

CATHERINE. E. CLARK. BA Hons MSc.

INVESTIGATION INTO COGNITIVE BEHAVIOURAL THERAPY FOR
CHRONIC FATIGUE SYNDROME/ MYALGIC ENCEPHALOMYELITIS

Section A: A review of the qualitative literature on service users' and their families' experiences of psycho-social interventions for CFS/ME.

Word Count: 7,993 (438)

Section B: "A life I can cope with." A grounded theory exploration of CBT for CFS/ME.

Word Count: 7,999 (167)

Overall Word Count: 15,992 (16,597)

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

APRIL 2019

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

Acknowledgements

First and foremost, I would like to thank the participants in my study, who inspired me with their stories, determination and motivation to participate in the research. I would also like to thank my supervisors Sue and John whose expertise was invaluable. I feel very fortunate to have had such supportive and approachable supervisors. I would like to thank my parents whose support is never ending; thank you for always being interested in my interests. Lastly, thanks to Adam for the Saturday morning pep talks.

Summary

Section A is a systematic review exploring service users' and their families' experiences of psycho-social interventions for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME). A thematic analysis was completed on the qualitative literature to explore the experience of interventions, the intervention components perceived as helpful and unhelpful and facilitators and barriers to benefitting from interventions. Resulting themes are discussed and study methodologies critiqued. Clinical and research implications are discussed.

Section B presents the results of a grounded theory study of cognitive behavioural therapy (CBT) for CFS/ME, specifically focused on the changes experienced by service users and the therapy components and conditions perceived to facilitate these. Semi-structured interviews were conducted with 13 service users recruited via a specialist CFS/ME service. In contrast to the NICE guidelines, the model of CBT delivered in this service was not one of 'reconditioning' in which service users are supported to increase their activity; instead the goal was better adjustment to CFS/ME to improve quality of life. A theorised model of the therapeutic process is discussed, in which CBT led to participants feeling more able to cope with CFS/ME and experience increased acceptance of the condition. Clinical and research implications are discussed.

Contents

Section A

1. Introduction.....	13
2. Methodology.....	19
Systematic search protocol.....	19
Scope.....	22
Analysis.....	34
3. Results.....	34
Quality.....	34
Themes.....	36
Challenging experiences pre intervention.....	37
Helpful and unhelpful aspects of intervention.....	39
Content.....	39
Format.....	42
Facilitators and barriers to engagement.....	44
Practitioner.....	45
Fit between intervention and client illness models.....	47
Overcoming hurdles.....	49
External life circumstances.....	52
Responses to intervention.....	53
Satisfaction and symptoms.....	53
Positive responses.....	54
Negative responses.....	58
4. Discussion.....	59
Therapeutic change and intervention components.....	59
Limitations.....	61
Implications.....	62
Clinical.....	62
Research.....	62
5. Conclusion.....	63
6. References.....	65

Section B

1. Introduction.....	79
2. Methodology.....	83

Design.....	83
Recruitment.....	83
Participants.....	84
Procedure.....	86
Ethical Considerations.....	86
Data Analysis.....	87
Quality assurance.....	88
3. Results.....	89
Categories.....	92
Dealing with ongoing symptoms.....	92
Feeling safe and understood.....	93
Seeing myself and CFS/ME differently.....	94
Finding ways to move forwards.....	96
Lightening the load.....	99
A life I can cope with.....	100
Accepting the reality of CFS/ME.....	103
Having tools.....	105
Putting less pressure on myself.....	108
Doing more of what I value.....	111
4. Discussion.....	112
Fatigue outcomes.....	113
Psychological outcomes.....	113
A life I can cope with.....	113
Acceptance.....	115
Limitations.....	116
Implications.....	116
Clinical.....	116
Research.....	117
5. Conclusion.....	118
6. References.....	119
 Section C: Appendices	
Appendix A: Quality Guidelines.....	125
Appendix B: Table 4. Studies evaluated against quality criteria.....	129

Appendix C: Table 5. Part A additional quotes.....	137
Appendix D: Recruitment letter.....	142
Appendix E: Participant Information Sheet.....	143
Appendix F: Participant questionnaire.....	149
Appendix G: Consent form for participation.....	151
Appendix H: Project approval documents.....	152
Appendix I: Example memo on ‘acceptance’.....	165
Appendix J: Initial topic guide.....	169
Appendix K: Questions added to topic guide.....	171
Appendix L: Maps of participants’ experiences.....	172
Appendix M: Iterations of the model	176
Appendix N: Research diary extracts.....	180
Appendix O: Positioning statement.....	186
Appendix P: Respondent validation covering email.....	187
Appendix Q: Respondent validation findings and responses.....	189
Appendix R: End of study summary (participants).....	196
Appendix S: End of study notifications.....	198
Appendix T: Author guidelines.....	202
Appendix U: Table 3. Part B additional quotes.....	205
Appendix V: Example of coded transcript.....	233

List of tables and figures

Section A

Table 1. Study inclusion and exclusion criteria.....	20
Table 2. Studies included in the review.....	23
Table 3. Themes identified within the literature.....	37
Table 4. Studies evaluated against quality criteria.....	129
Table 5. Part A additional quotes.....	137
Figure 1. Flow diagram of the systematic literature search.....	21

Section B

Table 1. Participant demographic information.....	85
Table 2.1. Categories and sub-categories identified in the data.....	90
Table 2.2. Subcategories within category ‘dealing with ongoing symptoms’.....	92

Table 2.3. Subcategories within category ‘seeing myself and CFS/ME differently’	94
Table 2.4. Subcategories within category ‘finding ways to move forwards’	96
Table 2.5. Subcategories within category ‘lightening the load’	99
Table 2.6. Subcategories within category ‘a life I can cope with’	100
Table 2.7. Subcategories within category ‘having tools’	105
Table 2.8. Subcategories within category ‘putting less pressure on myself’	108
Table 2.9. Subcategories within category ‘doing more of what I value’	111
Table 3. Part B additional quotes.....	205
Figure 1. Model of theory.....	91

CATHERINE. E. CLARK BSc Hons MSc

Section A: A review of the qualitative literature on service users' and their families' experiences of psycho-social interventions for CFS/ME

Word Count: 7993 (438)

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

APRIL 2019

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

Abstract

Background: Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) is a chronic condition for which there is currently no cure. Psychosocial intervention outcomes for CFS/ME vary widely across individuals and studies. Previous reviews of qualitative studies on coping with CFS/ME have not focused on understanding the experience of interventions. This review therefore aimed to explore this issue.

Methodology: A systematic search for qualitative studies exploring service users' and their families' experiences of psycho-social interventions for CFS/ME revealed 13 studies. Analysis included a quality evaluation followed by a thematic analysis of the qualitative results sections of each study.

Results: The majority of papers were found to be of an acceptable quality, however some methodological flaws may limit the generalisability of findings. The review highlighted positive experiences such as feeling more able to cope post intervention. Negative experiences included exacerbation of symptoms and feeling invalidated and blamed. The review identified several facilitators and barriers to benefitting from interventions.

Discussion: Results highlighted that service users can experience a range of therapeutic gains following psychosocial interventions for CFS/ME. This was perceived to depend on the format, content, goals and implied illness model of the intervention. Further research is needed to generate a more detailed understanding of how intervention components and processes interact.

Keywords: Chronic Fatigue Syndrome/ME; psychosocial interventions; therapeutic change; qualitative research; review

Introduction

The terms Chronic Fatigue Syndrome (CFS), Myalgic Encephalomyelitis (ME), and, less commonly, Post Viral Fatigue Syndrome (PVFS) have all been used to describe a long-term condition characterised by persistent fatigue, and a range of neurological symptoms. There is currently no consensus as to whether CFS and ME are the same conditions (Brurberg, Fønhus, Larun, Flottorp, & Malterud, 2014), however, the hybrid term CFS/ME is used widely in the literature. There are several sets of diagnostic criteria for CFS/ME, sharing common features including fatigue after minimal exertion, pain, impaired memory, poor concentration and sleep difficulties. There is currently no medical test for CFS/ME and diagnosis is based on symptoms. The condition affects at least 0.4% of the population and is around 2.5 times as common in women than men (Jason et al., 1999). Currently there is no cure for CFS/ME. The condition can be highly disabling and in some cases people are bedridden for years (Lian & Lorem, 2017). Prognosis is poor; without intervention less than 10% of sufferers recover to previous levels of functioning and less than 30% return to work (Cairns & Hotopf, 2005). Many limit their activity levels, resulting in social isolation and loss of identity and self-esteem (Anderson, Jason, Hlavaty, Porter, & Cudia, 2012).

Symptom profiles, illness course and biological markers vary widely between people with CFS/ME. For example symptoms differ depending on speed of illness onset (Reyes et al., 1999) and illness trigger (Kennedy, Abbot, Spence, Underwood, & Belch, 2004). It has been suggested that the term CFS/ME may encompass a range of illnesses or illness subtypes (Jason, Corradi, Torres-Harding, Taylor, & King, 2005). This has implications for intervention, as outcomes may vary depending on underlying illness processes and 'recovery' may only be possible for certain patients.

There is no definitive understanding of the causes and possible disease processes in CFS/ME, which are likely to be multifactorial (Institute of Medicine [IOM], 2015). However, a few biological systems have consistently been found to be involved in the illness. Symptoms often follow bacterial and viral infections (Komaroff, 2000b) and biomarkers suggest the involvement of infection for many but not all sufferers (Buchwald, Wener, Pearlman, & Kith, 1997; Jason et al., 2005). Other factors implicated in the condition include abnormal immune response (Lorusso, et al., 2009), genetics (Kerr et al., 2008) and psychosocial factors such as periods of high stress (Salit, 1997). CFS/ME has been linked with changes in cerebral white matter, dysfunction of the cardiopulmonary, central nervous system (CNS) and neuroendocrine systems, including blunted responses of the hypothalamic-pituitary-adrenal (HPA) axis, a component of the stress hormonal system (Brurberg et al., 2014; Jason et al., 2005; Keller, Pryor, & Giloteaux, 2014).

'Fatigue' itself is also a complex phenomenon. Fatigue is one of a group of behavioural, psychological, and physiological changes collectively known as 'sickness behaviour'. Other changes include fever, increased pain sensitivity and a range of symptoms often classified as neurological or psychiatric, including depression, anxiety, anhedonia, decreased motivation, poor concentration, confusion and impaired memory (Andreasson et al., 2018; Harrison et al., 2009). A prominent theory in the field of psychoimmunology is that sickness behaviour is induced by an immune response involving pro-inflammatory cytokines (Harrison et al., 2009; Maes et al., 2012). Changes in the sensitivity of the immune system have been used to explain fatigue, as well as other medically unexplained symptoms (MUS) such as pain and nausea (Van Ravenzwaaij et al., 2010). This theory builds on evidence that the brain cytokine system can be triggered by non-immunological stimuli such as stress and trauma, as well as by infections. It suggests that if the cytokine system is activated either

repetitively or during the early stages of development, it can become sensitised. When sensitised, the system is quickly re-activated in response to a new stimulus and less likely to shut down after the stimulus has been eliminated. This state of activation then elicits sickness behaviours despite the absence of a threatening stimulus. There is a growing body of evidence for this theory (Van Renswaaij et al., 2010).

