFS/ME. In contrast, Anderson et al. (2012) offered a review of qualitative explorations of the experiences of any population related to CFS/ME, including the experiences of physicians, people with other conditions involving fatigue (such as fibromyalgia) and fatigue related to cancer and cancer treatment. This review includes ten articles within Anderson et al.'s search period that they did not include and also three articles published since Anderson et al.'s (2012) search was carried out.

Objectives

This review explores qualitative research into the illness experiences of people with CFS/ME. Study designs include interviews, focus groups, observations of naturally occurring talk and online data collection.

Methods

Information Sources

A search was carried out of PsychInfo via Ovid (1860-2014) and ISI Web of Science (1900-2014) up to 16th April 2014. Qualitative, peer reviewed journal articles, in English, about experiences of adults with CFS/ME were sought.

Search Strategy

The lists of articles generated were searched for relevant papers. Inclusion criteria were mention of CFS or ME along with mention of qualitative or associated terms. The keyword search terms were “chronic fatigue” or “myalgic encephalomyelitis” or “immune dysfunction syndrome” or “post-viral fatigue syndrome”. These were combined with one or more of the following: “qualitative”, “phenomenological”, “discursive”, “discourse”, “grounded theory”, “thematic analysis”, “service user group”, “sufferer experience” or “narrative” or “semi-structured interview”. Plural versions of these search terms were included where appropriate (Appendix A).

The stages of search strategy included in Preferred Reporting Items for Systematic Reviews and Meta-Analyses, (PRISMA) (Moher, Liberati, Tetzlaff & Altman 2009) were followed. Duplicates were removed and all titles and abstracts were reviewed for eligibility. For the remaining articles, the full text was read. There remained 25 articles which were included in this review (see Figure 1).

Quality Appraisal

Quality Appraisal

The Critical Appraisal Skills Programme’s (CASP, 2013) quality appraisal tool (Appendix B) was used to assess the research design, sampling method, data collection, analysis, reflexivity, consideration of ethical issues and the value of the research (Table 1). It provides a systematic way of reviewing quality and conveying this information to the reader. The CASP is recommended by the Cochrane Collaboration (Hannes, 2011).

Articles were assessed as meeting (✓), partially meeting (P) or not meeting (X) each criterion. A three-point scoring system, developed by Duggleby, Holtslander, Kylma,

CFS/ME EXPERIENCES

Duncan, Hammond & Williams (2010) was applied to quantify the findings and determine an overall quality score for each article. One point was assigned to articles that offered little or no justification or explanation of meeting a criterion (1= not met), two points to articles that addressed the issue but did not fully elaborate (2=partially met) and three points to articles that justified and explained the issue (3=met). Scores for each criterion were totalled to give overall quality scores. All papers had a quality score between 22 and 30, meaning they were of moderate to good quality. All identified studies met the CASP (2013) threshold (the first two criteria met) for inclusion.

It has been argued that studies are labelled as of lower quality but may still be useful (Sandelowski, Docherty & Emden, 1997) and provide insights (Booth, 2001; Edwards, Russell & Stott, 1998) or offer confirmatory support for articles meeting more methodological criteria (Atkins, Lewin, Smith, Engel, Fretheim & Volmink, 2008; Campbell et al., 2003; Smithson, Britten, Paterson, Lewith & Evans, 2010).

Explicit discussion of reflexivity varies across analytic approach with some traditions, such as interpretative phenomenological analysis (IPA) (Smith, 1994) emphasising it more than others. The most common criteria not to be fully met were data collection, reflexivity and ethical issues. Several articles did not meet the criterion for appropriate design (Clarke et al., 1999, 2000; Travers & Lawler, 2008; Ware, 1998). Two articles by Horton-Salway (2001, 2007) did not meet the criterion for sampling. All articles not meeting criteria were reviewed and the problems appeared to be absences of detailed explanation rather than serious methodological flaws.

A study lacking explicit explanation of reflexivity or ethical process may be strong in another area such as theory or depth of analysis, or report from a difficult to recruit

CFS/ME EXPERIENCES

population. For example, the lowest score was for Horton-Salway's (2001) article (quality score=22) which appears to be strong in methodology and analysis but did not provide details about ethical issues or reflexivity, nor adequately justify choices about sampling and data collection (according to CASP criteria). Nevertheless, Horton-Salway's (2001) findings were influential, as reflected in the article's high citation rate and the number of articles in this review that explicitly drew on and aimed to extend her research.

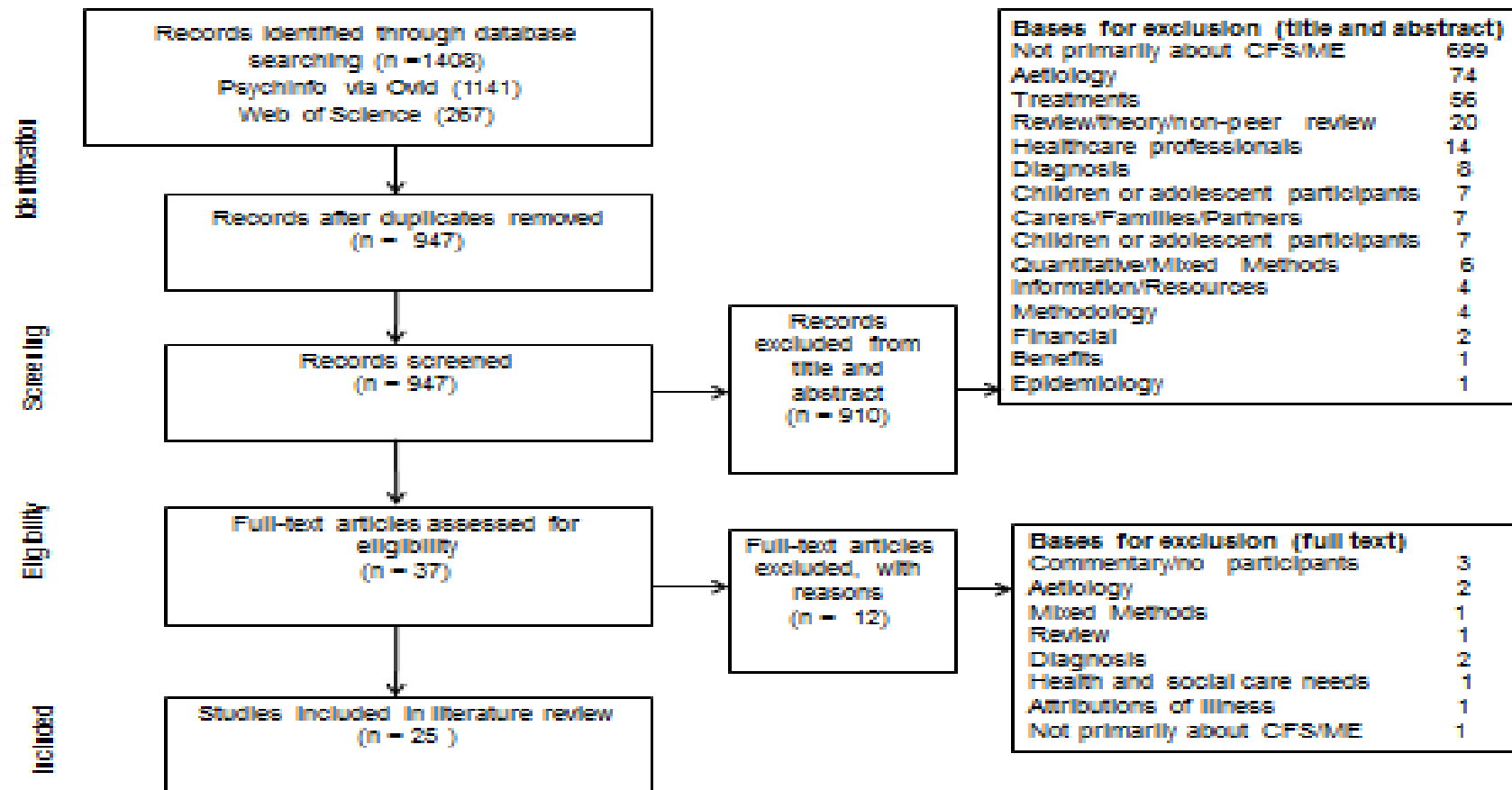


Figure 1. Search and selection flow diagram

CFS/ME EXPERIENCES

Table 1

Quality appraisal of all eligible articles using the CASP

First author and year	Country	Method of Data Collection	Sample Origins*	Participants	Analysis	Aims	Qualitative appropriate	Appropriate design	Sampling	Data collection	Reflexivity	Ethical Issues	Data Analysis	Findings	Value	Score
Arroll et al., 2008	United Kingdom	Telephone semi-structured Interview	CFS/ME support groups	n=8 (2 men, 6 women), ages 35 to 67 (average age 55.5), illness duration average 21.4 years (range: 6 to 53 years)	IPA	✓	✓	✓	✓	✓	X	P	✓	✓	✓	27
Arroll et al., 2013	United Kingdom	Semi-structured Interview	ME/CFS support and personal contacts. Purposive and snowballing	n=10 (7 women, 3 men), mean age 39.5, average illness duration 7.4 years, diagnosed with CFS/ME	IPA	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	30
Ax et al., 1997	United Kingdom	Semi-structured Interview	ME support groups	Study 1: n=9 (6 women), aged 16-68 (mean=44.22) years, diagnosed with ME, CFS or Post-viral fatigue syndrome by a medical practitioner. Mean illness duration 7.89 years. 4 employed Study 2: n=9 (8 women), aged 34-55, (mean=44.5) years. Mean illness duration 7.7 years.	Content Analysis	✓	✓	✓	✓	✓	X	P	P	✓	✓	16
Bulow, 2004	Sweden	Audiotaped conversation (n=31) Interview (n=13)	Patient school at a large hospital	n=31 Patient school, aged 30 to 60, diagnosed with CFS	Narrative analysis	✓	✓	✓	✓	✓	X	X	✓	✓	✓	26

CFS/ME EXPERIENCES

Dumit, 2006	Unknown	Archives of internet newsgroup postings	Newsgroup posters	180,000 postings over 3 year period	Conversations on map	✓	✓	✓	✓	✓	X	X	P	✓	✓	25
Edwards et al., 2007	United Kingdom	Semi-structured Interview	ME self-help network members recruited via posters and e-mail.	n=8 (all women), aged 36-48; English first language, diagnosed with CFS/ME; illness duration>1 year, CFS/ME main health problem, current symptoms of at least moderate severity. White British (n=6), Chinese (n=1) Mixed race-White British and Pakistani (n=1)	IPA	✓	✓	✓	✓	✓	X	P	✓	✓	✓	27
Gilje et al., 2008	Norway	Group interview during group meeting, questionnaire. One year later a follow-up meeting (n=5)	Local patient organisation. Purposive sample	n=12 (10 women, 2 men). Ten women and two men, aged 22-54 years (mean 41) illness duration>1 year, diagnoses confirmed by doctors, all on disability or rehabilitation pension.	Systematic text condensation	✓	✓	✓	✓	✓	X	P	P	✓	✓	26
Guise et al., 2010	Unknown	Asynchronous online sufferers' support group. Online general, open, non-directive questions answered	Members of internet-based ME/CFS support group	n=38	DA	✓	✓	✓	✓	✓	X	P	✓	✓	✓	27
Guise et al., 2007	United Kingdom	Focus groups and online interview. Chatline interviews (n=38), Personal interview (n=11), Face-to-face interviews (n=7)	Unknown	n=56	DA	✓	✓	✓	✓	✓	X	P	✓	✓	✓	27

CFS/ME EXPERIENCES

Hart et al., 2000	New Zealand	Semi-structured interview	ME support group (n=4), through GPs (n=4), contacts from participant (n=3)	n=11 (all women), have or have had CFS, aged mid-20s to late-60s	DA	✓	✓	✓	✓	✓	X	X	P	✓	✓	27
Horton-Salway, 2007	United Kingdom	Semi-structured interview and naturally occurring talk from ME support groups	Unknown	n=20 10 GPs, 10 support group members	DA	✓	✓	✓	X	✓	X	X	✓	✓	✓	24
Horton-Salway, 2001	United Kingdom	Interview	Unknown	Unknown	DA	✓	✓	✓	X	X	X	X	✓	✓	✓	22
Lombaard et al., 2005	South Africa	In-depth interview and autobiographical sketch	Physician referral, media advertisements, personal referrals	n=4, women, aged 20 to 50 years, diagnosed with CFS	Conceptual process of clarification	✓	✓	✓	✓	✓	X	X	P	✓	✓	25
Travers et al., 2008	Australia	Semi-structured interview	Advert in CFS newsletter and brochure in CFS clinics, Convenience and Snowballing and then Discriminate Sampling	n=19 adults (3 recovered from CFS), diagnosed with CFS, mean age of 45. Well-educated. Caucasian and Western-origin, average 7 year illness duration	Grounded theory	✓	✓	P	✓	✓	X	X	P	✓	✓	24

CFS/ME EXPERIENCES

Tucker, 2004	United Kingdom	Semi-structured interview	Support Group for CFS	n=4 (women=2, men=2)	DA	✓	✓	✓	✓	✓	✓	X	✓	✓	✓	28
Ware, 1998	United States	Longitudinal over 3 years. Face-to-face interviews and questionnaires	Unknown	n=66, aged 27 to 72 (mean age 43, 53 women, 62 Caucasian), met criteria for CFS, illness duration from 2.5 to 36 years	Thematic	✓	✓	P	X	✓	X	X	✓	✓	✓	25
Whitehead, 2006	United Kingdom	In-depth interviews and follow-up interviews over 2 years	Hospital (n=10) Support group (n=3) Snowballing (n=4) 13 to 63 years	n=17, CFS/ME and family members did not need diagnosis of CFS/ME	Hermeneutic phenomenology	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	30
Whitehead, 2006a	United Kingdom	In=depth interviews (up to 3 interviews with each person)	CFS/ME support Snowballing (neither attended a CFS/ME clinic nor a support group)	n=17 (6 men, 11 women), aged 13 to 63. Time since diagnosis 1-8 years, time since start of symptoms 2-40 years	Hermeneutic phenomenology	✓	✓	✓	✓	✓	X	X	✓	✓	✓	26

*Use of CFS, ME or CFS/ME terms reflects those used in the papers. P = Partially met criterion

Organisation of the Review

The search yielded 25 articles (see Table 1). The following recurrent themes were identified and used to structure the review: seeking a diagnosis, effects of the debate about legitimacy of CFS/ME, stigma, phases of forming a new identity, the new identity, role of coping strategies in forming a new identity and personal growth as a result of the experience of CFS/ME. The articles are critiqued, considering the sampling, recruitment, methodology and analysis used.

Perceived Legitimacy of CFS/ME

People with CFS/ME positioned themselves as active people, seeking information and treatments (Guise, McVittie & McKinlay, 2010), and thus not as passive recipients of an illness, or worse, marginalized “malingerers” (Horton-Salway, 2001). Participants in Horton-Salway’s (2007) study created a category of genuine sufferers as opposed to people deemed to have jumped on the CFS/ME bandwagon (Horton-Salway, 2007).

Likewise, Tucker (2004) found participants framed CFS/ME as a legitimate illness to avoid stigma and threat to their identity. Clarke and James (2003) highlighted the role of power and powerlessness in illness discourses where uncontested medical diagnosis is not available. In searching for meaningful self-identities, people with CFS/ME resist previously available discourses. While many studies employing discourse analysis (DA) explored why experiences were developed in particular ways, Hart and Grace (2000) elicited themes about the symptoms of CFS/ME, finding the predominant theme to be that fatigue was discussed in terms of its absence or presence or of sufferers lacking energy.

CFS/ME EXPERIENCES

Family and friends. Dickson, Knussen and Flowers (2007, 2008) argued that societal scepticism about CFS/ME can lead to people with CFS/ME questioning the value of friendship and social interaction and subsequent social withdrawal. Clarke and James (2003) described people with CFS/ME only having their illness experience believed by some family members; old friends frequently dropped out of their lives.

Seeking Diagnosis

A frequently-occurring theme was seeking diagnosis for a contested illness (Arroll & Senior, 2008; Cooper, 1997; Clarke, 2000; Whitehead, 2006a). Delays between seeking and obtaining a diagnosis were often experienced (Edwards, Thompson & Blair, 2007; Gilje, Söderlund & Malterud, 2008). Whitehead (2006a) found it took, on average, two years from symptom onset to diagnosis. Some were disbelieved when they sought a diagnosis (Cooper, 1997; Edwards et al., 2007; Gilje, et al., 2008) but wanted their doctors to acknowledge their symptoms, listen and ask questions (Gilje, et al., 2008).

In response to disbelief, some people sought diagnoses from different doctors (Tucker, 2004), sometimes encountering hostility and anger when returning to their usual doctor if presenting information or a diagnosis from elsewhere (Cooper, 1997). Clarke and James (2003) described someone visiting 25 doctors before obtaining a CFS/ME diagnosis. People with CFS/ME felt anger towards their doctors (Whitehead, 2006a; Edwards et al., 2007; Dickson et al., 2007) and described doctors as sceptical and lacking in knowledge (Dickson et al., 2007; Gilje et al., 2008).

CFS/ME EXPERIENCES

People with CFS/ME reported a sense of being “in tune” with their own bodies and having insight into their health (Dickson et al., 2007). Arroll and Senior (2008) described attempts to rationalize symptoms, followed by seeking diagnosis alongside ongoing struggle for recognition of their condition. When diagnosis was given, it was often experienced as a relief, although some experienced it as a shock or felt dissatisfied by the lack of effective treatment (Ax, Gregg & Jones, 1997).

Stigma

Both difficulty of gaining diagnosis and questioned legitimacy of the condition led people with CFS/ME to experience stigma (Dickson et al., 2007).

Stigma also arose from CFS/ME being viewed as a psychological rather than physical condition (Clarke, 2000; Cooper, 1997; Guise, Widdicombe & McKinlay, 2007; Horton-Salway, 2001; Tucker, 2004;). Several studies found that sufferers described their experience as physical rather than psychological (Ax et al., 1997; Bulow & Hyden, 2003; Clarke, 2000; Horton-Salway, 2001) although some doctors have suggested CFS/ME is an entirely psychological condition (Gilje et al., 2008).

Phases of experience of CFS/ME

Several articles outline a series of phases experienced by a person in moving from an old identity extant before onset of symptoms to a new identity incorporating the illness experience (Arroll & Howard, 2013; Edwards et al., 2007; Lombaard & Mouton, 2005; Travers & Lawler, 2008; Whitehead, 2006a).

Edwards et al. (2007) described two broad phases; firstly being overwhelmed by CFS/ME, feeling helpless and powerless, and, secondly, learning to live with the condition and seeking strategies to help pace their lives and develop a more positive outlook. Whitehead (2006) outlined a trajectory through which people passed before

CFS/ME EXPERIENCES

assuming a new identity. However, she stated that such a trajectory was better described by a 'pendulum' with movement back and forth between phases.

Lombaard and Mouton (2005) demonstrated how part of a new identity involved learning to live with the foreign entity of CFS/ME within the body and gradually, through learning to listen to the body and reaching a compromise between activity and restriction, beginning to repair the relationship with the body and ward off threats to personhood that the illness posed.

New Identity

Some research focused on the idea of people with CFS/ME forming a new identity in response to the onset of symptoms. Bulow (2004) described illness as a disruption that left a person with questions about how to incorporate their illness experience into a coherent life story. This involved re-framing their life narrative from the perspective of their illness; thus chronic fatigue became a shadow over life. Travers and Lawler (2008) described a self struggling to renew itself, following a violation of self caused by CFS/ME. A "Guardian Response" enabled the person to protect themselves and reclaim their sense of self while a "Reconstructing Response" fostered self-renewal and meaning. There were differences between articles: Clarke and James (2003) argued people rejected an old self while Travers and Lawler (2008) found people's new self involved some retrieved parts of their old self.

Role Constriction

Several studies found that participants experienced role restriction (Ware, 1998) because their symptoms limited their activities (Arroll & Howard, 2013; Clarke & James, 2003; Dickson et al., 2007; Edwards et al., 2007). Consequently,

CFS/ME EXPERIENCES

friendships changed and it became difficult to make new friends, except in support groups. Ware (1998) argued that people experienced role constriction in employment, forming part of a social process of marginalisation that occurred for people with chronic illness. Views differed amongst people with CFS/ME as to which was the greater loss: loss of career or difficulties fulfilling roles within the family (Edwards et al., 2007).

Coping Strategies

Several authors discussed a theme of coping strategies that allowed a person to adapt to a new lifestyle accommodating their illness (Ax et al., 1997; Edwards et al., 2007; Whitehead, 2006). Participants were active in gaining social support and acquiring greater knowledge as a way of moving towards feelings of control and acceptance (Edwards et al., 2007). Whitehead (2006) argued that coping strategies, including slowing down, taking up new activities and recognizing where they could exert some control over their lives, were used to create and maintain a new identity.

Growth through experience of CFS/ME

Several studies described people with CFS/ME making gains or experiencing personal growth through having CFS/ME. Arroll and Howard (2013) found two participants described growth through finding their “true” selves. Dickson, Knussen and Flowers (2008) found one participant reported gains, feeling more open-minded and less prejudiced. Lombaard and Mouton (2005) argued that, although it is not exactly a benefit of CFS/ME, the condition can lead sufferers to experience their bodies in a different way, requiring them to find a balance between the body and self but, as Guise et al. (2010) highlighted, positive outcomes did not mean successful treatment had occurred.

Data Collection

Owing to the debilitating effects of CFS/ME, those more severely affected may struggle to travel to or participate in interviews. This led researchers to explore other data collection methods. Dumit (2006) drew data from publicly accessible online newsgroups, allowing analysis of 180,000 postings; however the social composition of the pseudonymised sample could not be obtained. Clarke (1999, 2000) interviewed 60 participants by telephone to investigate gender differences in people's search for legitimacy.

Guise et al. (2007) explored combining data from face-to-face interviews and internet chatroom communications and found similar themes emerged from both. They concluded the internet was a fruitful source of data, with advantages when recruiting people suffering debilitating fatigue, possibly housebound and unable to attend interviews. Also, Guise et al. (2010) used an asynchronous online group to explore experiences of people with CFS/ME, allowing them to draw on the views of 38 participants and analyse interactions between them.

Data Analysis

The research used a range of qualitative methodologies including discourse analysis (DA), interpretative phenomenological analysis (IPA), grounded theory and thematic analysis.

Discursive approaches (Guise et al., 2007; Guise et al., 2010; Hart & Grace, 2000; Horton-Salway, 2001; Tucker, 2004) have been used to explore how people with CFS/ME react to questioning of their experience and delegitimising of CFS/ME. They were also useful for exploring the function of language and power issues. DA

CFS/ME EXPERIENCES

enabled investigation of how people with CFS/ME portrayed their experiences in order to counter dominant culturally-held discourses about what constituted illness.

Guise et al. (2007) furthered pre-existing DA research using both face-to-face and internet chatroom communication data to explore linguistic devices used to position CFS/ME as serious, enigmatic and not psychological. These included: listing symptoms experienced in order to portray CFS/ME as a range of problems; using vivid analogies to convey the serious impact of CFS/ME; comparing CFS/ME symptoms to more extreme versions of everyday experiences to enable others to empathise; describing difficulty carrying out mundane activities to highlight seriousness of illness; and using the second person plural to avoid personalising experiences and thus imply that the account is generally applicable. Guise et al. (2007) hoped their focus on the function of linguistic devices would allow reconsideration of why sufferers emphasise the seriousness and enigmatic nature of the condition.

DA was, however, less appropriate for eliciting detailed, embodied descriptions of experiences of CFS/ME; that was better addressed by IPA studies (Arroll & Howard, 2013; Arroll & Senior, 2008; Dickson et al., 2008; Dickson et al., 2007; Edwards et al., 2007) or hermeneutic phenomenology (Whitehead, 2006, 2006a).

IPA is better suited to offering an in-depth, rich exploration of individuals' expertise but can be difficult to generalise. Narrative analysis offers a sense of coherence and sequence to the illness experience but does not give the same emphasis on social interaction as DA.

Limitations

Sampling

The research reviewed contains some sampling limitations. Most studies overlooked co-morbid conditions, although Edwards et al. (2007) specified that participants considered CFS/ME their main health problem. Only a few articles specified the severity of illness of participants (Cooper, 1997; Edwards et al., 2007).

Studies commonly reported the gender breakdown of those with CFS/ME. Many studies included more female than male participants, although this might reflect the greater prevalence of the condition amongst women (Hart & Grace, 2000) and that women are more likely to seek help for physical health issues (Cook, Morris, Walker & Sharper, 1990; NHS Executive, 1998) or common mental health problems (Oliver, Pearson, Coe & Gunnell, 2005) and participate in research (Armstrong, White & Saracci, 1992). Ax et al. (1997), Edwards et al. (2007), Hart and Grace (2000) and Lombaard and Mouton (2005) interviewed only women. Clarke (1999) explored gender differences in the search for legitimacy in CFS/ME. He found men were more likely to suggest chemicals caused the condition and women more likely to suggest stress. Clarke (1999) found men and women were treated differently by doctors, men having the better relationships.

Other missing data includes socio-economic data. Research differs as to whether people are more or less likely to experience CFS/ME depending on socio-economic status. It may affect access to health interventions, information and financial and social resources.

Several studies give participants' educational levels (Clarke, 1999, 2000; Clarke & James, 2003; Travers & Lawler, 2008). Participants were described as

CFS/ME EXPERIENCES

“relatively” or “well” educated. It may be that people with more education are more likely to find and access health services and support groups and thus be visible to researchers.

Few studies provided details of participants' ethnic backgrounds (Edwards et al., 2007; Travers & Lawler, 2008; Ware, 1998) and, of those that did, participants were predominantly Caucasian/White.

The studies reviewed were conducted in Europe, Australasia and North America, with the exception of Lombaard and Mouton (2005), whose research was based in South Africa. Therefore, the illness experiences explored in this review are biased towards western cultures. This may, however, partly reflect the inclusion criterion of papers being published in English.

Sample Size

As many authors explicitly stated, qualitative studies offer detailed analysis of a few participants' experiences, rather than generate large-scale replicable results. Many studies had few participants but studied them in depth. Tucker (2004) interviewed only four participants. Lombaard and Mouton (2005) also only had four participants but they detailed the difficulties encountered in finding participants. In contrast, Clarke (2000) interviewed 60 respondents by telephone. Notably, Dumit's (2006) use of internet newsgroups allowed posts from thousands of people with CFS/ME to be gathered.

Longitudinal Studies

Most studies collected data at one point in time. Exceptions were Ware (1998) who used a longitudinal design, conducting interviews over a three year period, and Gilje et al. (2008) and Whitehead (2006) who used follow-up interviews. Other

CFS/ME EXPERIENCES

studies relied on retrospective accounts of illness experience to gain a sense of a narrative over time. There is a possible gap in the research for further longitudinal research to investigate changes in experience over time with the same participants.

Future Research

The reviewed research explored the experiences of people with CFS/ME but the studies often used in-depth interviews which required participants to be well enough to participate. As Guise et al. (2007), Guise et al. (2010), and Dumit (2006) have demonstrated, using online discussions allows exploration of the experiences of more participants, some of whom may be unknown to specialist services or too ill to attend support groups or research interviews. This is an emerging area of research with the potential for future online studies to make useful contributions to the knowledge base.

Implications for Clinical Practice

The reviewed studies offer an exploration of experiences of CFS/ME that could assist health professionals' understanding of the consequences of chronic health conditions for sufferers, beyond the primary effects of physical symptoms. The exploration of identity change offers insight into identity disruption by chronic health problems and how people move from this stage to incorporating their illness experience into coherent narratives of their lives. The reviewed research explored why people with CFS/ME chose to describe their experience in particular ways, such as countering debates about the legitimacy of their illness. This could highlight potential barriers to engaging people with CFS/ME in treatment, if the framing of such treatment is experienced as a threat to their views of their condition, or is perceived to position them as 'malingerers' (Horton-Salway, 2001).

CFS/ME EXPERIENCES

Research into CFS/ME accords with the NHS agenda to consider medically unexplained symptoms and to offer psychological treatment through an expansion of Improving Access to Psychological Therapies (Department of Health, 2008).

Conclusion

The qualitative literature about the experiences of people with CFS/ME has explored the effects of both the symptoms and the social reactions to the contested nature of the illness on people's identity. Discourse researchers have examined the way in which people with CFS/ME actively create their stories to emphasise both their own active role in attempting to combat the condition and the seriousness of the symptoms they experience. Other researchers have focused on the process by which a new identity forms through the illness experience, and the disruption of identity that occurs when moving from being healthy to having an unpredictable and chronic condition. Some studies have also highlighted positive benefits experienced as a result of CFS/ME. One drawback of the body of literature reviewed is that it has mainly been derived from small samples of people who are already in contact with specialist services and who are in good enough health to participate in in-depth interviews.

References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5*. Washington, D.C: American Psychiatric Association.
- Anderson, V. R., Jason, L. A., Hlavaty, L. E., Porter, N., & Cudia, J. (2012). review and meta-synthesis of qualitative studies as myalgic encephalomyelitis/chronic fatigue syndrome, *Patient Education and Counseling*, 86(2), 147-155.
- Armstrong, B. K., White, E. & Saracci, R. (1992). *Principles of Exposure Measurement in Epidemiology*. Oxford: Oxford University Press.
- Arroll M. A. & Senior V. (2008). Individuals' experience of chronic fatigue syndrome/myalgic encephalomyelitis: An interpretative phenomenological analysis. *Psychology & Health*, 23(4), 443-458.
- Arroll, M. A., & Howard, A. (2013). 'The letting go, the building up, [and] the gradual process of rebuilding': Identity change and post-traumatic growth in myalgic encephalomyelitis/chronic fatigue syndrome. *Psychology and Health*, 28(3), 302-318.
- Atkins, S., Lewin, S., Smith, H., Engel, M., Fretheim, A., & Volmink, J. (2008). Conducting a meta-ethnography of qualitative literature: lessons learnt. *BMC medical research methodology*, 8(1), 21.
- Ax, S. B. A., Gregg, V. J., & Jones, D. (1997). Chronic fatigue syndrome sufferers' evaluation of medical support. *Journal of the Royal Society of Medicine*, 90(3), 250-254.

CFS/ME EXPERIENCES

- Beard, G. (1869). Neurasthenia, or nervous exhaustion. *Boston Medical and Surgical Journal*, 3, 217-221.
- Bulow, P. H., & Hyden, L. C. (2003). In dialogue with time: Identity and illness in narratives about chronic fatigue. *Narrative Inquiry*, 1, 71-97.
- Bulow, P. H. (2004). Sharing experiences of contested illness by storytelling. *Discourse & Society*, 15(1), 33-53.
- Booth A. (2001). Cochrane or cock-eyed? How should we conduct systematic reviews of qualitative research? *BMC Medical Research Methodology*, 8(1), 21.
- Campbell R., Pound P., Pope C., Britten N., Pill R., Morgan M., Donovan J. (2003). Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Social Science and Medicine*, 56, 671-684.
- Carruthers, B. M., Sande, M., Meirleir, K., Klimas, N. G., Broderick, G. G., Mitchell, T. T., & ... Stevens, S. S. (2011). Myalgic encephalomyelitis: International Consensus Criteria. *Journal of Internal Medicine*, 270(4), 327-338.
- Critical Appraisal Skills Programme (2013). Ten questions to help you make sense of qualitative research. Retrieved from http://media.wix.com/ugd/dded87_951541699e9edc71ce66c9bac4734c69.pdf (accessed 3 January 2015).
- Charmaz, K. (1983). Loss of sense of self: A fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, 5(2), 169-195.

CFS/ME EXPERIENCES

Chew-Graham, C. A., Cahill, G., Dowrick, C., Wearden, A., & Peters, S. (2008).

Using multiple sources of knowledge to reach clinical understanding of chronic fatigue syndrome. *Annals of Family Medicine*, 6(4), 340-348.

Clarke, J. N. (1999). Chronic fatigue syndrome: Gender differences in the search for legitimacy. *Australian and New Zealand Journal of Mental Health Nursing*, 8, 123-133.

Clarke, J. N. (2000). The search for legitimacy and the "expertization" of the lay person: The case of chronic fatigue syndrome. *Social Work in Health Care*, 30(3), 73-93.

Clarke, J. N. & James, S. (2003). The radicalized self: The impact on the self of the contested nature of the diagnosis of chronic fatigue syndrome. *Social Science & Medicine*, 57, 1387-1395.

Cohn, S. (1999). Taking time to smell the roses: Accounts of people with Chronic Fatigue Syndrome and their struggle for legitimisation. *Anthropology & Medicine*, 6, 195-215.

Cook D.G., Morris J.K., Walker M. & Sharper, A. G. (1990). Consultation rates among middle aged men in general practice over three years. *British Medical Journal* 301, 647-650.

Cooper, L. (1997). Myalgic encephalomyelitis and the medical encounter. *Sociology of Health & Illness*, 19(2), 186-207.

Department of Health (2002). *Independent working group's report into chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME)*. London: Department of Health.

Department of Health (2005). *General Household Survey for England*. London: Department of Health.

CFS/ME EXPERIENCES

Department of Health (2008). *Improving Access to Psychological Therapies:*

Medically unexplained symptoms positive practice guide. London: Department of Health.