This theory may explain some of the psychological associations found in people with CFS/ME. People with CFS/ME are more likely to have personality traits such as “unhealthy perfectionism” (Deary & Chalder, 2010) and inflated responsibility (Nater, Maloney, Lin, Heim, & Reeves, 2012) and an “overactive” lifestyle (Van Houdenhove, Neerinckx, Onghena, Lysens, & Vertommen, 2001). One possibility is that certain personality traits predispose individuals to stress, triggering immune system sensitisation. Another theory is that CFS/ME is triggered by stress and arises from the same physiological processes as occur in ‘burnout’ (defined as a state of emotional exhaustion) (Jameson, 2016). There is evidence that burnout, CFS/ME and chronic pain are all characterised by dysregulation of the stress hormonal system. Specifically, sufferers of these conditions all exhibit a reduced response of the hormone cortisol, which acts as part of a negative feedback loop to suppress cytokine immune activity (Jameson, 2016). Thus, like immune sensitisation theory, burnout theory also implies that the immune and inflammatory systems have a role in the maintenance of fatigue.

The most prominent psychological theory of CFS/ME is however the ‘Cognitive Theory of CFS’ (Surawy, Hackmann, Hawton, & Sharpe, 1995). This suggests that CFS/ME is maintained by unhelpful beliefs about exercise and illness (e.g. ‘exercise makes symptoms worse’) which result in activity avoidance and subsequent changes in physiology (known as “deconditioning”). The model proposes that periods of overexertion and excessive focusing on symptoms also contribute to the maintenance of the condition. Evidence for the model

from cross-sectional analysis of people with CFS/ME is mixed (Vercoulen et al., 1998; Sunnquist & Jason, 2018; Song and Jason, 2005). In addition, de-conditioning does not explain specific endocrine and cardio-pulmonary abnormalities associated with CFS/ME (Jameson, 2016). A review by Wiborg and colleagues (2010) found that the improvement in fatigue following cognitive behavioural therapy (CBT) was independent of an increase in physical activity. Yet, the model continues to be widely cited to support the use of CBT and Graded Exercise Therapies (GET) interventions for CFS/ME. Explanations for CFS/ME have been a huge source of controversy and are often polarised into 'physical' or 'psychological' causes; people with CFS/ME typically strongly oppose the notion that their symptoms are maintained by their beliefs about the condition (Friedberg, 2016).

Interventions offered globally for CFS/ME include: complementary medicine; dietary modifications; immunological treatment; behavioural therapies such as CBT, GET and rehabilitation; psychotherapy; buddying/mentoring programmes and 'pacing' in which people learn to live within the limits of the illness, monitor energy levels and reduce activity when required (Chambers, Bagnall, Hempel, & Forbes, 2006; Goudsmit & Howes, 2008). In the UK, NICE (2007) recommends that people with CFS/ME of all severities be offered CBT, GET or 'activity management', all of which should involve gradual increases in activity. CBT should additionally incorporate assertiveness and problem-solving skills, reducing over-vigilance about symptoms and supporting adjustment to the diagnosis (NICE, 2007). GET should involve gradual increases in the duration and intensity of exercise until aerobic exercise can be achieved (NICE, 2007). NICE (2007) recommends that medication can be used to manage symptoms such as pain and nausea.

Meta-analyses (Larun L, Brurberg KG, Odgaard-Jensen J, & Price, 2016; Price, Mitchell, Tidy, & Hunot, 2008;) have suggested that both CBT and GET are more effective in reducing

fatigue than other therapies such as relaxation and pacing, or usual care. However, less than 50% of patients benefit, improvements are modest, and there is no robust evidence of long-term gains. In addition, these findings conflict with recent patient surveys in which symptom improvement was reported by only 8% of participants after CBT, 12% after GET and 44% after pacing therapy (Geraghty, Hann, & Kurtev, 2017). Intervention studies rarely report adverse effects, yet 74% of participants reported worsening of symptoms after GET and 18% after CBT (Geraghty et al., 2017). These discrepancies are an ongoing source of controversy. One patient association has advocated that interventions focused on better management of the condition, such as pacing, are more useful for CFS/ME than interventions whose primary goal is an increase in activity (M.E. Association, 2015).

Variation in outcomes across studies may reflect differences in research methodologies. Variation across individuals is likely to reflect differences in intervention delivery, physiological and psychosocial individual differences and the fit between the intervention and the individual. Studies have identified a range of factors predicting poorer outcomes following psychosocial interventions including older age, longer illness duration, depressive symptoms, being in receipt of benefits and lower cortisol levels (Bentall, Powell, Nye, & Edwards, 2002; Flo & Chalder, 2014; Roberts et al., 2010; Wearden, Dunn, Dowrick, & Morriss, 2012).

In addition, there are very few quantitative studies exploring psychological, rather than physical, outcomes following CFS/ME interventions, and no mediator or moderator studies in this area. Overall, therefore, there is much more to understand about how and why psychosocial interventions for CFS/ME work. Qualitative research takes an inductive approach and gives a voice to participants. It can therefore help to understand people in a wider context and generate a richer understanding of important factors and processes not

yet identified in a given area (Urquhart, 2013). Pinxsterhuis, Strand and Sveen (2015) conducted a meta-ethnography of qualitative studies aimed at identifying factors that promote coping with CFS/ME. Findings mirrored two earlier reviews of qualitative studies suggesting that people with CFS/ME often do not receive adequate support from the healthcare system and must learn to cope with the condition by themselves, using strategies such as pacing and balancing activities (Anderson et al., 2012; Larun & Malterud, 2007). All three reviews concluded that people with CFS/ME experience significant disruption to their identity. Three studies in Pinxsterhuis et al. (2015b) explored the experience of psychosocial interventions. Authors concluded that use of adequate coping strategies was facilitated by the psychological processes of accepting the condition and re-building identity. They noted, however, that the intervention studies rarely referred to these psychological processes. This may indicate that factors known to facilitate coping are not cultivated within current interventions. However, one quantitative study found that following CBT patients exhibited significantly increased acceptance (Brooks, Rimes, & Chalder, 2011). These possible therapeutic processes warrant further investigation within a comprehensive review of qualitative studies focused solely on the experience of psychosocial interventions. This review therefore seeks to explore the following questions:

1. What are service users' and families' experiences of psycho-social interventions for CFS/ME?
2. Which elements of the interventions were perceived as helpful and unhelpful and as promoting change? What elements could be improved?
3. What are the barriers and facilitators to benefitting from interventions?

Methodology

Systematic search protocol

A systematic search of PsychInfo, Ovid Medline and Applied Social Sciences Index & Abstracts (ASSIA) was conducted with the following search terms in the title, keyword or method:

- CFS or chronic fatigue* or Myalgic Encephalo* or post-viral fatigue syndrome

AND

- Intervention* or findings or interview* or focus group* or survey or qualitative* or mixed method* or mixed-method* or experience* or reflection* or perspective* or grounded theor* or thematic analys* or interpretative phenomenological analysis or IPA or discourse analys* or narrative analys*

Selection criteria used to identify relevant studies are provided in Table 1. Only qualitative papers were included in order to provide a rich and in-depth understanding of participants' experiences. Titles and abstracts were read and any articles which were clearly not relevant were excluded. The full texts of the remaining articles were retrieved, read and assessed against the inclusion criteria. The reference lists of articles meeting the inclusion criteria were then hand-searched for relevant articles, along with a search of the articles citing these papers. A diagram showing this process is displayed in Figure 1.

Table 1. Study inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
Studies in which participants are adults or children who identified as having, or met diagnostic criteria for CFS or ME or a mix of individuals with CFS or ME and their family members	
Studies in which participants have a diagnosis of CFS, ME or another fatigue diagnosis, but statistical analysis by authors demonstrates no major difference between qualitative themes in the data of the group of participants with CFS/ME and those with another fatigue diagnosis.	
Studies exploring participants' experience of psychosocial interventions for CFS	Studies of patient surveys which have not collected qualitative data.
Studies gathering qualitative data (includes mixed-method studies)	Studies in which the only qualitative data gathered is in end of group feedback forms.
Papers in English in a peer-reviewed journal or Theses, Dissertations, and Projects, with full text available via an academic institution.	Ethnographic studies in which qualitative data reflects researcher observations only.

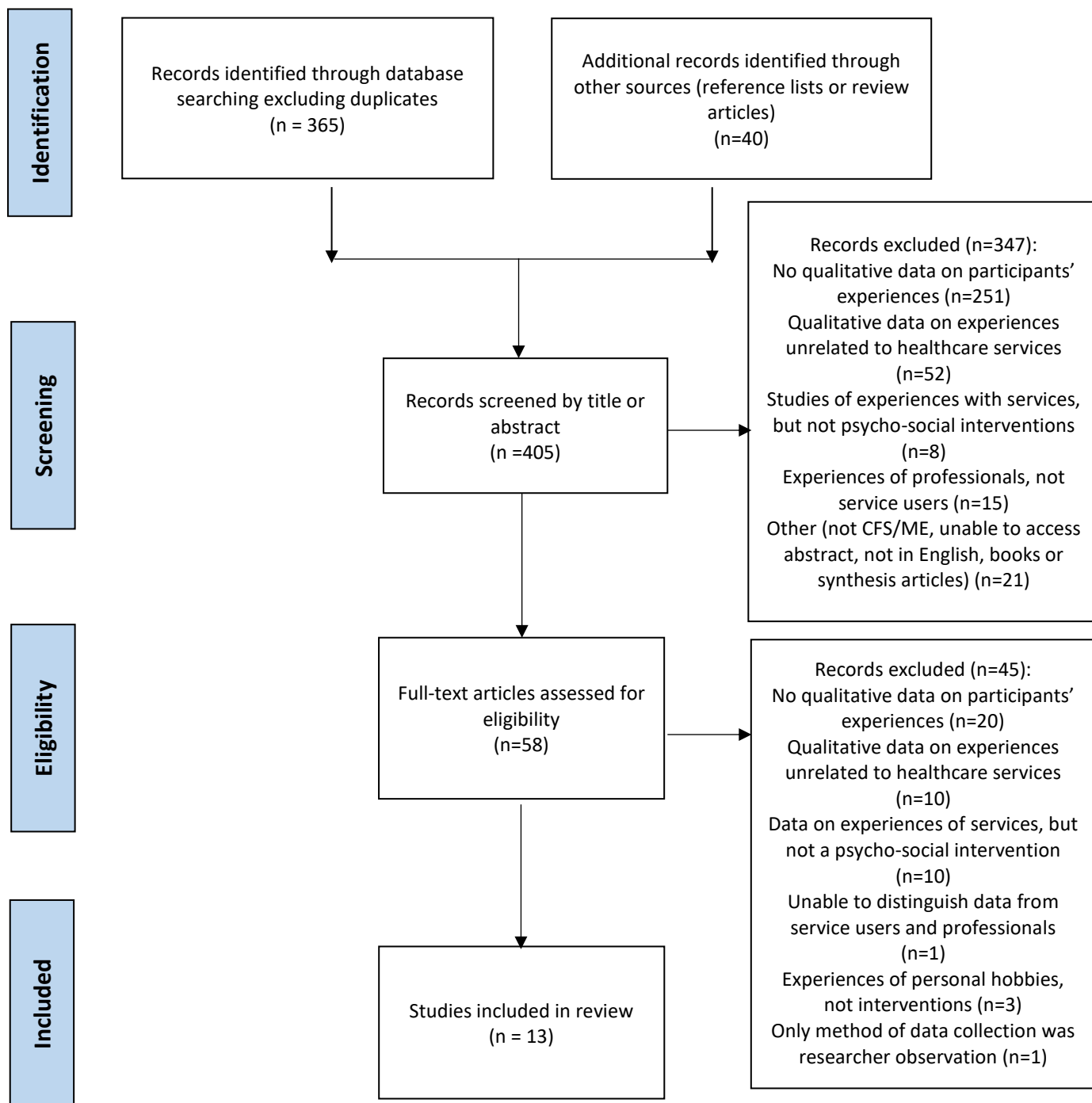


Figure 1. Flow diagram of the systematic literature search conducted, adapted from Moher, Liberati, Tetzlaff, Altman, & Prisma Group (2009).