Dickson., A., Knussen., C., & Flowers, P. (2007). Stigma and the delegitimisation experience: An interpretative phenomenological analysis of people living with chronic fatigue syndrome. *Psychology & Health, 22*(7), 851-867.

Dickson, A., Knussen., C., & Flowers, P. (2008). 'That was my old life; it's almost like a past life now': Identity crisis, loss and adjustment amongst people living with Chronic Fatigue Syndrome. *Psychology & Health, 23*(4), 459-476.

Duggleby, W., Holtslander, L., Kylma, J., Duncan, V., Hammond, C., & Williams, A. (2010). Metasynthesis of the hope experience of family caregivers of persons with chronic illness. *Qualitative Health Research, 20*(2), 148-158.

Dumit, J. (2006) Illnesses you have to fight to get: Facts as forces in uncertain, emergent illnesses. *Social Science and Medicine, 62*, 577-590.

Edwards, A. G. K., Russell, I. T. and Stott, N. C. H. (1998). Signal versus noise in the evidence base for medicine: An alternative to hierarchies of evidence. *Family Practice, 15*(4), 319-22.

Edwards, C. R., Thompson, A. R., & Blair, A. (2007). An 'overwhelming illness': Women's experiences of learning to live with chronic fatigue syndrome/myalgic encephalomyelitis. *Journal of Health Psychology, 12*(2), 203-214.

Gilje, A. M., Söderlund, A., & Malterud, K. (2008). Obstructions for quality care experienced by patients with chronic fatigue syndrome (CFS): A case study. *Patient Education and Counseling, 73*(1), 36-41.

CFS/ME EXPERIENCES

- Guise, J., Widdicombe, S., & McKinlay, A. (2007). 'What is it like to have ME?': The discourse construction of ME in computer-mediated and face-to-face interaction. *Health: An Interdisciplinary Journal for the Social study of Health, Illness and Medicine*, 11(1), 87-108.
- Guise, J., McVittie, C., & McKinlay, A., (2010). A discourse analytic study of ME/CFS (Chronic Fatigue Syndrome) sufferers' experiences of interactions with doctors. *Journal of Health Psychology*, 15(3), 426-435.
- Hannes, K. Chapter 4: Critical appraisal of qualitative research. In: Noyes J., Booth A., Hannes K., Harden A., Harris J., Lewin S., Lockwood C. (editors), *Supplementary Guidance for Inclusion of Qualitative Research in Cochrane Systematic Reviews of Interventions*. Version 1 (updated August 2011). Cochrane Collaboration Qualitative Methods Group, 2011. Available from URL <http://cqrmg.cochrane.org/supplemental-handbook-guidance>
- Hart, B. & Grace, V. M. (2000). Fatigue in chronic fatigue syndrome: A discourse analysis of women's experiential narratives. *Health Care for Women International*, 21, 187-201.
- Holmes, G. P., Kaplan, J. E., Gantz, N. M., Komaroff, A. L., Schonberger, L. B., Strauss, S. E., & ... Brus, I. (1988). Chronic fatigue syndrome: A working case definition. *Annals of Internal Medicine*, 108(3), 387-389.
- Horton-Salway, M. (2001). Narrative identities and the management of personal accountability in talk about ME: A discursive psychology approach to illness narrative. *Journal of Health Psychology*, 6(2), 247–259.

CFS/ME EXPERIENCES

- Horton-Salway, M. (2007). The 'ME Bandwagon' and other labels: Constructing the genuine case in talk about a controversial illness. *British Journal of Social Psychology*, 46, 895-914.
- Kleinman, A. (1988). *The illness narratives*. New York: Basic Books.
- Larun, L., & Malterud, K. (2007). Identity and coping experiences in chronic fatigue syndrome: A synthesis of qualitative studies, *Patients Education and Counseling*, 69(1-3), 20-28.
- Lombaard, A. & Mouton, J. (2005). Chronic fatigue syndrome, the body and the self: *A South African Journal of Psychology*, 35(2), 286-307.
- Moher, D., Liberati A., Tetzlaff, J., Altman D.G. (2009). The PRISMA Group: *Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement*. [PLoS Med 6\(6\): e1000097](https://doi.org/10.1371/journal.pmed.0060097).
- NHS Executive (1998). *National Survey of NHS Patients: General Practice*. The Stationery Office, London.
- NICE (2007). *Chronic fatigue syndrome /Myalgic encephalomyelitis (or encephalopathy): Diagnosis and management*. London: NICE
- NICE (2007a). *Chronic fatigue syndrome/Myalgic encephalomyelitis (or encephalopathy): Costing report implementing NICE guidance*. London: NICE.
- Oliver, M. I., Pearson, N., Coe, N. & Gunnell, D. (2005). Help-seeking behaviour in men and women with common mental health problems: cross sectional study. *The British Journal of Psychiatry*, 186: 297-301.

CFS/ME EXPERIENCES

- Robinson, I. (1990). Personal narratives, social careers and medicine courses: Analysing life trajectories in autobiographies of people with multiple sclerosis. *Social Science and Medicine*, 30(11), 1173-1186.
- Sandelowski, M., Docherty, S., & Emden, C. (1997). Qualitative metasynthesis: issues and techniques. *Research in Nursing and Health*, 20, 365-371
- Smith, J. A. (1994). Towards reflexive practice: Engaging participants as co-researchers or co-analysts in psychological inquiry. *Journal of Community & Applied Social Psychology*, 4(4), 253-260.
- Smithson, J., Paterson, C., Britten, N., Evans, M.A. & Lewith, G. (2010). The experience of using complementary therapies after a diagnosis of cancer: a qualitative synthesis. *Health*, 16, 19-37
- Travers, M. K., & Lawler, J. (2008). Self within a climate of contention: Experiences of chronic fatigue syndrome. *Social Science & Medicine*, 66, 315-326.
- Tucker, I. (2004). 'Stories' of chronic fatigue syndrome: An exploratory discursive psychological analysis. *Qualitative Research In Psychology*, 1(2), 153-167.
- Ware, N. C. (1998). Sociosomatics and illness course in chronic fatigue syndrome. *Psychosomatic Medicine*, 60, 394-401.
- Ware, N. C., & Kleinman, A. (1992). Culture and somatic experience: The social course of illness in neurasthenia and chronic fatigue syndrome. *Psychosomatic Medicine*, 54(5), 546-560.
- World Health Organization. (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva: World Health Organization.

CFS/ME EXPERIENCES

Whitehead, L. (2006). Towards a trajectory of identity reconstruction in chronic fatigue syndrome/myalgic encephalomyelitis: A longitudinal qualitative study.

International Journal of Nursing Studies, 43, 1023-1031.

Whitehead, L., C. (2006a). Quest, chaos and restitution: Living with chronic fatigue syndrome/myalgic encephalomyelitis. *Social Science and Medicine, 62*(9),

2236-2245.

Appendix A: Search Strings

Table A1

Search Strings

Database		Search string
PsychInfo via Ovid	1	chronic fatigue syndrome.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, dv, kw, bt, nm, kf, px, rx, ui, tc, id, tm, pt, an]
	2	myalgic encephalomyelitis.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, dv, kw, bt, nm, kf, px, rx, ui, tc, id, tm, pt, an]
	3	Immune Dysfunction Syndrome.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, dv, kw, bt, nm, kf, px, rx, ui, tc, id, tm, pt, an]
	4	Post-Viral Fatigue Syndrome.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, dv, kw, bt, nm, kf, px, rx, ui, tc, id, tm, pt, an]
	5	1 or 2 or 3 or 4
	6	qualitative.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, dv, kw, bt, nm, kf, px, rx, ui, tc, id, tm, pt, an]
	7	phenomenological.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, dv, kw, bt, nm, kf, px, rx, ui, tc, id, tm, pt, an]
	8	discursive.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, dv, kw, bt, nm, kf, px, rx, ui, tc, id, tm, pt, an]
	9	discourse analysis.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, dv, kw, bt, nm, kf, px, rx, ui, tc, id, tm, pt, an]
	10	grounded theory.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, dv, kw, bt, nm, kf, px, rx, ui, tc, id, tm, pt, an]

CFS/ME EXPERIENCES

11	thematic analysis.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, dv, kw, bt, nm, kf, px, rx, ui, tc, id, tm, pt, an]
12	service user group*.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, dv, kw, bt, nm, kf, px, rx, ui, tc, id, tm, pt, an]
13	sufferer* experience.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, dv, kw, bt, nm, kf, px, rx, ui, tc, id, tm, pt, an]
14	narrative.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, dv, kw, bt, nm, kf, px, rx, ui, tc, id, tm, pt, an]
15	semi-structured interviews.mp. [mp=ti, ab, tx, ct, sh, hw, tn, ot, dm, mf, dv, kw, bt, nm, kf, px, rx, ui, tc, id, tm, pt, an]
16	6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
17	5 and 16
ISI Web of Science	TOPIC: (("chronic fatigue syndrome" OR "myalgic encephalomyelitis" or "Immune Dysfunction Syndrome or Post-Viral Fatigue Syndrome") AND (qualitative OR phenomenological OR discursive OR discourse OR grounded theory OR thematic analysis OR internet OR online OR service user group OR service user groups OR sufferers experience or narrative or "semi-structured interview"))

Appendix B: Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist 31.05.13

Table B1

Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist

Screening Questions	Answer
<p>Q1 Was there a clear statement of the aims of the research?</p> <p>HINT: Consider</p> <ul style="list-style-type: none"> • What was the goal of the research? • Why it was thought important? • Its relevance 	<p>Yes / No/Can't tell</p>
<p>Q2 Is a qualitative methodology appropriate for the authors' stated aims?</p> <p>HINT: Consider</p> <ul style="list-style-type: none"> • If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants • Is qualitative research the right methodology for addressing the research goal? 	<p>Yes / No/Can't tell</p>
<p>Is it worth continuing?</p>	
<p>Q3 Was the research design appropriate to address the aims of the research?</p> <p>HINT: Consider</p> <ul style="list-style-type: none"> • If the researcher has justified the research design (e.g. have they discussed how they decided which method to use) 	<p>Yes / No/Can't tell</p>
<p>Q4 Was the recruitment strategy appropriate to address the aims of the research?</p> <p>HINT: Consider</p> <ul style="list-style-type: none"> • If the researcher has explained how the participants were selected 	<p>Yes / No/Can't tell</p>

CFS/ME EXPERIENCES

- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. wh some people chose not to take part)

Q5 Was the data collected in a way that addressed the research issue?

Yes /
No/Can't
tell

HINT: Consider

- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Q6 Has the relationship between researcher and participants been adequately considered?

Yes /
No/Can't
tell

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during

(a) Formulation of the research questions

(b) Data collection, including sample recruitment and choice of location

- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Q7 Have ethical issues been taken into consideration?

Yes /
No/Can't
tell

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)

CFS/ME EXPERIENCES

- If approval has been sought from the ethics committee

Q8 Was the data analysis sufficiently rigorous?

Yes /
No/Can't
tell

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Q9 Is there a clear statement of findings?

Yes /
No/Can't
tell

HINT: Consider

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Q10 How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Exploring online social identities of people with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): A discourse analysis approach

Submitted by Alice Catriona Kennedy, to the University of Exeter for partial fulfilment for the degree of Doctor of Clinical Psychology. May, 2014

Supervisor: Dr Janet Smithson

Word Count: 7,960 (excluding table, references and appendices)

Nominated Journal: Qualitative Health Research

This thesis is available for Library use (after embargo period) on the understanding that it is copyright material and that no quotation from the thesis may be published without proper acknowledgement.

Abstract

People with CFS/ME suffer from physical symptoms and restriction in roles. Having a contested condition means facing scepticism, stigma and disbelief. Previous researcher-mediated studies found that people with CFS/ME excluded psychological explanations, to ward off negative stereotypes and to position themselves as genuinely ill. In this study I used social identity theory and discourse analysis methods to explore the identities exhibited by people with CFS/ME on an online forum. This study confirmed previous findings, namely that posters experienced biographical disruption owing to symptom severity and loss of roles and relationships. It also found that posters re-asserted limited self-efficacy to renegotiate their roles, to persuade family, friends and doctors that they were seriously ill and to position themselves as experts in CFS/ME. This raised the social status of the ingroup, people with CFS/ME. A new finding was that some posters considered psychological factors as exacerbating or causing CFS/ME.

Keywords: discourse analysis; illness and disease, chronic; Internet; social identity

Introduction

CFS/ME is a contested condition, owing to lack of biological markers, and a diagnosis of exclusion (Chew-Graham, Cahill, Dowrick, Wearden & Peters, 2008). Symptoms vary and include “fatigue, malaise, headaches, sleep disturbance, difficulties with concentration and muscle pain” (NICE, 2007, p.4), and, most recognisably, extreme fatigue (Clarke, 2000). Causes remain unknown; current recommended treatments are cognitive behavioural therapy (CBT) and graded exercise therapy (NICE, 2007).

Identity Disruption

Chronic illness can be considered a “critical situation” (Giddens, 1979) causing “biographical disruption” (Bury, 1982), leading people to “experience a crumbling away of their former self-images” (Charmaz, 1983, p.168) and the positive experiences and meanings on which these were based. It disrupts assumptions and behaviours, explanatory systems, biography and self-concept and requires mobilisation of resources to face altered circumstances. Illness crosses the normal boundaries expected of the body (Lawton, 1998) and alters awareness of the body (Kelly, 1992).

Bulow (2004) described chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) as a disruption leaving a person questioning how to incorporate their illness experience into a coherent life story, while Travers and Lawler (2008) described ongoing disruptions to the self. Dickson, Knussen and Flowers (2008) argued people with CFS/ME experience identity crises with great diminishment of personal control and agency resulting from CFS/ME, although, longer-term, people experience acceptance and develop coping behaviours.

CFS/ME EXPERIENCES

Social Identity Theory

For the purposes of this study, social identity theory (SIT) was used as a framework through which to explore identities of people with CFS/ME. In SIT, a person is thought to identify with multiple social categories or groups, with different groups becoming salient depending on the context. Hogg, Terry and White (1995) defined a social category as one "...into which one falls, and to which one feels one belongs,.....[it] provides a definition of who one is in terms of the self-definition that is a part of the self-concept" (p.260). The group's defining characteristics provide a basis for a social identity.

Social categorisation theory (SCT) (Turner, 1985; Turner, Hogg, Oakes Reicher & Wetherell, 1987) draws on SIT to propose that people use categorisation of self and others into ingroup categories (those social groups they identify with) and outgroup categories, as a key process in developing a social identity, and to accentuate ingroup similarity and outgroup differences. Self-categorising fulfils psychological goals and boosts self-esteem (Brown, 2000) and wellbeing can be achieved if the group provides stability, meaning, purpose and direction and is perceived as superior relative to other groups (Haslam, Jetten, Postmes & Haslam, 2009). Positive evaluations of a particular category or group can boost self-esteem (Tajfel & Turner, 1979).

One way to make positive evaluations of ingroups is through making social comparisons (Festinger, 1954) between an ingroup and relevant outgroup, in order to enhance the positive distinctiveness of the ingroup (Hogg & Abrams, 1988). However, when a group is stigmatised or marginalised, such a comparison may not be favourable.

CFS/ME EXPERIENCES

If group boundaries seem permeable then individuals may disassociate from the group. However, if boundaries seem stable, impermeable and legitimate (Tajfel & Turner, 1979) people may draw upon a number of other strategies. One strategy is to make comparisons between the ingroup and outgroups on some new dimension that allows for a more favourable appraisal of the ingroup. Alternatively, efforts are made to change “the values assigned to the attributes of the group, so that comparisons which were previously negative are now perceived as positive” (Tajfel & Turner, 1979, p.43). Another strategy is to change the outgroup with which the ingroup is compared (Tajfel & Turner, 1979). A comparison with a high-status outgroup might be avoided and self-esteem enhanced by comparison with other lower-status groups (Tajfel & Turner, 1979).

Discourse Analysis Methods

Discourse Analysis (DA) methods from a discursive psychology approach (Potter & Wetherell, 1987) are used to view forum talk as purposeful, drawing on available discourses to express social identities. Posters are understood to be employing rhetorical tools to discuss their roles and identity, influenced by CFS/ME.

A DA approach to identity draws on the emphasis on categories in self-categorisation theory (SCT), and the social nature of SIT, but adds to these a postmodernist view of the fluidity of identity, where identity is flexible and dependent upon one’s current activity and currently salient social identities (Edwards, 1997). A key distinction between SCT and DA is that “rather than categorizations being switched into activity by situations, discourse works to define events and make relevant its situations, by the kinds of categorizations it deploys” (Edwards, 1998; p.18). DA views on identity are underlain by social constructionism (Potter & Wetherell, 1987); identity is “something actively, ongoingly and dynamically

CFS/ME EXPERIENCES

constituted in discourse” (Benwell & Stokoe, 2006, p.4). Identities can be reflected, validated or denied by others. Identities are viewed as “achieved” through interactions (Antaki & Widdicombe, 1998). People orient to or resist identity categories as a social action, performed through their talk.