Scope

Descriptive data were extracted using a data extraction form designed for this review. As shown in table 2, the 13 identified studies explored a range of psychosocial interventions. Three studies explored CBT-based interventions which aimed to gradually increase participants' activity levels. These interventions comprised education about managing energy. Two studies explored GET and other exercise rehabilitation therapies. Three studies explored interventions aimed at improving participants' self-management of CFS/ME, comprising education on pacing, exercise and relaxation techniques. One study explored the Lightning Process (LP) (Parker, 2018) which uses movement and cognitive restructuring to reduce stress. One study explored Acceptance and Commitment Therapy (ACT) and another explored Dance Movement Therapy (DMT) for CFS/ME. Two studies explored a range of counselling and psychotherapy interventions, including CBT. Five studies explored predominantly self-help based interventions. Two studies explored the experiences of young people and their families. Four studies explored the experience of group therapies.

Table 2. Studies included in the review

Study	Aim	Study design	Recruitment	Sample details	Intervention	Analysis method	Main findings	Main quality issues
1 Adamowicz et al (2017) USA	To identify change attributions offered by patients to explain changes in overall condition following a home self management intervention for severe CFS.	Mixed methods. Data from three month follow up post intervention. Quantitative: participant ratings on Patient Global Impression of Change (PGIC), (Friedberg & Sohl, 2009). Qualitative: participants' attributions for their PGIC ratings in telephone interviews using open questioning.	Randomized trial of a home-based self-management intervention (Friedberg, Adamowicz, Caikauskaite, Seva, & Napoli, 2016). 126 of the 137 participants in the trial included in this study (the remaining 11 not interviewed due to time constraints).	n=126 (114 female) Mean age 48.6 years. 54% on 'disability.' Mean illness duration 14.7 years. All met CFS criteria. Based on fatigue and physical functioning, participants severely ill (Friedberg et al., 2016) For this review only intervention data (n = 81), and not control included. Clinically significant improvements in fatigue for 24–28% of intervention compared to 9% of control group.	Fatigue self-management intervention with no clinical contact aimed at identifying and changing unhelpful beliefs and behaviours in order to achieve a balance between exertion and rest (increasing activity for some participants and reducing for others). Programme delivered by self-management booklet and audio CDs. Daily web diaries to identify baseline activities and symptoms.	Framework analysis (Ritchie & Spencer, 1994).	Intervention participants attributed symptom improvement to increased use of relaxation, better coping, more pacing, more physical activity and awareness of fatigue and behaviour, better sleep hygiene and dietary changes. No symptom change attributed to deteriorating health, not being able to comply with treatment or believing nothing could help. Worsening attributed to stress, life events, deteriorating health or worsening sleep.	LOW QUALITY + Sample well situated. + Two researchers involved in the main coding of themes but unclear how themes were categorised into 'active' or 'passive' styles. - Themes presented as single phrases not in context of quotes or further description, reducing meaning and resonance. - No reflection on researchers' position and orientations.
2 Blazquez et al (2010) Spain	To evaluate influence of dance movement therapy (DMT) on perception of well-	Mixed methods. Qualitative data: written reports from participants	Recruited 'randomly' from a university Physiology Department (no further details provided).	n=7 women (age 35- 55). All had duration of CFS > 1year.	Weekly one hour group DMT, and sporadic 1:1 DMT over 4 months. Intervention not described in detail but author states	"Organized the qualitative data into codes."	Participants reported: - sessions brought them happiness, relaxation, sense of	LOW QUALITY + Coding of raw data by two investigators and discrepancies

	being and functional capacity in women with CFS; and understand personal responses to the intervention.	after each session, therapist reports on participant oral feedback in-session and therapist notes on their post-session impressions.		All participants met either Holmes or Fukuda diagnostic criteria for CFS (Fukuda et al., 1994; Holmes, Kaplan, & Schonberger, 1993).	that DMT is based on theoretical interdependence between movement and emotion (Rossberg-Gempton & Poole, 1992) and describe key components as experimentation with the body to explore new ways of being and gain access to feelings that cannot be verbalized.		belonging and social support. - Sessions a secure environment; sense of trust in other group members. - Getting in touch with feelings they had not been aware of - Valued chance to express feelings via movement	discussed and resolved. - Themes are abstract in nature and lack close analysis of the quotes provided. - Results lack structure, coherence and detail, and do not resonate with reader. - Generally only positive comments reported, suggesting possible bias.
3 Cheshire et al (2018) UK	Explore the experiences of patients who have completed Guided Graded Exercise Self-help (GES), and differences between the experiences of those reporting an improvement compared with those reporting a deterioration in their condition.	Qualitative- face to face or telephone interviews	Recruited from standard medical care (SMC) and GES arms of GETSET pragmatic RCT (Clark et al, 2016). Participants were invited to participate if self-rated as improved or deteriorated on Clinical Global Impression change scale (Guy, 1976) after intervention. Those receiving GES had reduced fatigue (Chalder fatigue questionnaire (Chalder et al.1993)) and improved physical function (short form-36 physical function subscale ((McHorney, Ware & Raczek, 1993)),	Total n=19 (9 participants reported feeling “much better” and 10 “a little worse”) post intervention. n=17 female. Mean age 43 years for “a little worse” group and 39 for “much better” group. Median time since onset of CFS/ME 13 years for “a little worse” group and 4 for “much better” group. All had a diagnosis of NICE defined CFS/ME (NICE, 2007).	GES is based on GET principles but is self-management. Intervention: booklet describing self-management programme, which patients were encouraged to follow independently over 12 weeks with up to 4 support sessions with a physiotherapist experienced in delivering GET as a treatment for CFS/ME, who was trained to support and guide participants through booklet, but did not provide therapy.	Thematic analysis	- Similarities between “better” and “worse” groups in GES experiences - GES ‘hard work’ and some early dropout - Most initially noticed no change or exacerbation, which reduced motivation - Any improvement very gradual - GES best if fewer competing life commitments, and for lower functioning participants, as more capacity for exacerbation - Motivation impacted by	HIGH QUALITY + multiple quotes presented- very well grounded in examples. + Themes describe a comprehensive range of aspects of the therapy experience. + Coherently organised into themes and subthemes. - Only one researcher involved in coding raw data - Author orientations not described in detail.

			compared with SMC alone.				therapist understanding, activity choice, beliefs about GET, personal attributes and support networks. - The “better” group reported more facilitators to GES (e.g. significant-other support) and “worse” group more likely to report barriers, including greater symptom exacerbation and competing life commitments.	
4 Chew-Graham et al (2011) UK	To establish participants’ perspectives on the factors which are important for patient engagement in a Pragmatic Rehabilitation (PR) intervention.	Face to face semi-structured interviews at participants’ homes.	Drawn from patients participating in the FINE RCT (Wearden et al., 2006) of two nurse-led interventions for CFS across 44 primary care trusts. Sampling for this study was purposive to achieve mix of gender, age, postcode, duration of illness and level of functioning.	n=19 (13 female). Ages 23-61. Seven had marital status as single; 12 married or cohabiting. Suburban, rural, and inner city areas. Time since diagnosis 9 months to 16 years. All participants fulfilled Oxford inclusion criteria for CFS.	Five face-to-face sessions of PR in the patient's home with nurse therapist, interspersed with five 30-minute telephone calls. Authors describe PR as “a therapist facilitated self-management intervention for CFS/ME, which shares features in common with CBT and GET” (p113). PR conceptualises CFS/ME as a consequence of physiological dysregulation and deconditioning. Treatment involves	Thematic analysis	Factors impacting engagement: - Feeling believed, understood and accepted by therapist, which allowed positive relationship - Understanding and accepting reality and validity of symptoms and diagnosis - For some this reduced guilt and led to adjusting lifestyle - Acceptance of rationale for and	HIGH QUALITY + Sample purposively selected for mix of participants, including their beliefs about suitability of the treatment model + Data coding undertaken by five authors from different professional and academic backgrounds

					graded activity schedule with gradual increments. Clients given a manual.		feasibility of the treatment model	+ Many quotes provided to demonstrate themes.
					Participants in PR significantly improved fatigue but not physical functioning, compared with TAU but not maintained at 1 year follow up (Wearden et al 2010).			- No reflection on author orientations or beliefs.
5 Denmark (2017) USA	To explore the psychotherapy experiences of people living with ME/CFS, their opinions about their treatment and recommendations for psychotherapists working with people living with ME/CFS.	Mixed methods: online, anonymous survey that included space for qualitative comments.	A link to the survey was posted online and shared with participants by doctors specialising in ME/CFS and patient groups.	n= 169 (114 female, 14 male, 2 other, 39 not reported). Age range 18-90 (median age bracket 50-58). Country of residence: USA n=74 Australia n=19 UK n=12 Italy n=7 Other n= 12 Not reported n=45 Participants responded 'Yes' or 'Maybe' to the statement 'I have ME or CFS' (self-identification)	Not stated, but is clear from quotes that some practitioners were not specialists in ME/CFS. CBT is named as one of the models of psychotherapy undertaken.	'Analyzed for themes and subthemes'	Participants: - Brought grief and loss to therapy and could process it and accept. Others found discussion of acceptance unhelpful. - Valued finding meaning in new roles/identity and identifying strengths. - Valued listening and emotional support and validation. Unhelpful if providers deny biology of CFS or recommend over-exertion - common in CBT - Recommended practitioners be educated about CFS and make adjustments for symptoms.	HIGH QUALITY + Multiple quotes provided for each theme- very well grounded in the data. + A second reader reviewed themes and subthemes for validity. + Large sample size and breadth in participant demographics, capturing a diversity of experiences. - Details of the psychotherapy interventions received not included. - No reflection on researcher orientation

6 Dennison et al (2010) UK	To explore in detail adolescent patients' and their parents' experience of both family-focussed CBT and psychoeducation (PE) for CFS.	Qualitative - semi-structured interviews over the telephone	Recruited from the family focused CBT and psychoeducation arms of an RCT conducted around 3 years prior to interviews. The trial found that both interventions led to improvement in school attendance, fatigue, functional impairment and emotional and social responses.	n= 16 young people (10 female) meeting criteria for CFS. All White British. Ages 16-24. Seven participants had received CBT and nine PE. As part of trial the young people rated improvement and satisfaction with therapy outcome. 7 participants rated themselves 'very much better', 6 'much better', 2 'a little better', and 1 'about the same'. N=16 parents (one from each parent set). 14 mothers, 2 fathers, all White British. Nine participants had been involved in the CBT and 7 PE. 8 rated their child 'very much better', 3 'much better', 2 'a little better', and 2 'about the same'.	Family focused <i>CBT</i> : 13 one hour sessions of CBT every 2 weeks. Content included finding a balance between activity and rest, advising gradual increase in activity, establishing a sleep routine, addressing unhelpful beliefs e.g. about activity, and facilitating family communication. <i>Family psychoeducation</i> : four sessions over six months. Content was similar to CBT but did not include cognitive restructuring (Chalder, Deary, Husain, & Walwyn, 2010).	Inductive thematic analysis using constant comparison (Glaser & Strauss, 1967).	- Similar issues discussed in CBT and PE groups - Participants not expecting a magic cure and sought validation - Behavioural elements such as activity and sleep valued by many but unhelpful for others - Recognition, validation and emotional support important - Young people often found cognitive aspects of CBT less helpful as overemphasised psychological nature of CFS - Mixed feelings about family involvement in sessions - Views on helpfulness mixed - commonly modest improvement and regaining some sense of normality	MEDIUM QUALITY - No evidence of a second researcher auditing initial codes. + Coding blind to group allocation. - Some quotes provided, but the basis for some themes unclear. - Descriptions sometimes lacked detail and their meaning unclear in some instances. + Acknowledge position as health psychologists and CBT practitioners, but do not provide detail on orientation/beliefs
7 Friedberg et al (2016) USA	To identify and classify the types of personal attributions offered by patients to explain changes in their overall	Mixed methods. Data gathered at 3 month follow up post intervention.	Randomized trial of a 2-session behavioural self-management program for participants with CFS and unexplained chronic fatigue (UCF).	n=67 (55 female) 58.2% were diagnosed with UCF; 41.8% with CFS.	<i>Active behavioural self-management condition</i> : based on a modified version of a CBT protocol. Participants attended two individual sessions in which nurses provided education	Framework analysis (Ritchie and Spencer, 1994).	- Participants in intervention identified factors assisting improvement: increased awareness	LOW QUALITY + Analysis covers comprehensive range of factors relating to the phenomenon

	condition following a behavioural self management intervention and two control conditions.	Quantitative data: participant ratings on PGIC (Friedberg & Sohl, 2009). Qualitative data on participants' attributions for their PGIC ratings gathered in individual face-to-face interviews using open questioning.	67 of the 90 participants in the trial were included in this study (the remaining 23 were not interviewed due to time constraints).	Mean age 43.6 years. 52 percent working f/t, 16 percent unemployed. Mean illness duration 9.8 years. PGIC ratings revealed modest or no change for most patients. For this review only data from participants in intervention (<i>n</i> = 21), and not control conditions included.	about diagnosis, factors and behaviours which play a role in symptom exacerbation ('doing too much or too little') Participants assigned a self management booklet and daily web diary and supported with scheduling activities based on the information recorded- for some participants this involved gradual increase in activity levels, for others goals were set around pacing activity and introducing more pleasurable activity.		of fatigue and behaviour, increased use of relaxation and better coping, reduced activity/ increased rest, increased physical activity, improved sleep hygiene and increased pleasant activities. A few attributed improvements to specific life events and dietary supplements. - No change attributed to not being able to comply with treatment or believing nothing could help. - Worsening attributed to stress, life events or the course of illness.	- However, themes presented as single phrases without supporting quotes or further description. Reduces meaning and resonance. - 17 themes standalone themes not organised into categories
8 Gladwell et al (2014) UK	To explore the experiences of people with CFS/ME of rehabilitation therapies including GET, Exercise on Prescription (EoP) and Graded Activity Therapy (GAT).	Analysis of qualitative survey data in which respondents were encouraged to write about their experiences of the rehabilitation therapies, to build a picture of what	The 2010 Action for ME survey of rehabilitation therapies	<i>n</i> =76 (62 female) who started rehabilitation during or after 2008 (date selected due to NICE guidelines for GET 2007). Respondents self-identified as having	Participants had received one of three rehabilitation therapies: GET, Graded Activity Therapy (GAT), or Exercise on Prescription (EoP), in a range of clinical settings (e.g. at home, GP surgeries, hospital outpatient departments).	Thematic analysis	- Participants highlighted importance of therapist being supportive, believing in the illness and taking an individualised approach to goals	HIGH QUALITY + Very well grounded in the data with quotes to support each construct. + Participant's intervention and self-reported

		was helpful and unhelpful about the therapies.		a diagnostic label of CFS, ME or PVFS. 72% reported illness onset in previous 10 years. 28% reported feeling better after therapy; 22% unchanged and 51% worse (figures presented in study do not add up to 100%). [Probably rounding error] Age range of participants unclear.	Authors describe GAT as an approach in which “activities are selected, adapted and graded for therapeutic purposes to promote health and well-being.” (p. 388) Authors describe EoP as an intervention in which “a GP or practice nurse refers patients to leisure centres or gyms for supervised exercise programmes”. (p. 388)	- Routines, goal setting and pacing helpful - Learning about energy expenditure helpful and gave a sense of control - Challenges arose if therapist and client’s ideas about ME/CFS differed - Participants often felt pressured to comply with treatment - Many experienced lengthy adverse effects on symptoms - Participants felt blamed for lack of improvement	improvement provided with each quotes, facilitating interpretation. + Authors analysed diversity of participant demographics and experiences to ensure breadth + Coding of raw data agreed upon by two researchers. - No reflection on researchers’ orientations or ideas.	
9 Picariello et al (2017) UK	Explore the experiences of patients with CFS who undertook CBT for CFS and in particular why some patients engage in treatment more than others, and to assess whether CBT meets patients’ needs.	Semi-structured interviews conducted either face to face or via telephone.	Recruited from a specialist service for CFS. Participants were invited to participate if they had finished CBT or were in the follow-up stage of CBT. 44% of those approached consented to participate.	N=13 (11 female). Age range 18-64 (median age range 25-34). 13 white, 2 Black or Black British. 8 reported being ‘very satisfied’ with CBT, 3 ‘moderately satisfied’, 1 ‘slightly satisfied’ and 1 ‘slightly dissatisfied’.	Up to 15 fortnightly CBT sessions, depending on progress. Sessions face-to-face CBT from experienced therapists, guided by a standardized CBT manual. Participants supported to manage sleep problems and gradually increase activity by identifying and challenging unhelpful cognitions standing in the way of behavioural change.	Inductive thematic analysis using techniques from the grounded theory qualitative analysis framework.	Participants noted: - Marked improvements in well-being - Valuing therapist lack of judgment, and contributing to session agendas - Engagement influenced by acceptability of psychological explanations and intrinsic motivation - Challenging to integrate CBT into daily schedule, but	MEDIUM QUALITY + Data coded by two authors who reached consensus and created a coding manual. - All subthemes supported by quotes. However, quotes do not always clearly demonstrate the construct described. - Themes are almost all positive

							no barriers to attending sessions. - Gaining insight into energy expenditure and managing it. - Behavioural elements appreciated more than cognitive - Attributions for CFS varied - many acknowledged both physical and psychological explanations	(responses/helpful elements). Authors note potential bias in sample. - No detail on the duration of CFS or level of functioning in the sample. - Some descriptions lack detail and clarity, reducing resonance. + Subthemes presented in a thematic diagram
10 Pinxsterhuis et al (2015a) Norway	To elicit participants' experiences with a multidisciplinary patient education programme and their views regarding the usefulness of the programme.	Focus groups conducted immediately and nine months following participation in the programme. Group facilitators used semi-structured interview guides.	Information about the study was disseminated to all participants in the CFS patient education programme during a set time period.	n= 10 (8 female). Age range 32–57 (mean= 43.7 years). Illness duration 2.5-13.5 years. One participant in employment. Physical functioning ranged significantly. 6 of 10 had higher education, 6 married or lived with a partner. All met Canadian diagnostic criteria (Carruthers et al., 2003) and/or the Centers for Disease Control and Prevention criteria	Patient education programme for people with CFS consisting of 8 weekly two hour sessions of information giving and group discussion, facilitated by health care professionals and peer counsellors. The programme was designed to promote better coping. Topics included: coping skills, current medical approaches, personal relationships, pacing and energy conservation, physical exercise and relaxation, nutritional approaches and economic self-sufficiency.	Thematic analysis	- Before programme participants experienced confusion about whether had CFS, prognosis and how to cope. Some had received no advice or advice with no follow up or unhelpful advice. - After programme participants reported better understanding of CFS and its prognosis and how to cope. After 9 months, all	MEDIUM QUALITY - Analysis was primarily conducted by only one researcher. + Most analysis supported by quotes. - themes were almost entirely positive. Authors note potential biases in sample which could skew results to be more positive - E.g. one researcher was involved in

				(Fukuda et al., 1994) for CFS.			increased acceptance of being unwell. - Participants felt better equipped to cope, particularly energy and activities. - No change in health reported. - Participants identified mediating factors for these improvements as better knowledge about CFS and managing energy, and exchanging experiences and feeling understood by other group members.	delivering the intervention + Themes well structured in a process model highlighting relationships. - Minimal reflection on researcher orientation
11 Reme et al (2012) UK	To explore the experiences of young people with CFS who had undergone the Lightning Process, beneficial and adverse effects of the intervention and participants' attributions of these.	Qualitative- Semi-structured interviews over the telephone. Supplementary interviews were conducted with the mothers of participants aged 18 and below (n=3). Basic additional clinical and demographic information was also obtained	Advert on the Website of a fundraising and support organization for young people with CFS.	N= 9 Young people between the ages of 14 and 26 years, and 3 of their parents. Based on a checklist completed by participants, 8 of 9 participants met UK criteria (Sharpe, 1991) for CFS prior to intervention. The other participant met UK criteria at time of study.	The Lightning Process is a 3-day training programme, typically paid for privately. Authors state that the Lightning Process aims to 'modify the brain's thought patterns to reduce stress-related hormones' (p2) and that 'it appears to share some broad commonalities with psychological therapies, particularly CBT' (p3). Participants are also taught to reduce their physical stress response by using	Inductive thematic analysis (Yardley & Marks, 2004). In addition, two case histories of contrasting examples constructed by re-writing the two interviews into narratives,	- Treatment was intense and taxing - Providing theory increased motivation to engage, but Information given often hard to understand - Practical exercises and learning 'the process' most helpful for symptoms	HIGH QUALITY + Very well grounded in the data- quotes to demonstrate most statements. + Analysis focuses on broad range of elements of the therapy experience. Inclusion of two detailed case studies helpful. - No verification of codes by a second rater or participants.