In online forum research this involved examining “how initial posts are taken up by subsequent responses (including replies from the initial user) and the psychological business that is negotiated within the interaction” (Horne & Wiggins, 2009, p.176). Through studying online depression discussions, Lamerichs and te Molder (2003) found people continuously defined and redefined their identities. Horne and Wiggins (2009) examined interactions between posters on an online forum for suicidal people, including how initial postings were taken up and responded to. They found the forum provided a space for “identities to be tested out, authenticated and validated by individuals” (p.179) and that an identity of authentically suicidal was developed and negotiated with others.

CFS/ME Illness Experiences

How identities are affected by CFS/ME has been explored in qualitative research (Anderson, Jason, Hlavaty, Porter & Cudia 2012; Larun & Malterud, 2007). Existing literature shows people with CFS/ME resist the stigmatised category of having a psychological illness (Horton-Salway, 2001; Tucker, 2004) which questions moral character (Åsbring & Närvänen, 2004). To avoid categorisation in the lower status outgroup of having a psychological illness, psychological labels are rejected (Cohn, 1999; Clarke, 2000; Dickson et al., 2008; Guise, Widdicombe & McKinlay, 2007; Horton-Salway, 2002; Horton-Salway, 2007; Tucker, 2004).

CFS/ME EXPERIENCES

Horton-Salway (2007) found that people with CFS/ME distinguished between “genuine” cases, people with CFS/ME, and those “jumping on the bandwagon”. Here another outgroup is created of people who have misinterpreted symptoms and are less seriously ill. This protected the social identity of CFS/ME sufferers and positioned them as genuinely ill.

People with CFS/ME often experience difficulty gaining diagnosis, (Edwards, Thompson & Blair, 2007) and struggle for recognition of the condition (Arroll & Senior, 2008; Gilje, Söderlund & Malterud, 2008; Leite et al., 2011). Disbelief from the outgroup of family and friends may lead to CFS/ME sufferers questioning the value of friendship and social interaction, and subsequent social withdrawal (Dickson, Knussen & Flowers, 2008).

People with CFS/ME have attempted to alter the attributes of their ingroup. For instance, to counter accusations of “malingering”, some people self-identified as active prior to illness (Horton-Salway, 2001). Identity development was observed through the telling of before and after stories (Horton-Salway, 2002). They also positioned themselves as seeking information, conferring a sense of control over CFS/ME through increasing knowledge (Åsbring & Närvänen, 2004; Edwards et al., 2007) and somewhat redressing the patient/professional power imbalance (Anderson et al., 2012).

The Present Study

This study furthers existing research by using social identity theory (SIT) and discourse analysis (DA) to explore identities exhibited by people with CFS/ME on an online forum.

CFS/ME EXPERIENCES

Existing literature is mostly derived from researcher-mediated data, with the notable exception of Guise et al.'s (2007, 2010) research examining online discussions about interactions with doctors. Guise et al. (2007) combined data from face-to-face interviews and internet chatroom communications; similar themes emerged from both. The internet was a fruitful source of data, with advantages when recruiting people suffering debilitating fatigue, possibly housebound and unable to attend interviews.

This study differs from much of the existing literature through its use of naturally occurring talk from an online forum for people who self-identify as having CFS/ME. Naturally-occurring talk has been defined as “interactions that would have occurred regardless of whether a researcher was involved” (Lamerichs & te Molder, 2003, p.458). This lessens some methodological difficulties, such as the giving of socially desirable answers, and decreases researcher influence on data.

A study of a CFS/ME forum allows insights into how people talk about their experiences of CFS/ME online and into the social identities produced within a supportive community of fellow sufferers. Findings can be compared with existing literature derived largely from researcher-mediated data.

Research Aim

The research aim is:

- To use social identity theory and discourse analysis methods to explore the identities exhibited by people with CFS/ME on an online forum.

By accessing this forum, it is expected a social identity of having CFS/ME will become salient. An online forum contains peer-interactions that have not been

CFS/ME EXPERIENCES

created with a researcher or outsider in mind. Thus, it will enable examination of the social identities expressed amongst an ingroup of people with CFS/ME.

Visiting an online forum specifically for people with CFS/ME might be sufficient priming for identification as belonging to an ingroup of people with CFS/ME. In this social context, an ingroup of having CFS/ME may take precedence over other social identities such as membership of groups of family or friends. This would result in conflict with these outgroups and an ingroup bias being expressed towards those with CFS/ME. Another outgroup is doctors and, following SIT, posters might be expected to react to doctors as a homogenous and undesirable outgroup.

It might be expected people with CFS/ME would make comparisons with lower-status outgroups (for example people with a mental health problem) in an attempt to positively distinguish their ingroup. Posters might also be expected to denigrate and differentiate from those with psychological illnesses, as has been found in previous CFS/ME research.

Methods

Identifying the Online Forum

The forum was identified by entering the search term “ME online forums” into Yahoo and Google search engines. “Action for M.E.” was the first link in the Google search list (the first Yahoo result forbade research), was an open forum and had sufficient postings.

The Online Forum

“Action for M.E.” is the largest UK CFS/ME charity. “M.E. friends online”, one of five forums run by “Action for M.E.”, is “the place to come to for peer support and

CFS/ME EXPERIENCES

friendship". Posts appear directly, and if moderation occurs, posters are notified.

Posters use pseudonyms. Verifiable demographic data about posters was not available. Posts mainly discuss CFS/ME.

Ethical Considerations

The research was approved by The University of Exeter School of Psychology Ethics Committee (Appendix A).

Online forum posts are in the public domain, according to ethical guidance from the British Psychological Society (BPS, 2013) for internet-mediated research. "Public" is defined as "readily accessible by anyone" (p.5) and forum posts can be considered "in the public domain" (p.8).

Posters on "M.E. friends online" can reasonably expect posts may be viewed by strangers (BPS, 2006), and the forum warns of this ("Action for M.E.", 2014). No password protection or registration is required and there are no other barriers to access, rendering consent unnecessary (O'Brien & Clark, 2012).

Previous online health forum researchers have not notified forum users (Gavin et al., 2008; Giles & Newbold, 2011). However, as good practice (Vayreda & Antaki, 2009), the forum moderator was contacted and permitted a post outlining the research, offering posters one month to remove their data from the study. This post was regularly "bumped" to the forum front page (Appendices B and C).

Balancing authenticity of the results against identification (BPS, 2013) was considered. Verbatim quotes were included but identifying information removed and new pseudonyms assigned. Each extract was entered into Google to ensure it did not appear in the first three pages of search results.

CFS/ME EXPERIENCES

Sample

As is common in online forum research (Gavin et al., 2008; Horne & Wiggins, 2009; Vayreda & Antaki, 2009) a time period was chosen. All threads ending within a six-week period in 2013 were downloaded for analysis as Word files, retaining spelling, grammatical errors and formatting. From 168 threads, up to 11 threads were completed per day. Up to 21 posts were made on each thread.

Seven people opted out of the study. Threads comprising a majority of posts by opted-out posters were excluded. The number of posters included in the study was 59.

DA does not seek “genuine” attitudes or descriptions but focuses “exclusively on the writing itself and how it can be read” (Potter & Wetherell, 1987, p.160). Forum research does not purport to be representative of all data on all forums (Smithson et al., 2011). The thread completed each day that best matched the research aim was selected for analysis. Thus 41 threads were analysed in depth.

Analytic Approach

This research drew upon DA theory and methods outlined by Potter and Wetherell (1987): action, construction and variability. Other key principles include considering participant orientations and understanding talk as action-orientated (Lamerichs & te Molder, 2003). However, DA is not a process of following rules (Billig et al, 1988), but is based on shared underlying principles about the nature of talk, interaction and textual data.

Action. Social functions of language were sought. Descriptions were not viewed merely as passive accounts but as performing actions (Potter, 1996) and playing roles in forming attributions (Edwards & Potter, 1993). Posters’ selection of

CFS/ME EXPERIENCES

details was considered, and how events sequencing justified particular positions (Edwards, 1995). A response was viewed as oriented to its predecessor and setting up the context for its successor (Heritage, 1984).

Construction. Identity was viewed as a discursive subject, people develop identities through social interaction (Benwell & Stokoe, 2006). Posters were viewed as active in choosing and deploying discourses for many reasons, such as seeking or offering information or support, or making sense of their illness experiences, with, however, implications for their identity.

These discourses, on an English-speaking, UK-based forum in 2013, are necessarily situated in a specific context. Relevant to clinical psychologists were discourses about current social meanings of illness, disability, legitimacy of illness and allocation of healthcare resources.

Language is intimately connected to power (Fairclough, 1989); speakers are enabled or limited by available discourses. Many power-related questions are relevant to contested illnesses (Clarke and James, 2003), such as who defines illness, who is expert and sufferers' ability to decide treatment, influence outcomes and quality of life.

Variability. A principle of DA is that interactional context generates variability. Data was analysed for variability, differences in content, form of posts and commonality in posts' features (Potter & Wetherell, 1987).

Integrity of Data Analysis

A key tenet of DA is that all analysis is inevitably influenced by our assumptions (Billig, 1999) and is never fully impartial. However, Potter's (2004)

CFS/ME EXPERIENCES

advice for validating analysis was used to enhance objectivity. Firstly, posters' orientations were reviewed by re-reading posts to ensure interpretations made contextual sense. Analysis was reviewed to establish coherence. Topics generated were reviewed by the research supervisor, and extracts by a group of qualitative researchers. Secondly, when a generalization was made, deviant cases were sought, to explore whether departing from the normal pattern led to interactional trouble (Potter, 1996). Thirdly, findings were reviewed for coherence within this research and with existing literature. Changes from preceding literature were carefully reviewed. The final stage of validation, reader's evaluation, involved presenting extracts within the report.

The researcher made reflective notes throughout to facilitate reflection on her own role in interpreting the data (Appendix D). An audit trail was maintained and the whole process was discussed with the research supervisor.

Analysis

Posters' responses to this research are considered, broad themes emerging from data outlined, and four topics selected for in-depth DA are discussed.

Several posters used the Researcher-Initiated Thread to give views about the forum (see Appendix C)

Data Overview

Table 2 shows the ten topics discussed most frequently, from which topics for further exploration were chosen.

CFS/ME EXPERIENCES

Table 2

Frequency of topics (the ten most frequent)

Topic	Number of references in data
Healthcare	73
Symptoms	58
Family and friends	55
Treatments	54
Physical or psychological	36
Work	33
Feelings	27
Advice seeking	21
Giving advice	17
Severity of illness	15

Treatments have been extensively researched elsewhere. The other four most frequent topics were selected for detailed analysis: symptoms, healthcare, family and friends and physical or psychological.

Symptoms

Posters discuss others' reactions to their symptoms and lack of understanding or disbelief influencing their self-esteem.

CFS/ME EXPERIENCES

Extract 1, first reply to the opening poster's dilemma about whether to accept they are disabled, emphasises similarity of experience, reinforcing a sense of belonging and an ingroup affected by others' disbelief:-

Extract 1

1.A dilemma I too have had, fighting the illness that even had me
2. fooled, until it dawned on me that I was not the same person, I had to
3. take a close look at myself, honestly, warts an all, very scary, lonely
4. and isolated and no one believing that this illness (ME) exists.
5. Struggling on until total collapse. Now I am on my own, how far do I
6. go to acknowledging my limitations?as with all these cut backs, just
7. makes me feel as though I am a burden on Society. BUT, somewhere very
8. deep down tells me to fight for what is right and just.....

Poster 1 describes not being "the same person", echoing Bury's (1982) idea of biographical disruption. Throughout the thread, posters consider how much to accept "limitations" or "disability", or strive to continue as before illness. Poster 1's dilemma about how far to acknowledge limitations is a question, suggesting it be decided within social interaction. This shared narrative is furthered through validating each other's posts and recurring use of the word "limitation". Adaptation to accommodate limitations emerges since one is no longer "the same person". Implied is some, albeit limited, self-efficacy to determine these adaptations.

At other times the poster positions change as done to them, as causing isolation (Whitehead 2006) through others' disbelief. This implied lack of self-efficacy, with others' views being powerful, is reinforced by capitalisation of "Society". Identity is not inherent but reflected from others, an identity as a "burden on Society", linked to a particular historical and social context, a time of "cut backs", that brings both limitations on resources and diminished personal worth. Missing is comment on how the poster feels about inability to alter others' views, although the tone seems frustrated. Later the poster expresses agency through "fight for what is right and

CFS/ME EXPERIENCES

just”, the “fighting” discourse often applied to cancer (Seale, 2001, 2002). A fighting discourse also emphasises personal responsibility for illness (Wilkinson & Kitzinger, 2000). Using empiricist repertoire (Gilbert & Mulkey, 1984), “right and just”, to side with “right”, regains some power. Political or cultural change is not sought; the poster concludes one must change oneself, re-emphasising personal responsibility for health.

Poster 2 debates how much of “what I used to do” can be continued:-

Extract 2

1. Although I accept the Diagnosis and the title I think I am in denial
2. about my limitations (if that makes sense). I try and carry on to about
3. 50% of what I used to do, I dont 'work' adn spend a lot of time alone
4. and tell myself that it's alright to do this and that because I can take to
5. my bed when I need to. Is this the right way to deal with this illness or
6. do I reduce my undertakings to 10% of what I used to do and feel the
7. same everyday?

Poster 2 discusses disruption and change brought about by symptoms, expressing a dilemma between accepting “the Diagnosis”, implying acceptance of the social identity of having CFS/ME, or continuing an old life. Thus, CFS/ME is positioned as disruptive, leading to reappraisal.

Medical language, “illness” and “Diagnosis”, categorises CFS/ME as legitimate and existing separately from the poster, yet later the poster asserts agency through choices about the “right way to deal with this illness”. Selectively employing medical discourse both legitimises CFS/ME and retains self-efficacy in seeking improved health.

Poster 2 has apparently lost an employment role and seems uncertain how far to reduce “what I used to do”. Rather than creating a new identity or finding new activity, as some literature suggests (Whitehead, 2006), the poster appears to

CFS/ME EXPERIENCES

reduce activity. Quotation marks around “work” challenge what constitutes work; lack of elaboration, however, suggests the poster feels no need to justify their activity, rejecting a dominant discourse of paid employment as virtuous. This remains unchallenged in subsequent posts, which leads to a jointly developed social identity as actively managing the condition, in contrast to cultural discourse about shirking “work”.

Throughout this thread, posters extend and refine a discourse of managing others’ reactions and disbelief and crystallize the dilemma between adapting and being at the mercy of others’ reactions.

Poster 3 joins in with a reference to previous posts and positions their own experiences as similar, also using the language of limitations:-

Extract 3

1. like XXX I find it very difficult to accept my limitations, and when I 'fail' to
2. do what I think I should do I beat myself up. It drives me mad when
3. people comment on how well I look when inside I feel like crap. in some
4. ways I found it easier when I had cancer because when I had no hair it
5. was visible to people I was not well. I too have had people tell me how
6. 'tired' they are too, they have no idea and it makes me feel like
7. screaming.

As with Poster 1, “fail” implies the person is lacking for not sustaining all previous activities. They simultaneously challenge the idea of failing, through the use of quotation marks. Via the metaphor, to be “driven mad”, and the statement, “feel like screaming”, the poster conveys how extreme their experience is, reinforcing the idea of major disruption and legitimising the illness experience. The gap between the symptoms experienced and what outsiders acknowledge is stressed.

Echoing Poster 1’s “fighting” metaphor, Poster 3 directly compares responses to cancer (an illness currently perceived as more socially acceptable (Tucker, 2004))

CFS/ME EXPERIENCES

and CFS/ME. This could be understood as an attempt to seek positive evaluation for one's ingroup (Tajfel & Turner, 1979) through comparison with a less challenged illness category and to transfer the legitimate public discourse about cancer to CFS/ME. This bolsters an identity of legitimately ill but misunderstood.

Healthcare

The thread evolves from symptom severity conversation to discussing doctors' perceived shortcomings, allowing, in comparison, people with CFS/ME to emerge as the knowledgeable group actively managing health and developing expertise.

Poster 4 orients to the previous poster and self-positions as expert: -

Extract 4

1. ...do what I did....sit in the Doctors and DEMAND a referral to a
2. specialist....It worked for me...yes I had to raise my voice and
3. demand a couple of times to get one, it is YOUR right to get the
4. best help possible.....if you do let me know how you go on.....look
5. him straight in the eyes too, it helps,...