		(e.g. ratings of symptom improvement post treatment)		Duration of CFS from 2 to 12 years.	movement, posture, and coaching.	aiming to place therapy experience in the context of participants' lives more generally.	- Therapists generally encouraging, but often not open to critical questions - symptom improvement mixed - Criticism that staff suggest quick and/or guaranteed recovery	- Minimal reflection on authors' positions and state they are 'impartial'.
12 Roche et al (2017) UK	To assess the utility, feasibility and acceptability of Acceptance and Commitment Therapy (ACT) for individuals with CFS and ascertain which aspects of the intervention, if any, had promoted change and/or were useful from the participants' perspectives.	Mixed methods multiple single-case series. Qualitative data gathered via a change interview (Elliott, Slatick, & Urman, 2001) over the telephone.	From an established CFS service in the UK via written and verbal advertisement from the primary researcher and clinicians working within the service.	n=6 adults (5 females) aged 19-62. Duration of CFS symptoms 2-29 years. All had a diagnosis of CFS in line with CDC criteria (Fukuda et al., 1994). In discussion it is stated that participants reported "other health concerns and important external events", however further details absent. Participants recruited after standard service treatment of a 10	6 week guided bibliotherapy self-help intervention based on ACT principles (not tailored to be specific to CFS). Each week participants were encouraged to read a section of text from an ACT book and complete exercises. A researcher checked comprehension and adherence via a 10 minute weekly phone call.	"Quantitative data analysis was considered in conjunction with qualitative data from the change interviews" "In line with Elliott (2002), data from the change interviews were evaluated in terms of their congruence with data from the quantitative measures."	- Participants reported applying 'strategies' learnt from intervention (no details) - Participants made changes in their life e.g. work - Participants had increased direct efforts to increase valued activity e.g. physical and with family - Some attributed important changes to the intervention; others thought improvements would have happened naturally but that the intervention facilitated it. - Participants found the weekly nature	LOW QUALITY - No detail provided on method of analysis of the qualitative data. - Results not organised into themes - No quotes included so challenging to understand the basis for comments. - Results lack detail resulting in poor resonance + Triangulation with quantitative data - However, no evidence of checking of themes

				week group programme, based on psychoeducation inculcating a neurobiological model.			and cognitive demands of the intervention challenging, given CFS symptoms.	by a second rater or participants. - Intervention not described in detail.
13 Ward et al (2008) UK	Explore the perceptions of counselling interventions of people with ME, in particular what they found helpful and unhelpful and the kinds of issues which they discussed.	Qualitative- Semi-structured interviews over the telephone	Advertisements in the newsletters of the ME Association and the Action for ME user group.	n=25 adults (21 females) aged 23-65 who believed they had received a counselling intervention. Length of counselling varied from 8 weeks to 1 year, and included both NHS and private. All had received a formal diagnosis of ME from a medical practitioner. Length of illness from 2 to 19 years.	Counselling interventions: "In broad terms participants described four types of interventions aimed at managing their activity, stress or thoughts, or to examine the influence of the past on their current situation." (p. 75) Authors judged that from the data participants appeared to have had experienced CBT, person centred, psychodynamic and integrative/eclectic approaches. Predominant single approach was CBT.	Thematic analysis using grounded theory principles (Strauss and Corbin, 1990).	- Learning to pace useful but challenging to learn and often caused pain or fatigue - Responses to thought management strategies mixed, relaxation techniques positive and examining the past negative. - Experiences of therapists mixed- empathy, listening and knowledge of CFS valued. - A benefit was good relationship with someone who understands. - Negative experiences often related to the counsellor, e.g. feeling controlled or patronised - particularly common for CBT.	HIGH QUALITY + Transcripts were analysed by multiple authors and compared and discussed. + Participants experienced a diverse range of counselling approaches, intervention types, durations and settings. + Analysis was comprehensive and balanced, including positive and negative experiences. - This study could be more grounded in the data, as quotes are not provided for several concepts discussed.

Analysis

An evaluation of the methodological strengths and limitations of each study was conducted first, to include reference to quality in interpretation of the results. As this review focuses on qualitative studies, Elliot, Fisher and Rennie's (1999) criteria were used. They propose seven guidelines which apply to both quantitative and qualitative research and seven which specifically relate to qualitative research (Appendix A). As shown in Appendix B, each study was evaluated against each criterion. This analysis was used to generate an overall quality rating of 'low', 'medium' or 'high' for each study. In generating ratings, particular importance was placed on issues emphasised in Elliot et al. (1999), such as grounding in quotes. The author's supervisor rated five of the studies according to each criterion and any discrepancies were discussed and resolved.

For mixed-method studies, only the qualitative data were analysed and reported on for this review. A thematic analysis was conducted to identify patterns within the qualitative data. Results sections of each paper were coded line by line, allowing closeness to the data and the inductive development of themes (Braun & Clarke, 2006). The properties of emergent codes, and patterns across them, were explored and compared and codes were then grouped into overarching themes and subthemes. The author's supervisor reviewed line by line coding for two studies and discrepancies were discussed and resolved.

Results

Quality

Methodological limitations of the studies must be considered. Almost all studies met all seven of Elliot et al.'s (1999) general quality criteria with exceptions in clarity of language and

organisation (Blazquez et al., 2010), participant consent (Gladwell et al., 2014) and details of methodology (Roche et al., 2017).

As seen in Appendix B, the majority of papers were found to be of an acceptable quality, based on Elliot et al.'s (1999) criteria for qualitative research. Six studies were found to be high quality; three medium quality and four low quality (all mixed methods studies).

Most studies aimed to explore a specific intervention, with two studies exploring psychotherapy/counselling more broadly. Generally, analysis was comprehensive exploring a range of positive and negative elements of the experience, with some exceptions. However, three studies included almost exclusively positive themes, and only one study used purposive sampling to capture a breadth of experience. Most studies presented results in a cohesive way with an underlying structure, increasing understanding of the phenomenon. Two studies organised results into a thematic diagram highlighting the relationships between constructs. None of the studies evidenced sufficient reflexivity on the researchers' experience and orientation. This is particularly important in qualitative research, as researchers' values and assumptions impact their understanding and interpretation of the data (Elliot et al., 1999).

Most studies included a moderately well-situated sample. Interventions were well described in all but two studies. However, most studies did not provide an indicator of participants' levels of disability and functioning, class or ethnicity. Therefore, it was possible to understand the range of interventions but not the people for whom the findings might be relevant. The majority of studies provided many quotes, demonstrating that themes accurately reflected raw data. Three mixed methods studies did not provide any quotes.

The majority of studies used multiple researchers to code data. However, in five studies one researcher coded the raw data and other researchers contributed to a more abstract stage of analysis, decreasing the likelihood of objectivity. The only credibility check

used in Roche et al. (2017) was triangulation with quantitative data. No studies returned analysis to the original informants, thus reducing credibility of the overall body of research (Elliot et al., 1999). In two studies analysis was contributed to by patient representatives or a volunteer living with CFS/ME, allowing triangulation with their own experiences.

The high and medium quality studies are disproportionately represented in the thematic analysis because of the small size or lack of clarity (Blazquez et al., 2010) of the qualitative results sections of the four low quality, mixed-methods studies. Generally, themes in medium and high quality studies did not contradict each other. All subthemes were present in at least two high quality studies and more than half were in all six high quality studies.

Themes

As shown in table 3, four themes and ten subthemes were identified. Quotes have been included as examples of each theme, and further example quotes are included in table 5 in Appendix C.

Table 3. Themes identified within the literature

Theme	Subtheme
Challenging experiences pre-intervention	
Helpful and unhelpful aspects of intervention	Content: explanations, practical approaches and support to grieve Format: lack of adjustments and inappropriate setting but groups supportive
Facilitators and barriers to engagement	Practitioner: understanding versus dismissive and client-led versus controlling Fit between intervention and client illness models Overcoming hurdles: getting worse, slow progress and individual differences External life circumstances
Responses to intervention	Satisfaction and symptoms Positive: accepting, managing wellbeing and less distress Negative: feeling blamed and false promises

Challenging experiences pre-intervention.

This superordinate theme discusses participants' experiences and mindset before the intervention and was discussed in several studies.

Participants often reported that their symptoms had been disbelieved or minimised by healthcare professionals, friends and family and some had been instead been diagnosed with illnesses such as depression, malingering, or trauma (Denmark, 2017). Some participants

had been given the message that the illness was “all in your head” (Picariello et al., 2017, p. 390 [CBT]) which elicited negative responses about psychological interventions. For some, diagnosis was a turning point as their difficulties had been recognised; “almost part of the cure in itself” (Picariello et al., 2017, p. 390 [CBT]). However, many were not given a clear model of the illness, which could be anxiety provoking and confusing (Pinxsterhuis et al., 2015a). It led some to view their condition as a mental health problem:

“I actually thought at one point I was like cracking up.” (Chew-Graham et al., 2011, p. 116 [pragmatic rehabilitation])

Overall, participants held a mix of physical and psychological explanations for the condition and some believed it was possible to achieve full recovery, whilst others viewed CFS/ME as a chronic illness.

Generally, participants felt frustrated with the lack of support given by the healthcare system:

“Before the course I felt very alone, I had no one to talk to”. (Pinxsterhuis et al., 2015a, p. 467 [coping education programme])

Experience of prior interventions was extremely varied, including mainstream and alternative interventions and advice. Many of these reportedly led to no improvement or worsening of symptoms (Pinxsterhuis et al., 2015a; Reme et al., 2012) and were said by some to result in hostility towards further interventions (Dennison et al., 2010). Many participants did not feel able to manage the illness:

“I just knew that nothing else I was doing was improving things.” (Picariello et al., 2017, p. 390 [CBT])

Many were willing to try anything and viewed the intervention as a ‘last resort’ (Dennison et al., 2010). Participants were typically uncertain what the intervention would entail and were “confused and apprehensive” (Picariello et al., 2017, p. 389 [CBT]). Hopes were mixed; some expected improvement in symptoms, whilst many held some hope and some scepticism:

“I think I was a bit mixed with it, part of me thought it would make me better and part of me thought it wouldn’t work at all.” (Reme et al., 2012, p. 9 [Lightning Process])

Other benefits, such as resolution and validation were also hoped for (Dennison et al., 2010).

Helpful and unhelpful aspects of intervention.

This superordinate theme relates to aspects of the intervention content perceived as particularly helpful and unhelpful.

Content: explanations, practical approaches and support to grieve.

Explanations: Explanations about CFS/ME and prognosis were particularly valued, as this provided greater certainty and a model to make sense of symptoms, which reassured participants they were not “going round the twist” (Chew-Graham et al., 2011, p. 116 [pragmatic rehabilitation]). Explanations allowed participants to interpret information about the illness from a more discerning position:

“The course helped me to create my own room, to create walls that enabled me to extract relevant information, because I think if you want to try everything, you eventually will become insane”. (Pinxsterhuis et al., 2015a, p. 468 [CBT])

Explanations of the theory underpinning the treatment model seemed to increase motivation to engage, which was particularly important in interventions aiming to increase activity levels (Cheshire et al., 2018; Dennison et al., 2010):

“There is no point doing something unless you understand how it works...otherwise you won't believe in it enough.” (Reme et al., 2012, p. 11 [Lightning Process])

It was helpful when theory was used to make sense of previous intervention failures or deterioration in symptoms, increasing motivation to do something differently (Cheshire et al., 2018; Pinxsterhuis et al., 2015a). Participants across a range of interventions highlighted the value of learning about their energy levels and the impact of activity:

“The mindfulness around one's expenditure of energy was a very big thing for me. . . because I never gave any thought to how much [I do].” (Picariello et al., 2017, p. 394 [CBT])

Practical approaches: It was useful to learn ways of conserving energy, pacing and developing routines, particularly as many had previously adopted an all-or-nothing approach to activity (Dennison et al., 2010). Both better pacing and increasing activity were cited by participants

as reasons for symptom improvement (Adamowicz et al., 2017; Friedberg et al., 2016) and pacing as preventing further deterioration (Pinxsterhuis et al., 2015a). Sleep was cited as a reason for symptom improvement e.g. taking “less naps” (Friedberg et al., 2016, p. 693 [behavioural self-management]) and participants valued sleep hygiene advice and sleep monitoring activities.

Across CBT, exercise and other interventions, participants highlighted the value of setting goals, as this increased hope and allowed them to monitor progress and identify barriers (Gladwell et al., 2014; Picariello et al., 2017).

Learning tools for relaxation and managing emotions was reported to be helpful to reduce stress (Pinxsterhuis et al., 2015a, Ward et al., 2008). Some participants but not others believed this also helped CFS/ME symptoms (Adamowicz et al., 2017; Friedberg et al., 2016; Ward et al., 2008). Practical advice was valued, particularly around nutrition and accessing social support systems (Dennison et al., 2010; Pinxsterhuis et al., 2015a, Denmark, 2017).

Responses to learning cognitive tools were mixed; some did not see its relevance to CFS/ME:

“It was quite a lot thought based. Umm, I didn’t think that it, umm, the psychology, I didn’t really think that really helped me.” (Dennison et al., 2010, p. 175, [CBT])

Others found it helpful to understand the relationship between thoughts, feelings, behaviours and physical sensations and learned to challenge catastrophising or self-critical thoughts about CFS/ME and broader issues:

“all logical thinking and sensible thinking, if you know what I mean, and anybody could benefit from that way of thinking, not just somebody who was ill.” (Reme et al., 2012, p. 11 [Lightning Process])

Some participants who had undertaken exercise therapy felt that additional cognitive intervention components would be helpful:

“The graded exercise is good, but if you have mental activity, that’s just as straining as exercise isn’t it?” (Cheshire et al., 2018, p. 6 [GET])

Support to grieve: A key theme for participants in Denmark (2017) who had experienced a range of psychotherapies was the value of addressing the grief associated with having CFS:

“In my case, I believe what I most needed was help with the GRIEF of losing the life I had. She offered a few helpful tips - not about the disease because she's not an M.D. but about coping with the grief in general.” (Denmark 2017, p. 24 [psychotherapies])

Part of this process was support in finding new meaning and/or identity in life and building on existing strengths.

Format: lack of adjustments and inappropriate setting but groups supportive.

Lack of adjustments: A theme across interventions was the lack of accommodation for CFS/ME. Sessions were seen as long and overstimulating resulting in brain fog, exhaustion

and sensory overload, particularly in the Lightning Process where sessions were seen as dense and confusing:

“It was like quite a massive thing. And by the end of the first day I was absolutely shattered.” (Reme et al., 2012, p. 10 [Lightning Process])

High demands were a barrier to engaging with sessions, and impacted on overall health:

“Sometimes I would leave the sessions so mentally exhausted that I would completely forget about what was even discussed.” (Denmark 2017 p. 33 [psychotherapies])

Coping strategies and intervention tasks could also be too demanding, with both psychotherapy and exercise interventions often not factoring in concentration and memory difficulties (Cheshire et al., 2018; Roche et al., 2017):

“It's insanely frustrating when a therapist is trying to teach coping skills and mindfulness to somebody who is too physically ill to actually use them. It makes me feel so much worse and even more hopeless.” (Denmark, 2017, p. 33 [psychotherapies])

Some interventions were not accessible due to issues with stairs or parking (Denmark, 2017). Travelling to face to face sessions resulted in exhaustion for some, but others felt face to face contact was important.

Inappropriate setting: Participants often felt it was not appropriate when interventions were held in a psychology or psychiatry setting, as this sent an implicit message about the nature of the condition (Picariello et al., 2017). This was exacerbated by the use of questionnaires related to mental health issues such as depression (Dennison et al., 2010) and reduced motivation to benefit from the intervention (Cheshire et al., 2018).

Groups supportive: Participants often found groups particularly supportive (Denmark, 2017, Pinxsterhuis et al., 2015a):

“feeling everyone’s support was amazing, I was so excited. I was very touched, I felt accompanied.” (Blazquez et al., 2010 2010, p. 288 [dance movement therapy])

In both online and in-person groups, people felt understood and validated, which was often a unique experience (Denmark, 2017, Pinxsterhuis et al., 2015a). Hearing others’ experiences made people more willing to open up. Sharing advice and information was the most valuable element of groups. It was less helpful if group discussions were predominantly negative, creating feelings of helplessness (Denmark, 2017). Peer counsellors were useful role models in groups (Pinxsterhuis et al., 2015a). Young people felt it was helpful to have their parents at the sessions for emotional support and to absorb advice but were not able to speak about certain topics in their presence (Dennison et al., 2010).

Facilitators and barriers to engagement.

This overarching theme was discussed in almost all studies. It describes factors which increased and decreased participants’ likelihood of engaging with the intervention. “Inability

to engage” was cited as a reason for lack of symptom improvement (Adamowicz et al., 2017; Friedberg et al., 2016 [behavioural self-management]).

Practitioner: understanding versus dismissive and client-led versus controlling.

The interventions reviewed were conducted by a range of professionals including therapists, nurses, physiotherapists and peer counsellors, and collectively will be referred to as practitioners. Most studies discussed this theme, and often the overall usefulness of the intervention was determined by the perception of the practitioner.

Understanding versus dismissive: It was universally seen as important for practitioners to be non-judgemental, respectful and validating, regardless of the intervention model. Participants could then feel safe opening up:

“I wasn’t having to justify myself. . .so if I said I couldn’t get out of bed it was fine”
(Picariello et al., 2017, p. 390 [CBT])

Feeling understood was often linked with validation of symptoms and increased confidence in the intervention (Denmark, 2017; Gladwell et al., 2014):

“somebody sitting there saying to you, I know what you are going through and I have got other people who are going through the same thing” (Chew-Graham et al., 2011, p. 115 [pragmatic rehabilitation])

And reduced distress:

“When the counsellor is truly empathic with you, it’s at that moment when there’s a release.” (Ward et al., 2008, p. 77 [counselling])

Typically, participants found it unhelpful when practitioners suggested that symptoms were psychosomatic (Denmark, 2017; Gladwell et al., 2014; Ward et al., 2008):

“Be educated about the biology/medical basis of this illness. It is unlikely that it is a result of a traumatic childhood/stress/perfectionist personality.” (Denmark, 2017, p. 32 [psychotherapies])

It was suggested that practitioners lacking basic knowledge of the condition could lead to inappropriate or damaging interventions (Denmark, 2017) or an unhelpful focus on secondary issues:

“...there is a danger with some counsellors who don’t understand ME to focus on the depression” (Ward et al., 2008, p. 77 [counselling])

Client led versus controlling: Participants felt that their own expertise on their condition was often ignored and they felt patronised (Gladwell et al., 2014; Ward et al., 2008).

“The trainee therapist was absolutely brilliant. The other therapists were stuck in their own entrenched ideas and assumptions i.e. they know what's going on in my body and mind better than I do.” (Denmark, 2017, p. 32 [psychotherapies])

Participants felt more able to benefit when interventions were tailored to their individual needs and values (Cheshire et al., 2018; Chew-Graham et al., 2011; Picariello et al., 2017). Participants across studies often perceived interventions as narrow (Dennison et al., 2010, p. 177, [CBT]) and “prescriptive” (Denmark, 2017, p. 34 [psychotherapies]). Therapists were often perceived as inflexible and unresponsive to participants’ concerns (Chew-Graham et al., 2011, Gladwell et al., 2014; Reme et al., 2012):

“without adaptability to the individual or any real listening to patients' concerns.”
(Denmark, 2017, p. 34 [psychotherapies])

Participants described feeling “forced” (Denmark 2017, p. 32 [psychotherapies]) to comply with interventions, particularly increases in activity beyond what they felt able to do (Gladwell et al., 2014; Reme et al., 2012; Ward et al., 2008).

“I felt bullied into things - even when I was too tired to do things I had to do them”
(Gladwell et al., 2014, p. 391, [GET])

This dynamic was particularly challenging when overexertion led to significant relapse.

Participants in the LP experienced additional pressure to appear positive and agree with the theory presented. Therapists were described as “evangelical” (Reme et al., 2012, p.10).

Fit between intervention and client illness models.

Acceptance of the CFS/ME diagnosis was perceived as necessary for engagement and this could occur prior to or during intervention (Chew-Graham et al., 2011). Participants were

more engaged when their model of the illness matched that implied by the intervention (Chew-Graham et al., 2011). Some clients adopted a new illness model during intervention if it resonated with their experiences, whereas others maintained existing models. Discrepancies arose around the role of physical and psychological factors in maintenance of CFS/ME. Some participants viewed psychological elements of interventions as irrelevant (Dennison et al., 2010; Picariello et al., 2017; Ward et al., 2008), which was identified as a barrier to engagement:

“It [CBT] can still help people with chronic health conditions. So I think if you don’t buy into that, then it probably is [sic] going to be very helpful.” (Picariello et al., 2017, p. 393 [CBT])

Disagreement also occurred about whether CFS/ME was maintained by de-conditioning and therefore whether increasing fitness was helpful. Often this was determined by pre-illness beliefs about the relationship between exercise and health and fitness (Cheshire et al., 2018).