Poster 4 positions referral as "YOUR right", capitalisation emphasising entitlement. It echoes an expert patient discourse, countering an older public discourse of expert doctors. This implies an identity as competent, knowledgeable and active in obtaining healthcare. This identity appears when the poster describes not receiving validation of being genuinely ill from the doctor. "Look him straight in the eyes" positions someone with CFS/ME as needing to assert power to access resources via the doctor, challenging medical legitimacy.

Extract 5 occurs part way through a thread entitled "I have ME." Posters responded to an opening post describing the carer's experience and severity of

CFS/ME EXPERIENCES

illness with a shared sense that health professionals' assistance is inadequate and people should arrange their own care.

Poster 5 positions Doctors as "pretty useless with ME" and someone with CFS/ME as unable to cure themselves, allowing only limited self-efficacy:-

Extract 5

1. As doctors are pretty useless with ME you shouldn't expect to be
2. able to cure it yourself. However some of us have been able to
3. make improvements in our health by eating well, improving sleep
4. quality and taking supplements. There is hope.

"Cure" is a counter-discourse to CFS/ME as a psychological condition and an NHS discourse of treatment. Instead "cure" evokes discourses of defined illnesses where cures are expected, legitimising people with CFS/ME as genuinely ill. For Poster 5 the normal sequence of illness and treatment cannot be followed, setting up the call to improve one's own health and echoing a public discourse of alternative medicine filling a void where traditional medicine cannot help.

Doctors' medical legitimacy is here challenged. The juxtaposition of the inadequacy of doctors with advice about alternative treatment serves to position the poster as knowledgeable, expert and retaining somewhat limited self-efficacy. This identity, formed through social interactions, becomes salient when interacting with doctors.

Family and Friends

Forum members often discuss CFS/ME's effects on relationships with friends and partners, describing wide-ranging experiences, from becoming closer to partners to misunderstanding or rejection. The onus is on posters to explain their condition and renegotiate their relationships.

CFS/ME EXPERIENCES

Extract 6 concludes the opening post of a thread entitled “I wish these feelings would stop”. Earlier posts’ discussions of difficulties balancing housework and finances expressed an identity of being struggling but conscientious.

Poster 6 extends this and values emotional support but contrasts it with her husband’s absence: -

Extract 6

1. My husband is very loving and helps me mentally but not so much
2. with the stuff that needs doing around the house. He is playing golf
3. tomorrow and is going away next week playing golf, his way of
4. escaping, which is fair enough and I do understand that but I don’t
5. have an escape, its with me all the time and i feel like I am wading
6. through mud.

This draws on an established “golf widow” discourse. Although she states this is “fair enough”, she highlights not having “an escape”, serving three purposes: framing CFS/ME as relentless, contrasting her and her husband’s lives, and persuading readers he should do more housework. Not just her activities, but also her ability to negotiate with her husband appear restricted by CFS/ME. He is positioned as more powerful, able to choose his activity. The metaphor, “wading through mud”, frames someone with CFS/ME as struggling but still trying, despite CFS/ME. This may be an attempt to refute negative stereotypes of people with CFS/ME as “malingering” (Horton-Salway, 2001) and orient towards a discourse of being a “genuine case” (Horton-Salway, 2007). Poster 6’s viewpoint is validated through other posters’ empathetic and reflective statements. Posters jointly progress a discourse of self-kindness, compassionate but also lonely, as opposed to an outgroup in the form of the husband. Empathy and advice are frequently offered. These activities reinforce the group identity as a more positive category; on this forum the ingroup of people with CFS/ME are actively supportive.

CFS/ME EXPERIENCES

In the opening post of the thread, “Living Alone With ME/CFS”, Poster 7 portrays CFS/ME as disrupting relationships:-

Extract 7

1. The friends I have can be a challenge as they can be very unsure,
2. understandably, afraid even, of how to be despite my regular and gentle
3. input to inform and support their understanding. Yesterday, I spent time
4. with a very dear friend who just hugged me and let me cry
5. without trying to fix or change anything...for herself or me. She just made
6. little "sore" noises when I was crying which was so healing...like she
7. understood and empathised without a word spoken.

Sadness is exacerbated by these earlier attempts to indicate friends' failure to help (3). Here, friends are framed as a salient outgroup who lack knowledge and who “can be a challenge”. While the poster states friends' reactions are understandable, this is qualified by trying to overcome lack of understanding through sensitive education, similarly to suggestions Poster 6 received, building an identity as thoughtful, understanding and patient. Here, identities are not formed in isolation but are socially reflected and relationships are re-negotiated through patient educating of friends.

One friend's reaction provides further proof that other friends could react differently. Rather than seeking treatment or cure, “sore noises”, empathy and comforting offer healing. In contrast to extract 5, action is not sought.

Subsequently posters gradually differentiate “aloneness and loneliness” and “relationships that help us, those that are understanding, and those that increase stress”. Posters generate a shared view of healthy relationships and good partners, balancing wishing not to be a “burden” with missing opportunities to trust and love “the right person”, someone who can tolerate the fluctuations of CFS/ME. Partners must be “understanding” and “supportive” and “willing to make allowances”. People

CFS/ME EXPERIENCES

with CFS/ME retain self-efficacy to choose whether to leave relationships and are strong, “m.e. warriors” who can live alone when necessary.

Posters write of positive attributes they bring to a relationship owing to their CFS/ME experience, positioning themselves as lonely but craving and valuing social connection and Poster 7 states “I think ME/CFS does bring a deeper sense of self and what matters in the world”. As noted earlier, a positive social identity is being collaboratively developed.

Physical or Psychological Condition

Posters discussed the causes of CFS/ME. While some posters were emphatic that the condition was physical and regarded mental health symptoms as secondary, others wrote of stress triggering illness. Some posters developed a shared identity as strong and brave and considered psychological causes of CFS/ME.

Extract 8 is a reply to an opening post by the partner of someone with CFS/ME. The partner with CFS/ME is described as needing “mental help”. Collectively, posters resist this and portray mental health difficulties as secondary to CFS/ME whilst retaining empathy. Poster 8 directly rejects the idea of CFS/ME as a mental illness: -

Extract 8

1. You say you have no experience in mental help - your partner is not
2. mentally ill, they have ME. As with any serious illness that can cause
3. severe depression but if the physical problems could be dealt with it's
4. quite likely he wouldn't be depressed. I'm sure it grieves him not to be
5. able to help you but he can't physically do it.

Poster 8 positions the opening poster as unknowing and lacking in expertise (1), allowing posters with CFS/ME an expert identity. “Mentally ill” draws upon a

CFS/ME EXPERIENCES

medical discourse of mental health problems as illness, yet depression is described as an understandable response to physical problems and CFS/ME as explicitly a physical condition. The poster appeals to notions of normality to explain how depression can authentically co-exist with CFS/ME. Depression resulting from living with physical problems is thus legitimised and the assertion that it is “quite likely he wouldn’t be depressed” if the physical problems were “dealt with” further develops the causes of CFS/ME as physical. This complements Söderland, Skoge & Malterud’s (2000) finding that some people with CFS/ME acknowledged having depression but perceived it as secondary, and protects the social identity of having CFS/ME against negative psychological illness stereotypes and helps refute questioning of moral character. Interestingly the opening poster refines their stance during the thread, replying “My partner is mentally ill with depression that his ME causes...”, adopting the same discourse.

Threads showed variation in how psychological influences were discussed. In one entitled “good news on homepage”, Poster 9 believes “excessive stress” plays a role in CFS/ME: -

Extract 9

1. Although I firmly believe that excessive stress plays a part in this illness,
2. it is clear that this causes overactivation of the immune system.
3. Stress often precipitates an asthma attack or psoriasis and excema but a
4. doctor would never send any of these patients to a psychiatrist. If an
5. asthma patient was refused an inhaler and left to cough and fight for
6. breath there would be national uproar. Nuff said!!!!!!!

This opposes a Cartesian dualism and instead views mind and body as inter-related, contrasting with previous findings (Horton-Salway, 2001; Guise et al., 2007) that, when interacting with GPs, people with CFS/ME rejected portrayals of CFS/ME as psychological or psychosomatic. The poster shows certainty, stating “it is clear”.

CFS/ME EXPERIENCES

“Excessive” conveys undue external stress rather than describing someone with CFS/ME as vulnerable to stress, thereby protecting themselves from accusations of psychological weakness or vulnerability.

Poster 9 normalises CFS/ME within references to less contested medical conditions, and supports the consensus of psychiatrists as superfluous. This social comparison subtly raises the status of CFS/ME sufferers, who become the experts, determining appropriateness of treatments or referrals.

A comparison is made with asthma and psoriasis sufferers to argue for the same level of care offered to those with physical health conditions where stress plays a role while “Fight for breath” emphasises the lack of treatment and suggests imperilled lives. Again, this serves to align CFS/ME sufferers with higher status groups, those with recognised physical illnesses.

The general public are invoked to support the poster’s view as correct through the assertion “there would be national uproar”; the rhetorical device “Nuff said” and exclamation marks validate the poster’s argument and close the conversation by discouraging contrasting contributions.

Poster 9’s opening post is developed and confirmed by subsequent posts, creating a shared opinion of CFS/ME being exacerbated by stress. One poster asserts that “the big S [stress] word does play a part” and questions why people with CFS/ME are referred to psychiatrists. The idea of stress exacerbating CFS/ME and vice versa recurs as an established view in several threads.

Extract 10 is a response to a description of a childhood with a physically and emotionally abusive mother: -

CFS/ME EXPERIENCES

Extract 10

1. I can fully relate to all of this. I had to bear the brunt of a
2. violent and mentally ill mother. Although she was able to look after us
3. physically she was emotionally absent and I never once remember
4. being sat on her knee or given a cuddle. I am sixty now my brother is
5. mid fifties. We are both very ill and disabled. Abuse in childhood is
6. massive in this illness, it causes no end of physical problems.
7. The facts simply speak for themselves. xx

Poster 10 first orients to the opening poster before reciprocating with their own experience, furthering discourse of psychological influences before making a causal link between childhood abuse and CFS/ME.

Poster 11 explicitly states (5-6) childhood abuse can cause physical problems and, like Posters 8 and 9, gives no supporting evidence beyond personal experience. "The facts simply speak for themselves" frames this as definitive, as with "Nuff said!!!!!!!" in extract 9. In extracts 8, 9 and 10, personal experience is valued and applied to others' experiences of the same condition, again elevating the social status of CFS/ME sufferers as the only people with a legitimate claim to such personal experience.

Here CFS/ME legitimacy is not threatened but, instead, posters experience acknowledgement and recognition. Posters praise courageous stories: , "I salute your courage!". Considering psychological factors does not threaten; instead, posters express a shared identity as courageous.

Posters maintain an external cause of CFS/ME while considering psychological factors, framing negative experiences as things done to them. Expressions of goodwill ("I will send you my love and hugs") and empathy are offered to posters who share their stories. The supportive environment of this thread may enable posters to consider psychological causes for CFS/ME, demonstrating

CFS/ME EXPERIENCES

the fluid nature of social identity dependent upon context. No outgroups were present or invoked, meaning there was little threat to an identity of being authentically ill. This may have enabled exploration of psychological influences on CFS/ME. Such a finding has not been previously reported in qualitative studies of CFS/ME illness experiences.

Discussion

This study sought to use SIT and DA methods to explore identities exhibited by people with CFS/ME on an online forum. This study explored discursively how people with CFS/ME talked about symptoms, family and friends' reactions, experiences of healthcare and whether CFS/ME is viewed by posters as a psychological or physical condition, and related these to SIT. In contrast to previous research, this study found that, when amongst an ingroup, people with CFS/ME can contemplate a social identity of having a psychologically influenced or caused illness. This has clinical implications for the acceptability of psychological treatments to people with CFS/ME.

Summary of Findings

Posters expressed an ingroup identity as being seriously ill, active in seeking information and experts on their own condition. They used this expertise to share knowledge and experiences amongst the forum ingroup and educate outgroups of "useless" doctors and disbelieving or ill-informed friends and family. Posters also used this expertise to debate and determine the extent to which they should accept and adapt to the limitations imposed by CFS/ME or attempt to continue life as before. Illness had resulted in identity disruption and required renegotiation of roles and relationships.

CFS/ME EXPERIENCES

Social Identity Theory

In line with predictions made from SIT, posters appeared to prioritise membership of the salient CFS/ME ingroup, rather than other social identities. Thus, family and friends became outgroups, along with doctors. Posters were not expecting recovery in the short-term, so could not use a strategy of disassociating from the CFS/ME ingroup. Instead posters attempted to raise the group status (and their self-esteem) through favourable social comparisons with the aforementioned outgroups.

Posters also made social comparisons with cancer sufferers, attempting to access this outgroup's higher social status.

In contrast to predictions made from SIT and previous research, posters did not always differentiate from those with psychological problems but sometimes identified with an ingroup of people experiencing mental health difficulties.

In line with SIT, posters described an ingroup of those who are "seriously ill". A positive evaluation of a higher status "seriously ill" ingroup is being made through an implied comparison with those who are not genuinely ill. The positive distinctiveness of the "seriously ill" was achieved by emphasising the severity and all-pervading nature of their symptoms. This echoes Horton-Salway's (2007) differentiation of "genuine cases" and those "jumping on the bandwagon".

Social comparisons were also used to align people with CFS/ME with the higher social status group of cancer sufferers. The "fighting" metaphor echoed a discourse surrounding cancer sufferers (Seale, 2001, 2002), evoking a comparison (Festinger, 1954) with a group culturally accepted as genuinely ill.

CFS/ME EXPERIENCES

Doctors were positioned as an outgroup against which identities were formed. They were described as “pretty useless” (Extract 5), confirming previous research where people with CFS/ME bemoaned doctors as sceptical and lacking in knowledge (Dickson et al., 2007; Gilje et al., 2008, Horton-Salway, 2007). Previously, Clarke (2000) found people with CFS/ME became experts through seeking information and finding “good doctors” who would diagnose CFS/ME. However, in this study it is through the comparison with the outgroup of “pretty useless” doctors that people with CFS/ME became the experts. A dismissal of medical legitimacy enhanced their own status as expert in the recognition, definition, understanding and management of CFS/ME.

Another outgroup was family and friends. As in previous research people felt misunderstood by family and friends (Anderson & Ferrans, 1997; Clarke & James, 2003; Dickson et al., 2007, 2008) and partners (Brooks, King & Wearden, 2014) and that their moral characters were being questioned (Åsbring & Närvänen, 2004). However, whereas existing literature emphasises people with CFS/ME responding by socially withdrawing (Dickson et al, 2008), this study shows posters gaining limited self-efficacy through developing a shared discourse of educating the outgroup, their families and friends, about CFS/ME. Posters positioned the healthy friends and family outgroup as having greater agency and lifestyle choices, as well as lacking knowledge. This comparison enables an identity for the ingroup as educators, furthers a discourse of expertise and highlights the difficulties and limitations with which they live. Posters also positively evaluated their ingroup as, in contrast to their reception by friends and family, they described themselves as a welcoming forum community where expressions of empathy and acceptance were frequently exchanged, bolstering an ingroup identity as patient and caring.

CFS/ME EXPERIENCES

This is an example of how identities can be validated or delegitimised by others (Antaki & Widdicombe, 1998, Benwell & Stokoe, 2006). In this study, a new identity as ill was not internal or fixed, but open for discussion and based in both people's physical experiences and others' reactions. In line with discursive theories of identity, their CFS/ME identity was socially shaped and either validated or threatened by others. In another social context, a social identity as a friend or family member might have had greater salience.

Posters faced loss of employment roles and the stigma of being a "burden to Society". Instead of accepting these negative attributes of a CFS/ME ingroup, posters questioned what constituted "work" and resisted discourses of failure and being burdensome. Within a SIT framework we can view this as raising the social status of those in the unemployed CFS/ME group by attempting to access a higher social status group of people who work, by redefining work and comparing their own efforts with those of employed people. Redefining "work" increased positive evaluations of the CFS/ME group, and might thereby increase members' self-esteem (Tajfel & Turner, 1979).

In the introduction, it was predicted from SIT and previous research (Clarke, 2000; Dickson et al., 2008; Guise et al., 2007; Guise et al., 2010; Horton-Salway, 2001, 2002, 2007, Tucker, 2004) that posters might resist psychological explanations of CFS/ME in order to distance themselves from the lower status outgroup of people with psychological conditions and avoid the negative stereotypes and stigma of having a mental health problem. Proposing psychological influences acted to delegitimise CFS/ME, and was felt by sufferers to be casting aspersions on their moral characters (Åsbring & Närvänen, 2004).

CFS/ME EXPERIENCES

However, in this study, reactions to the idea of people with CFS/ME belonging to a social category of having a psychological illness varied. When an outgroup member, a partner of someone with CFS/ME, labelled CFS/ME as psychological (Extract 8) posters reacted to this external threat to their identities by positioning mental health difficulties as a consequence of CFS/ME. Here, posters distinguished between psychological consequences of having CFS/ME and having a primary mental health problem.

In contrast, elsewhere, when outsiders were neither present nor evoked through discussion, people with CFS/ME proposed their illness was exacerbated by stress (Extract 9). Contrary to Cohn's (1999) findings, some posters transcended the mind-body divide, considering interplay between physical and psychological factors such as stress. This could be explained by the function of the talk, which was not to ward off threats to the social status of the group, but to explore what might be helpful for fellow sufferers, and the context of an understanding and sympathetic ingroup. Other posters (Extract 10) extended this idea and discussed CFS/ME being caused by experiences of childhood abuse. In the social context of an ingroup of people with CFS/ME, where outgroups were neither present nor invoked, people considered an identity of having an illness exacerbated or caused by psychological influences. Perhaps to counter the low social status of this identity, posters' talk in this conversation framed people with CFS/ME as strong and striving, perhaps the more so for having survived childhood abuse. Thus, Tajfel and Turner's (1979) requirement for a positive evaluation of the group was still met.

Biographical Disruption

This research indicated a disruption owing to the effects of CFS/ME on health, roles and relationships. Consistent with Bury's (1982) idea of biographical disruption,

CFS/ME EXPERIENCES

posters described no longer being “the same person” and, as in previous research (Dickson, Knussen and Flowers, 2008), symptoms were experienced both as physically limiting and as limiting personal agency

Together, posters developed agreement that CFS/ME necessitates change. This is a common theme in existing literature, which views CFS/ME as precipitating a change in identity or self (Arroll & Howard, 2013; Edwards et al., 2007; Lombaard & Mouton, 2005; Travers & Lawler, 2008; Whitehead, 2006a). As in previous studies, people with CFS/ME described a constriction of roles (Ware, 1998) owing to the limitations resulting from symptoms (Arroll & Howard, 2013; Clarke & James, 2003; Dickson et al., 2007; Edwards et al., 2007). Posters framed loss of roles as necessary by explaining and emphasising the severity of CFS/ME symptoms.

However, posters also debated to what extent they needed to limit their previous activities and roles, suggesting some aspects of life before illness could be retained. Tension existed between choosing to change oneself, and change being enforced through social isolation. Here, posters were developing a discourse of some limited self-efficacy. This is important because self-efficacy has long been established as a beneficial component of health change models (Ajzen, 1991; Schwartzer, 1992, 2001). Furthermore, self-efficacy is a moderator in outcomes in CFS/ME (Findley, Kerns, Weinberd & Rosenberg, 1998).

Expert Patient Discourse

The expert patient discourse used by posters mirrors a larger movement in chronic disease management away from patients being passive recipients of care (Barlow, 2002). An example is the NHS Expert Patient Programme (Department of Health, 2001). This may encourage creation of health information resources as found

CFS/ME EXPERIENCES

by Ziebland and Wyke (2012); professionals should understand patients' management of their own healthcare. This study goes further than previous literature by demonstrating how the role of expert emerges from social encounters where disbelief and lack of knowledge are perceived.

Limitations

Generalizing context-dependent DA results (Willig, 2008) and complete objectivity when selecting data are difficult despite careful precautions.

Data was from one forum and excludes those unable to interact online. Consistent with the epistemology of DA, findings necessarily reflect discourses available in English, a UK-based forum and 2013; anonymous posters cannot be verified.

Validity could have been furthered by presenting findings to posters for confirmation, although their responses would have been researcher-mediated rather than naturally occurring talk.

Clinical Implications

The parameters within which an exploration of psychological influences can take place are significant because the only current interventions recommended by NICE (2007) are psychological, namely cognitive behavioural therapy and graded exercise therapy. Therefore the ability to engage people with CFS/ME in psychological approaches is essential for their access to evidence-based interventions.

CFS/ME EXPERIENCES

Formulation. Clinical psychologists could transcend the mind-body dualism noted by using formulation. Formulation can include social relationships and contexts (BPS, 2011). Recommendations are:-

- Teaching in formulating for contested illnesses;
- Offering team formulation, within MDTs, integrating psychological and physical aspects, promoting understanding of systemic factors such as role restriction and isolation;
- Offering family interventions, including addressing negative behavioural responses or causal attributions (Brooks, Daghish & Wearden, 2013) and considering family contexts.

Healthcare professionals. Avoiding legitimacy discourses, recognising and acknowledging experiences of CFS/ME as important. Recommendations are:-

- Producing awareness materials about CFS/ME patients' difficult experiences, psychosocial aspects of illness; avoiding reinforcing legitimacy discourses.

Online support. This study demonstrates how online forums may provide a space for ingroup discussions and encourage an identity of being both knowledgeable and supportive. Recommendations are:-

- NHS providing online systems for peer interactions;
- Providing online information about CFS/ME to aid a sense of agency;
- Researching online interventions, offering the NICE (2007) recommended CBT and pacing materials online, and
- Evaluating online interventions.

CFS/ME EXPERIENCES

Future Research

Online forum research is proliferating; new means of online communication are constantly emerging. Researchers used Second Life (Best & Butler, 2013; McElhinney, Cheater & Kidd, 2014), Facebook groups (Young & Jaganath, 2013) and Twitter (Jashinsky et al., 2014) and data from multiple online sources (Xu, Yoon & Tourassi, 2014). Online communications offer useful understanding of peer-to-peer discussions and participant-led understanding of illnesses.

This research highlights possible changes in patients' views about psychological and physical influences of CFS/ME. Future research might explore factors mediating acceptability of psychological interventions. However, posters were sensitive to being "used" for research.

Future research might explore couples' (Brooks et al., 2014) and families' (Donalek, 2009) experiences. Recommendations are: -

- Investigating using varied online communications in health research;
- Researching user-generated data gathered across online platforms;
- Involving people with CFS/ME in research design
- Researching experiences of families and friends, and
- Investigating conditions for patient acceptance of a psychological component for CFS/ME

Conclusion

Posters jointly attempted to raise the social status of a social identity of having CFS/ME by making social comparisons with outgroups and seeking positive attributes for their ingroup. Through comparison with family, friends and doctors, posters positioned themselves as active in seeking information about and managing their condition. Comparisons with “pretty useless” doctors furthered a discourse of people with CFS/ME as experts in their condition. In particular, this study highlights how the supportive forum talk and development of an ingroup with shared understandings formed an environment in which some posters were able to explore having an illness with possibly psychological causes.

References

- Abrams, D. & Hogg, M. A. (1988). Comments on the motivational status of self esteem in social identity and intergroup discrimination. *European Journal of Social Psychology, 18*, 317-334.
- Action for M.E. (2014). Retrieved from <http://www.actionforme.org.uk/get-involved/join-a-discussion-forum>.
- Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes, 50*, 179-211.
- Anderson J.S., & Ferrans C.E. (1997). The quality of life of persons with chronic fatigue syndrome. *Journal of Nervous Mental Diseases, 185*, 359–67
- Anderson, V. R., Jason, L. A., Hlavaty, L. E., Porter, N., & Cudia, J. (2012). A review and meta-synthesis of qualitative studies on myalgic encephalomyelitis/chronic fatigue syndrome. *Patient Education and Counselling, 86*(2), 147-155.
- Antaki C, and Widdicombe, S. (eds.) (1998). *Identities in Talk*. London: Sage.
- Antaki, C., Billig, M. G., Edwards, D., & Potter, J. A., (2003). Discourse analysis means doing analysis: A critique of six analytic shortcomings. *Discourse Analysis Online*, retrieved from <http://extra.shu.ac.uk/daol/articles/v1/n1/a1/antaki2002002.html>
- Arroll, M. A., & Howard, A., (2013). The letting go, the building up, [and] the gradual process of rebuilding: Identity change and post-traumatic growth in myalgic

CFS/ME EXPERIENCES

encephalomyelitis/chronic fatigue syndrome. *Psychology & Health*, 28(3), 302-318

Arroll M. A., & Senior V. (2008). Individuals' experience of chronic fatigue syndrome/myalgic encephalomyelitis: An interpretative phenomenological analysis. *Psychology & Health*, 23(4), 443-458

Åsbring, P., & Närvänen, A. (2004). Patient power and control: A study of women with uncertain illness trajectories. *Qualitative Health Research*, 14(2), 226-240.

Barlow, J., Wright, C., Sheasby, J., Turner, A. & Hainsworth, J. (2002). Self management approaches for people with chronic conditions: A review. *Patient Education and Counseling*, 48, 177–187.

Benwell, B. and Stokoe, E.H. (2006) *Discourse and Identity*. Edinburgh: Edinburgh University Press.

Best, K., & Butler, S. (2013). The necessity of control for computer and internet users with myalgic encephalomyelitis/chronic fatigue syndrome. *Information Communication & Society*, 16(7), 1042-1060.

Billig, M., Condor, S., Edwards, D., Gane, M., Middleton, D., & Radley, A. R. (1988). *Ideological dilemmas: A social psychology of everyday thinking*. London: Sage Publications.

Billig, M. (1999). Conversation analysis and the claims of naivety. *Discourse and Society*, 10(4), 572–576.

CFS/ME EXPERIENCES

British Psychological Society (2006). *Code of ethics and conduct*. Leicester: British Psychological Society.

British Psychological Society (2011). *Division of clinical psychology: Guidelines: Practice guidelines on the use of psychological formulation*. Leicester: British Psychological Society.

British Psychological Society (2013). *Ethics for internet-mediated research*. Leicester: British Psychological Society.

Brooks, J. M., Daghish, J., & Wearden, A. J. (2013). Attributions, distress and behavioural responses in the significant others of people with chronic fatigue. *Journal of Health Psychology, 18*(10), 1288-1295.

Brooks, J. M., King, N., & Wearden, A. J. (2014). Couples' experiences of interacting with outside others in chronic fatigue syndrome: A qualitative study. *Chronic Illness, 10*, 5-17.

Bulow, P. H. (2004). Sharing experiences of contested illness by storytelling. *Discourse & Society, 15*(1), 33-53.

Bury, M. (1982). Chronic illness as biographical disruption, *Sociology of Health and Illness, 4*, 167-82.

Brown, R. (2000). Social identity theory: Past achievements, current problems and future challenges. *European Journal of Social Psychology, 30*, 745-778.

Charmaz, K. (1983). Loss of sense of self: A fundamental form of suffering in the chronically ill. *Sociology of Health & Illness, 5*(2), 169-195.

CFS/ME EXPERIENCES

Chew-Graham, C. A., Cahill, G., Dowrick, C., Wearden, A., & Peters, S. (2008).

Using multiple sources of knowledge to reach clinical understanding of chronic fatigue syndrome. *The Annals of Family Medicine*, 6(4), 340-348.

Clarke, J. N., (2000). The search for legitimacy and the “expertization” of the lay person: The case of chronic fatigue syndrome. *Social Work in Health Care*, 30(3), 73-93.

Clarke, J. N., & James, S. (2003). The radicalized self: The impact on the self of the contested nature of the diagnosis of chronic fatigue syndrome. *Social Science & Medicine*, 57, 1387-1395.

Cohn, S. (1999). Taking time to smell the roses: Accounts of people with Chronic Fatigue Syndrome and their struggle for legitimisation. *Anthropology & Medicine*, 6, 195-215.

Department of Health (2001). *The expert patient: a new approach to chronic disease management for the 21st century*. London: Department of Health.

Dickson, A., Knussen, C., & Flowers, P. (2007). Stigma and the delegitimation experience: An interpretative phenomenological analysis of people living with chronic fatigue syndrome. *Psychology & Health*, 22(7), 851-867.

Dickson, A., Knussen, C., & Flowers, P. (2008). 'That was my old life; it's almost like a past life now': Identity crisis, loss and adjustment amongst people living with Chronic Fatigue Syndrome. *Psychology & Health*, 23(4), 459-476.

Donalek, J. G. (2009). When a parent is chronically ill: Chronic fatigue syndrome. *Nursing Research*, 58(5), 332-339.

Dumit, J. (2006). Illnesses you have to fight to get: Facts as forces in uncertain, emergent illnesses. *Social Science and Medicine*, 62, 577-590.

CFS/ME EXPERIENCES

- Edwards, D. (1995). Two to tango: Script formulations, dispositions, an rhetorical symmetry in relationship troubles talk. *Research on Language and Social Interaction, 28*(4), 319-350.
- Edwards, D. (1997). *Discourse and cognition*. London: Sage.
- Edwards, D., & Potter, J. (1993). Language and causation: A discursive action model of description and attribution. *Psychological Review, 100*(1), 2341.
- Edwards, D. (1998). The relevant thing about her: Social Categories in use. In Antaki, C. & Widdicombe, S. (Eds). *Identities in Talk* (pp.15-33). London: Sage.
- Edwards, C. R., Thompson, A. R., & Blair, A. (2007). An 'overwhelming illness': Women's experiences of learning to live with chronic fatigue syndrome/myalgic encephalomyelitis. *Journal of Health Psychology, 12*(2), 203-214.
- Fairclough, N. (1989). *Language and Power*. London: Longman.
- Festinger, L. (1954). A theory of social comparison processes. *Human Relations, 7*, 117-140.
- Flinkfeldt, M. (2011). 'Filling one's days': Managing sick leave legitimacy in an online forum. *Sociology of Health & Illness, 33*(5), 761-776.
- Findley, J. C., Kerns, R., Weinberg, L.D. & Rosenberg, R. (1998). Self-efficacy as a psychological moderator of chronic fatigue syndrome, *Journal of Behavioural Medicine, 21*(4), 351-62.

CFS/ME EXPERIENCES

- Gavin, J., Rodham, K., & Poyer, H. (2008). The presentation of 'pro-anorexia' in online group interactions. *Qualitative Health Research, 18*(3), 325-333.
- Giddens, A. (1979). *Central Problems in Social Theory*. London: Macmillan.
- Gilbert, G N., & Mulkay, M. (1984). *Opening Pandora's Box: A sociological analysis of scientists' discourse*. Cambridge: Cambridge University Press.
- Giles, D. C., & Newbold, J. (2011). Self- and other-diagnosis in user-led mental health online communities. *Qualitative Health Research, 21*(3), 419-428.
- Gilje, A. M., Söderlund, A., & Malterud, K. (2008). Obstructions for quality care experienced by patients with chronic fatigue syndrome (CFS): A case study. *Patient Education and Counseling, 73*(1), 36-41.
- Guise, J., Widdicombe, S., & McKinlay, A. (2007). What is it like to have ME?: The discourse construction of ME in computer-mediated and face-to-face interaction. *Health: An Interdisciplinary Journal for the Social study of Health, Illness and Medicine, 11*(1), 87-108.
- Guise, J., McVittie, C., & McKinlay, A., (2010). A discourse analytic study of ME/CFS (Chronic Fatigue Syndrome) sufferers' experiences of interactions with doctors. *Journal of Health Psychology, 15*(3), 426-435.
- Haslam, S. A., Jetten, J., Postmes, T. & Haslam C. (2009). Social identity, health and well-being: An emerging agenda for applied psychology, *Applied Psychology: An International Review, 58*(1), 1-23.
- Heritage, J. C. (1984). *Garfinkel and ethnomethodology*. Englewood Cliffs: Prentice-Hall.

CFS/ME EXPERIENCES

- Hogg, M. A., & Abrams, D. (1988). *Social identifications: A social psychology of intergroup relations and group processes*. London: Routledge.
- Hogg, M. A., Terry, D. J., & White, K. M. (1995). A tale of two theories: A critical comparison of identity theory with social identity theory. *Social Psychology Quarterly*, 58, 255-269.
- Horne, J. & Wiggins, S. (2009). Doing 'being on the edge': Managing the dilemma of being authentically suicidal in an online forum. *Sociology of Health and Illness* 31(3), 170-184
- Horton-Salway, M. (2001). Narrative identities and the management of personal accountability in talk about ME: A discursive psychology approach to illness narrative. *Journal of Health Psychology*, 6(2), 247-259.
- Horton-Salway, M. (2002). Bio-psycho-social reasoning in GPs' case narratives: The discursive construction of ME patients' identities. *Health: An Interdisciplinary Journal for The Social Study Of Health, Illness and Medicine*, 6(4), 401-421.
- Horton-Salway, M. (2007). The 'ME bandwagon' and other labels: Constructing the genuine case in talk about a controversial illness. *British Journal of Social Psychology*, 46(4), 895-914.
- Jashinsky, J., Burton, S. H., Hanson, C. L., West, J., Giraud-Carrier, C., Barnes, M., & Argyle, T. (2014). *Crisis: Journal of Crisis Intervention & Suicide*, 35(1), 51-59.
- Kelly, M. (1992). Self, identity and radical surgery, *Sociology of Health and Illness*, 14, 390-415.