“What I have got is not just a reconditioning problem, I have got something where there is damage and a complete lack of strength actually getting into the muscles and you can’t work with what you haven’t got in terms of energy” (Chew-Graham et al., 2011, p. 117 [pragmatic rehabilitation])

It was particularly challenging if the intervention model conflicted with advice from other CFS/ME specialists (Reme et al., 2012).

Lack of fit in illness models could undermine participants' belief in the rationale for treatment or result in them perceiving potential harm:

“That’s a lovely idea but it doesn’t work like that, yeah. The point is there was a problem that stopped me doing things and Chronic Fatigue stopped me doing things it made me tired and it made me weak because of this” (Dennison et al., 2010, p. 176, [Psychoeducation])

Participants had mixed reactions to practitioners positioning the intervention goal as acceptance (Denmark, 2017). Some found this realistic and validating of their experience of lack of improvement in symptoms, whilst for others this did not match their concept of the illness:

“I think the strategy of trying to get patients to grieve, accept, and cope with their life conditions is horrifying because how and why should anyone ever accept and learn to cope with symptoms like these?” (Denmark, 2017, p. 25 [psychotherapies])

Overcoming hurdles: getting worse, slow progress and individual differences.

Getting worse: A range of interventions, most commonly those involving increases in activity, resulted in severe discomfort, temporary exacerbation of symptoms or progressive deterioration (Cheshire et al., 2018, Gladwell et al., 2014; Dennison et al., 2010; Denmark, 2017; Reme et al., 2012). Pacing interventions could also lead to initial worsening whilst participants struggled to establish their limits (Pinxsterhuis et al., 2015a; Ward et al., 2008)

This was discouraging:

“I was increasingly discouraged by the adverse reaction I experienced to the exercise after each session.” (Gladwell et al., 2014, p. 391, [Exercise on prescription])

And persevering with engagement was challenging:

“It was so hard to watch. She was so exhausted and not going to bed it was so painful”
(Parent, Dennison et al., 2010, p. 175, [CBT])

Symptoms of co-diagnosed conditions such as fibromyalgia added additional hurdles to adhering to interventions (Cheshire et al., 2018), along with symptoms such as lack of appetite which prevented changes to diet (Pinxsterhuis et al., 2015a).

Slow progress: Across exercise and psychotherapy interventions, participants often experienced long periods with no noticeable improvement in symptoms, resulting in frustration and anxiety (Cheshire et al., 2018, Picariello et al., 2017, Reme et al., 2012):

“For the first 1 or 2 years it was difficult.” (Cheshire et al., 2018, p. 5 [GET])

This often resulted in re-evaluating goals, which was further demoralising:

“I don’t think I was getting any nearer [to] sort of goals of going on walks and things like that” (Cheshire et al., 2018, p. 4 [GET])

Adults undertaking CBT and GET could find tasks and routines become “incredibly tedious” (Picariello et al., 2017, p. 393 [CBT]):

“There was a point at which I was oh I’m just sick of this routine and I just want to do whatever I feel like doing.” (Cheshire et al., 2018, p. 4 [GET])

Individual differences: Whether participants continued the intervention depended on their physical capacity:

“My condition worsened so much that I couldn’t physically carry out the exercises any more” (Gladwell et al., 2014, p. 392, [GET])

And emotional capacity:

“At that point, there was too much else on my mind.” (Cheshire et al., 2018, p. 4 [GET])

Other factors identified as motivators included personal attributes (e.g. stubbornness, positivity) and values (e.g. taking personal responsibility and preferring not to be on medication) (Cheshire et al., 2018).

Medication and complementary therapies facilitated engagement for some participants in both exercise and psychotherapy interventions:

“They [antidepressants] actually did [give]me a good start because it lifted my down moods and helped me to focus better” (Picariello et al., 2017, p. 393 [CBT])

External life circumstances.

External life circumstances influenced people's ability to engage with interventions and lack of resources or time was cited as a reason for no improvement in symptoms (Friedberg et al., 2016). Tasks such as activity monitoring were highlighted as time consuming in CBT (Picariello et al., 2017). Interventions requiring gradual increases in activity were perceived as more suitable by participants with fewer life commitments, typically lower functioning participants:

“But applying it, I think you needed not to have anything else going on in your life, particularly out of the ordinary, to be able to apply it properly and really stick to it” (Chew-Graham et al., 2011, p. 118 [pragmatic rehabilitation])

Higher functioning participants could either struggle to fit in activity or over-exert themselves due to commitments. In addition, participants felt they needed sufficiently few commitments to allow an exacerbation in symptoms:

“I think it would've been a lot, lot harder to, balance my days and be systematic about the increases, if, if I'd had to, look after children” (Cheshire et al., 2018, p. 4 [GET])

Practical support from family and friends helped with this. Emotional support helped maintain motivation (Cheshire et al., 2018); participants in the Lightning Process were encouraged not to discuss the intervention with others, which was challenging:

“You don't have anyone to talk to about it with so you feel kind of alone” (Reme et al., 2012, p. 12 [Lightning Process])

In some cases, social networks were actively unsupportive about the intervention:

“We were getting, my parents as well, were getting flack from some quarters and we felt like we had betrayed the ME cause” (Dennison et al., 2010, p. 174, [CBT])

Psychosocial stressors and life events were a common reason cited for lack of symptom improvement (Adamowicz et al., 2017; Friedberg et al., 2016).

Responses to intervention.

This overarching theme describes participants’ responses to the overall intervention.

Satisfaction and symptoms.

General satisfaction across interventions was mixed; some found it extremely helpful, others not at all helpful and many found it useful to some extent. Experiences of change in symptoms were also mixed; including quick recovery:

“Just WOW really, I mean.... I was thinking last night, “I’m better”. The fact that I ever had ME just seems like a million miles away, it doesn’t affect me anymore at all. I don’t do the process anymore, it is just automatic, I don’t need to” (Reme et al., 2012, p. 10 [Lightning Process])

..short and long term deterioration:

“18 months and still not back to pre-GET levels” (Gladwell et al., 2014, p. 392, [GET])

..but, most commonly, some improvement in wellbeing, although with ongoing symptoms:

“I’m actually getting to live a life. And the symptoms are more just part of that now if I get them they just sort of run alongside and they are managed” (Dennison et al., 2010, p. 177, [CBT])

Many participants continued to feel unable to cope after the intervention and fear of relapse was a common experience. Participants often wanted additional support either to maintain strategies or seek a different approach. Intervention was seen by some as a “starting block” (Dennison et al., 2010, p. 176 [CBT]) providing resources or motivation to progress further.

Positive responses: accepting, managing wellbeing and less distress.

Accepting: Participants across interventions described developing greater acceptance of having CFS/ME. For some acceptance meant giving up on the hope of getting better, whereas for others it was acknowledgement that a different approach was required (Pinxsterhuis et al., 2015a). Participants viewed education about CFS/ME and validation as important factors for reducing guilt and increasing acceptance:

“She helped me come to terms with being ill, and to stop blaming it on myself. I had felt that I was feeling so bad because I was fat, I wasn't exercising.” (Denmark, 2017, p. 25 [psychotherapies])

For some acceptance came after processing the impact of the condition:

“I needed help to go through the stages of grieving and come to a place of acceptance.” (Denmark, 2017, p. 25 [psychotherapies])

Acceptance often led to making adjustments:

“I think I sort of denied there was anything wrong with me, so I kept pushing on when I knew that after I had done so much I would crash, and it was seeing Nurse B that gave me an understanding that I have to take a step back and slow down, I have learnt to not punish myself.” (Chew-Graham et al., 2011, p. 117 [pragmatic rehabilitation])

Some participants felt more confidence discussing CFS/ME with others, but many still preferred to avoid the subject. Participants described increased acceptance of ignorance or negative attitudes from others about CFS/ME (Denmark, 2017, Pinxsterhuis et al., 2015a).

Managing wellbeing: Participants across CBT, counselling and education interventions described feeling more able to manage their energy levels after intervention:

“When I am quite exhausted I have learned that I have to take it very easy, lie down until my body says, “now it’s better, now it’s enough”” (Pinxsterhuis et al., 2015a, p. 468 [coping education programme])

Participants were more likely to say no to activities, re-prioritise their energy use and make adjustments:

“I sit on a bar stool in front of the stove when making pancakes” (Pinxsterhuis et al., 2015a, p. 469 [coping education programme])

This often resulted in a greater sense of confidence, control and independence:

“Planning your days so that YOU can manage it, rather than depending on someone else to plan your day, and to help you through because you need to be able to help yourself.” (Picariello et al., 2017, p. 394 [CBT])

In the exercise therapies, increased confidence and control could arise from feeling more physically able (Gladwell et al., 2014).

Participants also felt empowered with knowledge to improve wellbeing (e.g. about diet), and skills such as problem solving (Pinxsterhuis et al., 2015a, Ward et al., 2008).

Less distress: Participants often felt less stressed after psychotherapy interventions (Blazquez et al., 2010; Pinxsterhuis et al., 2015a; Ward et al., 2008). They described the “release” from talking about and processing their difficulties, even if their symptoms did not improve:

“It’s a very definite release, almost a click, it’s like I don’t need to hold on to these unhelpful thoughts and feelings.” (Ward et al., 2008, p. 77 [counselling])

The opportunity to talk without concerns was often unique and resulted in feeling less preoccupied in their wider life:

“It was so good just to open up completely like you are unable to do at home. I feel in a way that when we had finished talking and I went home, I had left it all behind, and I could live a bit more at home again.” (Pinxsterhuis et al., 2015a, p. 470 [coping education programme])

Participants often felt they had more strategies to cope with emotional difficulties:

“All this restlessness and anxiety and things like that come up in between anyway, but then you know that it probably will pass when you use techniques or just take it very easy.” (Pinxsterhuis et al., 2015a, p. 468 [coping education programme])

This was empowering:

“It was more the choice that helped me, the choosing, am I going to go into the pits?”
(Reme et al., 2012, p. 11 [Lightning Process])

..and could lead to feeling less need to search for treatments:

“I have become more relaxed after the course and have stopped trying new things all the time.” (Pinxsterhuis et al., 2015a, p. 468 [coping education programme])

Negative responses: feeling blamed and false promises.

Feeling blamed: Participants reported that in some interventions practitioners expected quick reductions in fatigue. This often resulted in participants feeling blamed for a lack of progress, resulting in feelings of guilt and anger (Denmark, 2017, Gladwell et al., 2014; Reme et al., 2012).

“I said to him that it wasn’t working and I didn’t know why, he basically told me it was my fault and that if it wasn’t working it must be because I wasn’t doing it properly” (Reme et al., 2012, p. 12 [Lightning Process])

“It also made me feel guilty about being physically ill, as if it was my fault and that if only I tried harder I could get better” (Gladwell et al., 2014, p. 392, [GET])

This was experienced as invalidating (Denmark, 2017; Gladwell et al., 2014).