CFS/ME EXPERIENCES

- Larun, L., & Malterud, K. (2007). Identity and coping experiences in chronic fatigue syndrome: A synthesis of qualitative studies. *Patient Education and Counseling* 69, 20–28.
- Lawton, J. (1998). Contemporary hospice care: The sequestration of the unbounded body and 'dirty dying', *Sociology of Health and Illness*, 20, 121-43.
- Lamerichs, J. & te Molder, H. F. M. (2003). Computer-mediated communication to a discursive model. *New Media Society*, 5(4), 451-473
- Leite, J. C. d. C., Drachler, M. d. L., Killeit, A., Kale, S., Nacul, L., McArthur, M., & Poland, F. (2011). Social support needs for equity in health and social care: a thematic analysis of experiences of people with chronic fatigue syndrome/myalgic encephalomyelitis. *International Journal for Equity in Health*, 10, 1-17.
- Lombaard, A. & Mouton, J. (2005). Chronic fatigue syndrome, the body and the self: *A South African Journal of Psychology*, 35(2), 286-307.
- McElhinney, E., Cheater, F. M., & Kidd, L. (2014). Undertaking qualitative health research in social virtual worlds. *Journal of Advanced Nursing*, 70(6), 1267-1275.
- National Institute for Health and Clinical Excellence 2007). *Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): Diagnosis and management*. London: NICE
- Nimrod, G. (2012). From knowledge to hope: Online depression communities. *International Journal on Disability and Human Development*, 11(1), 23 30.

CFS/ME EXPERIENCES

O'Brien, M. R., & Clark, D. (2012). Unsolicited written narratives as methodological genre in terminal illness: Challenges and limitations, *Qualitative Health Research*, 22, 274- 284.

Parsons, T. (1951). *The social system*. London: Routledge & Kegan Paul

Potter, J., & Wetherell, M. (1987). *Discourse and social psychology: Beyond attitudes and behaviour*. London: Sage.

Potter, J. (1996). *Representing reality: Discourse, rhetoric and social construction*. London: Sage.

Potter, J. (2004). Discourse Analysis as a way of analysing naturally occurring talk. In D. Silverman (Ed.), *Qualitative research: Theory, method and practice*. (pp.200-221). Thousand Oaks, California: Sage

Schwarzer, R. (1992). Self-efficacy in the adoption and maintenance of health behaviors: Theoretical approaches and a new model. In R. Schwarzer (Ed.), *Self-efficacy: Thought control of action* (pp.217-243). Washington, DC: Hemisphere.

Seale, C. (2002). Cancer heroics: A study of news reports with particular reference to gender, *Sociology*, 36, 107-126.

Seale, C. (2001) Sporting cancer: Struggle language in news reports of people with cancer. *Sociology of Health and Illness* 23(3), 308-329.

Smithson, J., Sharkey, S., Hewis, E., Jones, R.B., Emmens, T., Ford, T., & Owens, C. (2011). Membership and boundary maintenance on an online self-harm forum. *Qualitative Health Research*, 21(11), 1567-1575.

CFS/ME EXPERIENCES

- Söderlund, A., Skoge, A. M. & Malterud, K. (2000). 'I couldn't lift my arm holding the fork...': Living with chronic fatigue syndrome. *Scandinavian Journal of Primary Health Care*, 18(3), 165-167.
- Tajfel, H., & Turner, J. C. (1979). An integrative theory of intergroup conflict. In W. G. Austin & S. Worchel (Eds.), *The social psychology of intergroup relations* (p. 94-109). Brooks-Cole.
- Travers, M. K., & Lawler, J. (2008). Self within a climate of contention: Experiences of chronic fatigue syndrome. *Social Science & Medicine*, 66, 315-326.
- Tucker, I. (2004). 'Stories' of chronic fatigue syndrome: An exploratory discursive psychological analysis. *Qualitative Research in Psychology*, 1(2), 153-167.
- Turner, J. C. (1985) Social categorization and the self- concept: A social cognitive theory of group behavior. In E. J. Lawler (Ed.), *Advances in group processes* (Vol. 2, pp. 77-122). Greenwich: JAI Press
- Turner, J.C., Hogg, M.A., Oakes, P.J., Reicher, S.D. & Wetherell, M.S. (1987). *Rediscovering the social group: A self categorization theory*. Oxford, UK: Blackwell.
- Vayreda, A. & Antaki, A. (2009). Social support and unsolicited advice in a bipolar disorder online forum. *Qualitative Health Research*, 19, 931--941.
- Ware, N. (1998). Sociosomatics and illness course in chronic fatigue syndrome. *Psychosomatic Medicine*, 60, 394-401.

CFS/ME EXPERIENCES

- Wetherell, M., & Maybin, J. (1996). The distributed self: A social constructionist perspective. In R. Stevens (Ed.), *Understanding the Self*. (pp.219-280). London: Sage.
- Wetherell, M. (2007). A step too far: Discursive psychology, linguistic ethnography and questions of identity. *Journal of Sociolinguistics*, 11(5), 661-681.
- Whitehead, L. (2006). Towards a trajectory of identity reconstruction in chronic fatigue syndrome/myalgic encephalomyelitis: A longitudinal qualitative study. *International Journal of Nursing Studies*, 43, 1023-1031.
- Whitehead, L. C., (2006a). Quest, chaos and restitution: Living with chronic fatigue syndrome/myalgic encephalomyelitis. *Social Science and Medicine*, 62(9), 2236-2245.
- Wilkinson, S., & Kitzinger, C. (2000). Thinking differently about thinking positive: A discursive approach to cancer patients' talk. *Social Science Medicine*, 50(6), 797-811.
- Willig, C. (2008). *Introducing Qualitative Research Methods in Psychology*. Maidenhead: Open University Press.
- Xu, S., Yoon, H-J. & Tourassi, G. (2014). A user-oriented web crawler for selectively acquiring online content in e-health research. *Bioinformatics*, 30(1), 104-114.
- Young, S. D., & Jaganath, D. (2013). Online social networking for HIV education and prevention: A mixed-methods analysis. *Sexually Transmitted Diseases*, 40(2), 162-167.

CFS/ME EXPERIENCES

Ziebland, S. U. E., & Wyke, S. (2012). Health and illness in a connected world: How might sharing experiences on the internet affect people's health? *Milbank Quarterly*, 90(2), 219-249.

CFS/ME EXPERIENCES

Appendix A: Ethical Approval Letter

From: apache@exeter.ac.uk <apache@exeter.ac.uk> on behalf of Ethics Approval System
<D.M.Salway@exeter.ac.uk>

Sent: 13 February 2013 05:40

To: Kennedy, Alice

Subject: Your application for ethical approval (2013/325) has been accepted

Ethical Approval system

Your application (2013/325) entitled Constructing the experience of CFS/ME through interactions in online forums has been accepted

Please visit <http://www.exeter.ac.uk/staff/ethicalapproval/>

Please click on the link above and select the relevant application from the list.

Appendix B: Researcher Posts to Researcher-Initiated Thread

23 May 2013

Hello,

My name is Alice Kennedy and I'm undertaking a research study into use of online forums about ME/CFS.

The research aim is to explore people's use of online forums about ME/CFS. I hope this study will better help healthcare staff understand the issues facing those with ME/CFS and their experiences of trying to access help or treatments in the NHS or elsewhere. The study will also explore the effects of ME/CFS on people's lives, activities, relationships, their identity and how people talk about their experience of illness.

The data from posts will be combined with other participants' posts as part of a study to appear in scientific journals. Where appropriate, the results of the study will also be presented at healthcare and scientific conferences. You will not be identified in any report, presentation or publication.

The research will make use of posts on the forum that are publically available and can be viewed by anyone. This won't include posts in sections of the forum where people have to register to view the threads. All posts are anonymised, with names or any forum pseudonyms changed. Other details such as age or location will also be changed. Anonymised quotes from parts of posts may be used.

However, I would like to offer the opportunity for anyone to request their posts be excluded from the study. If you would prefer your posts be excluded, please e-mail me with your forum name/pseudonym within the next month (i.e. before 24 June) at ack211@exeter.ac.uk.

The research is part of a Doctorate in Clinical Psychology at the University of Exeter. The study is supervised by Dr Janet Smithson and the study has been given ethical approval by the University of Exeter.

Please ask me if there is anything that is not clear or if you would like more information.

Thank you for taking the time to read this.

Kind regards

Alice Kennedy

Trainee Clinical Psychologist

CFS/ME EXPERIENCES

28 May 2013

Hello,

Thank you to everyone who has taken time to read this thread and reply.

The research will look at retrospective posts on this forum over a six-week period or longer if more data is needed. Posts by those who have opted-out via e-mail or on this thread will be excluded. All forum user names (including pseudonyms) and any other identifying information will be changed.

There is a lot of interest in the health and medical worlds about online forums where people talk about their experiences. Research into forums is a way of taking people's concerns and experiences seriously, including those whose condition means they do not have the health or energy to take part in other forms of research.

I am training to be a clinical psychologist and this research study forms part of my doctorate in clinical psychology. As part of my training I also work in the NHS.

If you have any more questions about this research please do e-mail me at ack211@exeter.ac.uk

Thank you again for your interest and I appreciate all your comments.

Alice Kennedy

Trainee Clinical Psychologist

Appendix C: Responses to the Researcher-Initiated Thread

The researcher started a new thread on the forum with a post outlining the research and the option to opt out. This elicited 42 replies (the largest number of posts in any thread analysed) and a variety of views ranging from opposition to hopes that the research would mean greater awareness of CFS/ME and that sufferers would be recognised and acknowledged.

Those with CFS/ME are portrayed as socially isolated; Extract 1 illustrates the frequently held belief that those without CFS/ME cannot offer sufficient support:-

Extract

1. I have found this forum very friendly and supportive as while our
2. symptoms may be different the one thing in common is CFS/ME. There
3. is always advice and guidance from someone when you post a
4. question/query. On a personal note I have had ME for 15 years but only
5. recently reached out and joined the Forum as I don't know anyone else
6. with this condition and it's lovely not to feel so isolated.

. The forum becomes an ingroup where “people feel freer to open up and chat” because posters are “not professionals judging them”, the outgroup.

Advice being “always” available suggests a pervading truth. The forum’s social values and sense of community are framed as transcending differences between posters; a shared CFS/ME social identity is being defined and taking primacy over individual differences. The sense of belonging reduces isolation.

Other replies gave information posters felt important to convey to a researcher and highlighted the problematic nature of the condition through descriptions of symptoms and severity of individuals’ CFS/ME.

Other posters feared judgement and lack of understanding from the researcher. One opted-out poster asked for further details and reinforced a

CFS/ME EXPERIENCES

developing minority group opposing research. Another commented, “I dont doubt that Alice is sunning herself in her garden, not lying on bed with the severest flu ever day in and day out”. The researcher is positioned as an outsider with the figure of speech “sunning herself” deployed to contrast with and so strengthen the severity of the poster’s experience of CFS/ME. The vivid imagery conveys the serious impact of the illness (Guise et al., 2007). The next poster suggested the researcher must have “had this plague herself or knows someone close who does”. The “sunning herself” comment was thus countered by suggesting the researcher might herself be affected by CFS/ME and thus a group member. Again, the discourse of whether someone belongs to the forum or is an outsider, someone without CFS/ME, appears fundamental.

Another wrote, “I just feel strongly and passionately that this aspect of research is hugely unrecognised/underestimated/undervalued as a CONTRIBUTORY element to ...[ameliorating]...the wearing down....physically and emotionally”, framing research as a way to gain recognition for the condition, with lack of recognition exacerbating ill-health. Constructing CFS/ME as misunderstood could be a response to delayed diagnoses, mis-diagnoses, failed treatments and to the misconceptions of people without experience of CFS/ME. Research was thus constructed as seeking meaningful truth about people’s experiences and as a useful way to reach a wider audience.

Posters also used this thread to explain their wishes. One wrote, “...perhaps we can tell you, Alice, what messages we'd like professionals to get” followed by expressing dissatisfaction with NHS treatments, diagnostic tests and co-existing conditions being ignored. The poster conveyed feeling neglected and rejected by the NHS and that people with CFS/ME are not currently being heard and need a voice.

CFS/ME EXPERIENCES

The research was thus reframed as a means of communication to the healthcare system. Another poster stated, "...the main thing we all want is for the medical profession to stop trivializing the illness and underestimating the devastating effects it has". Construction of CFS/ME as serious and "devastating" offers a counter-discourse to that questioning the legitimacy of CFS/ME.

There were no overt attempts to urge other posters to opt out or not. Some posted several times before deciding whether to opt out, suggesting the process of deciding was multi-staged and that interacting with others about the issues was useful towards deciding. One opting-in poster stated that forum members had been "stung in the past" by research, and another stated that previous research had made them ponder the vulnerability to scrutiny of open forums.

Appendix D: Reflexive Analysis

I was drawn to researching people's illness experience from my interest in how they negotiate important transitions in their life stories. I was influenced to choose CFS/ME as a few close friends have experience of this illness. Our conversations over the years have included discussing their way of life before illness onset and how life necessarily changed owing to their symptoms. During this research I needed to be mindful of how my existing ideas might affect my interpretation of data and guard against this through re-examination of data through multiple re-reading and discussions with the research supervisor and a group of other qualitative researchers.

Initially, I found the data review challenging. I previously thought of analysis as being a set of statistical techniques or set qualitative method guidelines that can be applied and reproduced. For me, discourse analysis has some similarities to my clinical work. When in a therapeutic conversation with a client, I do not presume an objective truth is being told but, instead, attend both to the content (what is said and what is not said) and to how it is said in order to gain an understanding and sense of the person. However, in therapy, I can form hypotheses, ask further questions and can, jointly with the client, amend our understanding over a course of several sessions. In contrast, during this research I have needed to remain faithful to the data, balancing this with the need to interpret and not just describe it (Antaki, Billig, Edwards & Potter, 2003).

An area that has required much reflection during the research process was my interaction with forum users. I was sensitive to the potential for disrupting a community through the act of observation and when the results were disseminated. I

CFS/ME EXPERIENCES

did not wish to be an exploitative voyeur but instead attempt to understand the experience of CFS/ME from the perspective of the people using the forum. To neglect the results by not disseminating them or to disseminate them without due consideration to the feelings of forum users would seem unethical. I was very aware that I was an outsider looking in. As some posters commented, they had felt “used” by research in the past. I have attempted to take a stance of respectful observer towards the posters, without whom this research would not have been possible.

Appendix E: Dissemination Plan

Careful consideration will be given, by the researcher and the supervisor, to deciding how to sensitively feed back the results to the forum. A short and accessible report will be written to share with forum users.

Results will be presented to colleagues and University staff and the research will be submitted for possible publication in “Qualitative Health Research”, a peer-reviewed monthly journal that aims to enhance healthcare and further the development and understanding of qualitative research in healthcare settings.

Appendix F: Qualitative Health Research: Instructions for authors

“Qualitative Health Research” welcomes submissions on the methodological diversity and multi-disciplinary focus of qualitative research within the social sciences.

The guidance from p.8 of the “Qualitative Health Research” manuscript guidelines is reproduced below.

General Information

This section of the Guidelines covers matters of QHR journal style, which are not subject to author preference; adherence is required.

Note: If you still have questions after carefully reading these instructions, please refer to the sample manuscripts (there are several types) beginning on page 35 before contacting the QHR office.

Important Considerations

- Qualitative Health Research is a peer-reviewed journal. Only complete, finished manuscripts should be submitted for consideration.
- We do not publish stand-alone abstracts, quantitative studies, manuscript outlines, pilot studies, manuscripts-in-progress, letters of inquiry, or literature reviews. Research articles must be pertinent to health
- Write both the abstract and the text of your manuscript in first-person, active voice.
- For best results, review this entire document prior to preparing and submitting your manuscript.

CFS/ME EXPERIENCES

- Proper manuscript preparation will speed the peer-review process for your manuscript, and will facilitate a smoother production process if it should be selected for publication.
- Improper manuscript preparation could result in burdensome revisions, lengthy delays in the review and production processes, and the possible rejection of your manuscript.

General Style

We ask authors considering submission to QHR to review these guidelines, survey several issues of the journal, and make their own decision regarding the “fit” of their article for QHR’s mission.

Please refrain from writing or calling to ask if we are interested in your particular manuscript or idea. In general, QHR adheres to the requirements of Sage Publications, Inc., and the guidelines contained in the Publication Manual of the American Psychological Association [“APA”], 6th edition (ISBN 10:1-4338-0561-8, softcover; ISBN 10:1-4338-0559-6, hardcover; 10:143380562, spiral bound), with regard to manuscript preparation and formatting. Elsewhere in these Guidelines this book is referred to as the APA Publication Manual, or just APA. Additional help may be found online at <http://www.apa.org/>, or search the Internet for “APA format.” Many universities and private organizations have Web sites devoted to APA style. However, when guidelines found on those sites, or in the APA Publication Manual, conflict with QHR Guidelines, you must follow the QHR Guidelines.

Manuscript Preparation (pp.21-28)

Elements of a Manuscript

The following elements are required for each manuscript, and should be compiled in the following order:

CFS/ME EXPERIENCES

- Title page Submit the title page as a separate document.
- Abstract The abstract is placed on page 1 of the main document.
- Keywords Place the keywords below the abstract, on the same page.
 Leave a (double-spaced) blank line between the abstract and
 the keywords.
- Main manuscript The main text of the manuscript begins on page 2 of
 the main document.
- References References begin on a new page, after the end of the
 manuscript text, or after the notes, if any (do not submit
 references in a separate document).

The following elements are ***optional***, and may be included in your submission:

- Notes Place notes (also known as endnotes) after the main
 text, before the first page of references.
- Table: Place tables, one per page, at the end of the main manuscript
 document, after the references (do
 not submit tables as separate documents).
- Figures Submit each figure in a separate document, in order, by
 number.
- Appendices Appendices are published only at the editor's discretion. Place
 any appendices after the reference list, and before any tables
 (place them before the bios in accepted manuscripts).

Preparation of Manuscript Elements

A maximum of four (4) types of documents should be submitted: (a) title page; (b) main manuscript; (c) figures (if any); and (d) permissions (if needed). Despite what the online submission system (Scholar One Manuscripts / Sage Track) might

CFS/ME EXPERIENCES

allow, do not submit such elements as abstracts, references, and tables in separate documents. Be sure to refer to the sample manuscripts, beginning on page 35.

Title Page

The title “page” may be longer than one page. To maintain author anonymity during peer review, it is submitted as a separate document. Title page information should not be included in the main manuscript document.

Do not format a running header. The title page should include the following, in this order:

Article title A title should convey, as clearly and succinctly as possible, the main idea, focus, or content of a manuscript. It should be clear in meaning even when standing alone.

Make your title 10 to 12 words (or fewer) in length; avoid long, “wordy” titles.

Avoid titles with colons or quotations unless they are necessary to convey an important concept or idea in the article.

Type your title in Title Case; this means you should:

- capitalize the (first letter of) the first word
- capitalize all important words
- capitalize all words that have four (4) or more letters
- capitalize the first word after a colon (:), period (.), or em dash (—)

Author names List the name (not just initials) of each author, without credentials, in order, horizontally across the page.

If there are two authors, list them as follows: Janice M. Morse and
Author Two

CFS/ME EXPERIENCES

If there are three or more authors, list them as follows: Janice M. Morse, Author N. Two, Writer Three, and Fourth Author (and so forth)

After each name (or after the comma following a name, if applicable), use a superscript number to link that particular author with his or her primary affiliation (see the section on author affiliations, below).

Author affiliations Using the same superscript numbers as used with the authors' names (see above), list only the primary affiliation of each author, not multiple affiliations (see the sample manuscripts).

Spell out all city, state, and country names (exception: use USA instead of United States). Spell out any organization or institution names (for example, University of Utah instead of U of UT, or World Health Organization instead of WHO).

Corresponding author information Use only the following format for the corresponding author information, and , do not include any information that is not listed below. List information only for the individual who should be contacted by readers after (if) the article is published. Note that this should be a complete mailing/postal address. Example:
Janice M. Morse, University of Utah College of Nursing, 10 S. 2000 E., Salt Lake City, UT 84112-5880, USA Email: QHR-Editor@nurs.utah.edu

Author's / Authors' Note This is optional. This is the place to mention, perhaps, that portions of the article were presented at a professional meeting, or other information of that sort.

CFS/ME EXPERIENCES

Acknowledgments This is optional. The section is limited to two (2) or three (3) brief sentences. Overlong acknowledgments will be reduced at the copyeditor's discretion. Do not include long descriptions of persons being acknowledged, and do not include roles, titles, or credentials. Avoid phrases such as

We wish to thank, We would like to thank, and We want to thank; just use a simple, We thank, or We acknowledge

Declaration of conflicting interests You must use one of the following statements, in the **exact words** shown below.

If you have no conflicts of interest (or potential conflicts of interest):

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

If you have conflicts of interest

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: [Then, in sentence form, list all specific author relationships with organizations and/or products that were declared].

Funding You must use one of the following statements, in the exact words shown below.

If you did not have financial support

CFS/ME EXPERIENCES

The author(s) received no financial support for the research, authorship, and/or publication of this article. If you did have financial support

If you did have financial support

The author(s) disclosed receipt of the following financial support for the research, authorship, and or publication of this article:

[Then list, in sentence form, all entities/organizations that funded the research and/or authorship].

Bios

Bios are simple and concise, 1-sentence statements about each author. Long bios will be reduced by the copyeditor. In this space you may include department or division names, and secondary affiliations (if any). Use only the format shown below for your bios. Note that primary credentials (the most importantly, with a limit of three per person; QHR does not publish long credential strings) and current positions (or affiliations or professional pursuits) are required.

Janice M. Morse, PhD, FAAN, is a professor and presidential endowed chair at the University of Utah College of Nursing in Salt Lake City, Utah, USA. [Template: Name, bolded, credentials, role or title, affiliation (here you may include department, school, division, and so forth), city, state or province (if any), country.]

Abstract and Keywords

The abstract should be placed at the top of page 1 of the main manuscript document. It should be a single paragraph, no more than 150 words in length, and

CFS/ME EXPERIENCES

briefly describe your article. It should not contain headings or citations, and should not be divided into sections. Place your keywords below the abstract, on the same page (see “Keywords,” above). Double space the entire abstract page (including the keywords). Briefly state the purpose of your research, the main findings, and your primary conclusions. Make sure the abstract is written in the first-person, active voice.

Main Manuscript

Note that the sample manuscripts beginning on page 35 are abbreviated for illustration purposes, and might not contain all optional elements that could be included in an actual manuscript. The sample articles contain all four heading levels. The main text of the manuscript begins at the top of page 2 of the document, immediately after the abstract page. Write your article in the first-person, active voice. The main text of the manuscript should be broken into appropriate sections by the use of section headings. Sections should flow in a logical sequence, and include, at a minimum, *Methods*, *Results*, and *Discussion* (these are all level-1 headings); other level-1 headings and subheadings may be used at the author’s discretion. The author may choose to use different names for the three main sections, but the basic content should be that which would appropriately fall under the headings of *Methods*, *Results*, and *Discussion*.

There are very specific requirements for the preparation of in-text citations; refer to the APA Publication Manual , 6th edition, for details. Every in-text citation should have a corresponding reference in the reference list—no exceptions.

During the review process, author citations should include only the word

CFS/ME EXPERIENCES

Author and the year: (Author, 2008). If and when the manuscript is accepted for publication, the missing information can be restored. Double space the entire manuscript document, except for text contained in figures. Use only U.S.-English spelling (except in the references, as appropriate, and for direct quotations from published written sources). Use U.S.-English translations of non-English quotations or excerpts. Use a minimum of two (2) heading levels. Attend to copyright regulations and permission requirements (required). Submit, at the time of manuscript submission, written permission for the use of any names, photographs, or copyrighted tables, figures, and/or text; written permission must come from the person(s) depicted in the photographs, or in the case of copyrighted work, from the copyright holder (which is not necessarily the author or the journal in which it is published; see page 7).

References

Note: Proper formatting of the reference list is the responsibility of the Author , NOT journal personnel.

The reference list (also known as a bibliography) should include complete references for the sources used in the preparation of your manuscript.

Every reference must be cited in the text.

The reference list should begin on a separate page (not in a separate document) following the last page of manuscript text (or after the notes, if any). Each type of reference (journal article, book, chapter in edited book, newspaper, online reference, and so forth) must be formatted in accordance with the precise guidelines contained in APA , 6th edition.

Elements such as listing order, spelling, punctuation,

CFS/ME EXPERIENCES

spacing, capitalization, and the use of italics or Roman (regular) font are as important as the content of the reference. Note that if an author has two or more initials, there should be spaces between the initials; incorrect = X.Y.Z.; correct = X. Y. Z.

References should be listed in hanging paragraph format (with indentations at ½ inch or 1.3 cm.), in alphabetical order by the last name of the first author; additional considerations might apply (see APA). The hanging paragraphs should be created by using Word's Format > Paragraph feature.

During the review process, author references in the reference list should include only the word "Author" and the year: Author. (2008). To prevent author identification during the review process, do not include the article title, journal name, or any other part of the reference. Do not place these references in alphabetical order in the reference list; place them at the very beginning or very end of the list. If and when the manuscript is accepted for publication, the missing information can be restored and properly placed.

Avoid the use of unnecessary references and lengthy reference lists.
Extensive bibliographies will not be published; articles should include only the "essential" or key references. If the author wishes to offer a secondary reference list (for example, references used in meta-analysis), it should be so stated in a note, and made available to readers by contacting the author directly. Do not include such a list in the manuscript document, but it may be submitted separately for purposes of review.

Use only the 6th edition of the Publication Manual of the American Psychological Association (APA) as your source of instruction for references (this is critically important). Translate non-English titles into English (see

CFS/ME EXPERIENCES

APA for instruction on how to do this). Reference and cite all other studies mentioned in the article. Test all Internet URLs (Web addresses) immediately before submission to ensure that they are accurate, and that the sites are still accessible; do this prior to submission of all revisions and accepted manuscripts, as well.

Appendices

Appendices are not encouraged, and are published only at the editor's discretion. If included, appendices should be placed in the main manuscript document following the reference list, and before any tables (place them before the bios in an accepted manuscript). Appendices must be referred to in the text

What You Should Not Do

Title page

- Do not type your title in ALL CAPITAL letters (this is especially important when entering the article title in the Scholar One Manuscripts/Sage Track system).
- Do not place a period (full stop) at the end of your title.
- Do not include unnecessary words, such as A Qualitative Study, A Doctoral Student's Investigation of, An Ethnographic Study, and so forth.
- Do not list secondary or additional author affiliations (departments, divisions, hospital units, and so forth).
- Do not use abbreviations (except USA).
- Do not include department or division names, or secondary unit names.

Abstract

- Do not include the manuscript title on the abstract page.
- Do not indent the first line of the abstract.
- Do not include citations.

CFS/ME EXPERIENCES

- Do not show the word count.
- Do not repeat text from the manuscript in the abstract.

Main document

- Do not include the manuscript title.
- Do not include any author-identifying information.
- Do not include participant identifiers (name, pseudonym, age, and so forth) except to identify a particular category of respondent (e.g., men aged 18 to 24; community professional; psychologist; and so forth), and even then, include identifiers only when necessary for reader understanding.
- Do not include names of specific study sites (hospitals, organizations, small towns or villages).
- Do not use any headings (such as “Introduction” or “Background”) at the beginning of the manuscript.

References

- Do not format the hanging paragraphs with hard returns (“enter”) and tabs.
- Do not submit the reference list as a separate document (except for lists such as meta-analysis references, as noted above).

Final Checklist for Submission

GOAL: To submit the perfect manuscript. This checklist is intended to facilitate the swift internal review of your manuscript prior to submission.

General Manuscript Preparation

Refer to the instructions contained in the QHR Manuscript Guidelines Review the section addressing QHR style, beginning on page 8.

Avoid common problems:-

- Refer to your article as an article, not as a paper or a study.

CFS/ME EXPERIENCES

- Avoid anthropomorphism. Neither your study nor your article conducted the research: you did. Neither your study nor your article considered, chose, utilized, explored, selected, or took any other type of action: you did. :

Checklist

- ❑ Consistently use the first-person, active voice in your writing.
- ❑ Be accurate and consistent with verb tense: things that happened, were written, or were said in the past should be written about in the past tense.
- ❑ Submit the title page as a separate document.
- ❑ Obtain (and submit) any needed permissions for use of copyrighted work and/or for the use of photographs/images.
- ❑ Obtain an informal peer review of your manuscript prior to submission (see the review criteria on page 55).
- ❑ Have your manuscript professionally edited prior to submission. If English is not your first language, make certain your editor is an expert in the English language.

Quotations

Read the instructions regarding quotations on page 14 of the QHR Manuscript Guidelines.

Avoid Common Problems

- Participant identifiers and/or codes included with quotations pose a potential threat to participant confidentiality; do not use them. Even pseudonyms should be used with caution, especially if it is possible for the reader to “track” multiple comments presented from a particular participant.
- Ellipses/ellipsis points (. . .) are to be used only to represent deleted words or phrases, and not pauses in speech.

CFS/ME EXPERIENCES

Checklist

- ❑ Set quotations of fewer than 40 words within regular sentences. Set quotations of 40 or more words as block quotes. (Use Word's "Word Count" feature.)
- ❑ Indent block quotes by ½ inch (approximately 1.3 cm.) from the left margin only. (Use Word's "Format > Paragraph" feature to create the indentation.)
- ❑ Type your quotations in 12-point Times New Roman font, double spaced. Do not use italics.
- ❑ Cite and reference all quotations taken from sources other than research participants, and include page numbers in the citations.
- ❑ If you add words of explanation or comment within quotations, place those words in [brackets] rather than (parentheses).
- ❑ Properly capitalize and punctuate all participant quotations.

References and Citations

See page 24 in the QHR Manuscript Guidelines. Follow the sixth edition of the APA Publication Manual.

Avoid Common Problems

- *APA* has stipulated a particular format for each specific reference type; be sure to use the correct format. Note that not all types of periodicals are referenced in the same manner as journal articles.
- References and citations should be prepared with exactness and attention to detail. The order of listing, spelling, punctuation, spacing, capitalization, and use of italic or Roman font are all important.

Checklist

CFS/ME EXPERIENCES

- ❑ Spell out all journal names, and provide complete page numbers (e.g., 172-185 rather than 172-85).
- ❑ “Blind” your personal (author) references and citations as noted in the above.
- ❑ Double check the spelling of all reference author names, and ensure that both spelling and years of publication are consistent between the reference list and the in-text citations.
- ❑ Provide English translations for all non-English titles (retain the original titles).
- ❑ Format your references in hanging-paragraph style and double line spacing. Indent the “hanging” text by ½ inch (approximately 1.3 cm.), using Word’s “Format > Paragraph” feature.

Tables

GOAL: To organize and present relevant data that would be too cumbersome or complex to write into the text. Our standard is space. If your material can be more efficiently presented as text, do not make a table. A table must not duplicate material already appearing in the text. Read the instructions for table preparation on page 29 of the QHR Manuscript Guidelines. Place each table on a separate page at the end of your manuscript document.

Avoid Common Problems

- The typesetting process removes all bullets from tables (whether numerals, letters, or dingbats); do not use them.
- The use of underlining, all uppercase (capital) letters, and italics can make a table look busy and cluttered, and can obscure important data. Use these features sparingly or not at all. Use bold font sparingly.

Checklist

CFS/ME EXPERIENCES

- ❑ To maintain anonymity, present participant characteristics in aggregate (group) form, and refrain from listing individual participant characteristics.
- ❑ Make sure your table has a minimum of two (2) columns, a minimum of two (2) rows, and a clear and concise heading for every column. Double space the table.
- ❑ Create your table in “portrait” orientation on the page, within the regular 1- (approximately 2.5 cm.) margins of the document.
- ❑ Give your table a clear, descriptive, and concise title.
- ❑ Place individual data items or grouped data in separate rows of the table, rather than placing multiple items in a single row.

Figures

Goal: To create useful and coherent figures that clarify complex concepts or accurately illustrate models and/or processes.

See the instructions for preparing figures on page 31 of the QHR Manuscript Guidelines. Make your figure simple, clear, and easy to read and understand.

Avoid Common Problems

- Put your efforts into presenting clear, meaningful data rather than “fancy” or artistic creations. Achieving simplicity, accuracy, and clarity should be your goals.
- Do not use shading, color, or bolded font.
- Too many lines and arrows, and especially lines and arrows that cross each other or cross text boxes, can lead to confusion and make a “muddle” of a figure, obscuring rather than revealing intended meaning.
- Do not use “heavy” or “bolded” lines and arrows.

Checklist

CFS/ME EXPERIENCES

- ❑ Prepare and submit each figure in a separate document.
- ❑ Create your figure to be read from left to right and from top to bottom.
- ❑ Arrange text boxes in an orderly fashion, making them no larger than necessary to contain your text.
- ❑ Make your lines and arrows the proper length, so their beginnings and endings join the cells and clearly indicate direction.
- ❑ Use single line spacing for the text, and place the text in a horizontal orientation so it is not necessary to turn the document to read the figure. 28
- ❑ Give your figure a clear and concise title or legend. Include any notes after the title or legend rather than placing them below the figure.
- ❑ If using a participant's artwork, be sure the lines are sufficiently distinct and dark enough to reproduce well if printed in the journal.