“Made me feel like they didn’t believe how unwell it was making me and that it was my fault I wasn’t improving” (Gladwell et al., 2014, p. 392, [GET])

False promises: When interventions were positioned as delivering quick reductions in fatigue, participants often felt they had been given inaccurate information about treatment outcomes and underlying theory:

“I think the people that run it say they have 100% success rate, but obviously that is not true” (Reme et al., 2012, p. 12 [Lightning Process])

“It said research shows that, there will be no ill effects, and I already knew at that point that yes there can be ill effects and, yes there was, was ill effects for me.”
(Cheshire et al., 2018, p. 5 [GET])

“When the nurse came round and explained the theory to me, it was sold to me as fact, this is what is happening, there was no element of this is actually quite a contentious issue” (Chew-Graham et al., 2011, p. 117 [pragmatic rehabilitation])

Discussion

This review aimed to explore service users’ and families’ experiences of psycho-social interventions for CFS/ME, identify helpful therapy components and the barriers and facilitators to benefitting from these. These will each be discussed in the context of extant literature, considering limitations of the review alongside implications for clinical practice and future research.

Therapeutic change and intervention components

In considering changes in physical outcomes, results of this review were consistent with quantitative literature showing that for the majority of service users, interventions do not result in significant improvement in symptoms and can often result in short and long term deterioration, particularly in interventions focused on increasing activity (Geraghty et al., 2017; Larun et al., 2016; Price et al., 2008). This review highlighted that in interventions which made claims about quick reductions in fatigue, participants often felt misled with false promises or blamed by practitioners for a lack of progress.

Previous reviews (e.g. Pinxsterhuis et al., 2015b) have found that coping with CFS/ME is predominantly facilitated by gaining experience and learning from other sufferers. Strategies learned include pacing, planning rest and lowering expectations of themselves. This review suggests that there is considerable overlap between strategies learned independently and as a result of interventions. Almost all interventions incorporated practical strategies for living with CFS/ME which resulted in participants feeling more able to manage the condition. This was not, however, reported in the exercise interventions. Participants particularly valued learning about energy expenditure, pacing, routines, sleep, problem solving and managing emotions. This led to participants making adjustments in daily life, feeling more able to cope and in control of their physical and emotional health and feeling less distressed and preoccupied with their condition. This review echoed Pinxsterhuis et al. (2015b) in highlighting that groups are particularly helpful sources of gaining support and sharing resources.

In terms of psychological processes, this review extended Brooks and colleagues' 2011 study of CBT by suggesting that participants experienced increased acceptance of their CFS/ME diagnosis after a range of interventions. Participants attributed this to receiving information and validation of the condition. In addition, participants who had undertaken "psychotherapies" in Denmark (2017) reported processing grief and self-blame and rebuilding identity, which also facilitated acceptance. This echoes previous findings that processing the changes associated with chronic illness can lead to identity reconstruction, which can in turn reduce the "struggle" to accept the illness (Charmaz, 2002). This review suggested a bi-directional relationship in which gaining acceptance then further facilitated the ability to engage with interventions and adopt coping strategies.

Turning to facilitators and barriers, this review suggested that across interventions participants found interventions more useful when they felt validated and understood by their practitioner. The review echoed previous findings that service users often oppose psychosomatic explanations for the condition (Freidberg, 2016). Lack of fit between participants' and practitioners' illness models was often a barrier to benefitting from the intervention; this was particularly common in interventions focused on increasing activity. Another barrier arose when practitioners were perceived as controlling or prescriptive, which again was particularly common in interventions focused on increasing activity. This reflects the findings of Heins, Knoop and Bleijenbergh (2013) suggesting that working alliance mediates improvement in fatigue after CBT.

Limitations

The quality of studies included in this review was mixed. Many of the studies are likely to be biased due to the use of opportunity sampling in Western countries. Only one study used purposive sampling to capture a breadth of experience. Some studies did not require evidence of participants' diagnosis, which may have resulted in the inclusion of participants who did not meet diagnostic criteria for CFS/ME. Thus, the findings of these studies may not be applicable to all individuals with the condition. None of the studies evidenced sufficient reflexivity; therefore results are more likely to be influenced by researchers' assumptions. Studies lacked some specific details, such as the length of interventions, which limits conclusions which can be drawn around timescales related to processes highlighted in the results. However, a strength of this review is that all themes were consistently found in both higher and lower quality studies.

Implications

Clinical

This review highlighted that progress in interventions was often perceived as slow and frustrating, particularly for interventions aimed at increasing activity. Participants' ability to benefit from interventions was influenced by individual differences in physical and emotional health, time, social support, life commitments and levels of acceptance of having CFS/ME. Clinicians should be aware of these factors and offer support where possible. Offering therapy groups or signposting to support groups may be a way of service users accessing increased resources.

A theme across interventions was the lack of adjustments made by services to accommodate CFS/ME. Services might consider less stimulating and demanding intervention formats such as shorter sessions with more manageable tasks. Accessibility issues such as stairs and parking and the option of internet interventions should be considered. Some participants highlighted that locating interventions in psychiatry settings was a barrier to engagement. In the long term, policy makers may wish to consider ways of reducing stigma around seeking psychological support for physical health conditions. In the short term, it may be useful for individual services to acknowledge and explore this issue with service users. Practitioners lacking knowledge of CFS/ME was highlighted in some studies, and non-specialist services may wish to consider further training for clinicians.

Participants often felt misled about interventions. Service users should be provided with sufficient information to manage expectations and allow informed choice.

Research

This review has identified that participants can feel more able to cope, more in control, more accepting of their difficulties and more likely to make adjustments after interventions. Further

qualitative research, using methodology such as grounded theory may generate a more detailed understanding of the nature of these experiences and relationships between them. Pinxsterhuis et al.'s (2015b) review of coping suggested that acceptance was a “painful” process, facilitated largely by time, yet the longest intervention reported in this review was 30 weeks, suggesting that some form of this process can occur more quickly. The nature of acceptance may itself need examining, using qualitative or quantitative methods, as well as the particular aspects of acceptance facilitated by intervention. Diversity of data is recommended in qualitative research (Allmark, 2004) and the heterogeneity of interventions and participants captured by this review is a strength. However, a more focused study would allow a more in-depth exploration of a specific therapeutic approach.

Conclusion

This review highlighted several findings in the existing literature. In addition, it differentiated experiences occurring across interventions from those unique to individual interventions. In most interventions, except those focused solely on increasing activity, participants learned strategies for managing the physical and emotional challenges of living with CFS/ME. This resulted in greater self-efficacy and reduced distress. A range of interventions appeared to facilitate greater acceptance of the condition, particularly interventions providing space to grieve and re-build identity.

This review highlighted several experiences which were particularly common in interventions focused on increasing activity; exacerbation of symptoms, practitioners being perceived as controlling or prescriptive, a lack of agreement between participant and practitioner as to the causes of CFS/ME and participants feeling blamed or misled.

These findings highlight the value of interventions providing strategies to manage the difficulties associated with CFS/ME and addressing acceptance and identity. Further research

is needed to explore the relationships between different intervention components and processes.

References

- Adamowicz, J. L., Caikauskaitė, I., Friedberg, F., & Seva, V. (2017). Patient change attributions in self-management of severe chronic fatigue syndrome. *Fatigue: Biomedicine, Health & Behavior*, 5(1), 21-32. <https://doi.org/10.1080/21641846.2017.1278634>
- Allmark, P. (2004). Should research samples reflect the diversity of the population? *Journal of medical ethics*, 30(2), 185-189. <http://dx.doi.org/10.1136/jme.2003.004374>
- Anderson, V., Jason, L., Hlavaty, L., Porter, N., & Cudia, J. (2012). A review and meta-synthesis of qualitative studies on Myalgic Encephalomyelitis/chronic fatigue syndrome. *Patient Education and Counseling*, 86(2), 147–155. <https://doi.org/10.1016/j.pec.2011.04.016>
- Andreasson, A., Wicksell, R. K., Lodin, K., Karshikoff, B., Axelsson, J., & Lekander, M. (2018). A global measure of sickness behaviour: Development of the Sickness Questionnaire. *Journal of health psychology*, 23(11), 1452-1463.
- Bentall, R. P., Powell, P., Nye, F. J., & Edwards, R. H. (2002). Predictors of response to treatment for chronic fatigue syndrome. *The British Journal of Psychiatry*, 181(3), 248-252. <https://doi.org/10.1192/bjp.181.3.248>
- Blazquez, A., Guillamó, E., & Javierre, C. (2010). Preliminary experience with dance movement therapy in patients with chronic fatigue syndrome. *The Arts in Psychotherapy*, 37(4), 285-292. <https://doi.org/10.1016/j.aip.2010.05.003>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101. <https://doi.org/10.1191/1478088706qp063oa>
- Brooks, S. K., Rimes, K. A., & Chalder, T. (2011). The role of acceptance in chronic fatigue syndrome. *Journal of psychosomatic research*, 71(6), 411-415. <https://doi.org/10.1016/j.jpsychores.2011.08.001>

- Brurberg, K. G., Fønhus, M. S., Larun, L., Flottorp, S., & Malterud, K. (2014). Case definitions for chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): a systematic review. *BMJ open*, 4(2), e003973. <http://dx.doi.org/10.1136/bmjopen-2013-003973>
- Buchwald, D., Wener, M. H., Pearlman, T., & Kith, P. (1997). Markers of inflammation and immune activation in chronic fatigue and chronic fatigue syndrome. *The Journal of Rheumatology*, 24(2), 372-376.
- Cairns, R., & Hotopf, M. (2005). A systematic review describing the prognosis of chronic fatigue syndrome. *Occupational medicine*, 55(1), 20-31. <https://doi.org/10.1093/occmed/kqi013>
- Carruthers, B.M., Jain, A.K., De Meirleir, K.L., Peterson, D.L., Klimas, N.G., Lerner, A.M., Basted, A.C., Flor-Henry, P., Joshi, P., Powles, A.P. and Sherkey, J.A., (2003). Myalgic encephalomyelitis/chronic fatigue syndrome: clinical working case definition, diagnostic and treatment protocols. *Journal of chronic fatigue syndrome*, 11(1), 7-115. https://doi.org/10.1300/J092v11n01_02
- Chalder, T., Berelowitz, G., Pawlikowska, T., Watts, L., Wessely, S., Wright, D., & Wallace, E. P. (1993). Development of a fatigue scale. *Journal of psychosomatic research*, 37(2), 147-153. [https://doi.org/10.1016/0022-3999\(93\)90081-P](https://doi.org/10.1016/0022-3999(93)90081-P)
- Chalder, T., Deary, V., Husain, K., & Walwyn, R. (2010). Family-focused cognitive behaviour therapy versus psycho-education for chronic fatigue syndrome in 11-to 18-year-olds: a randomized controlled treatment trial. *Psychological medicine*, 40(8), 1269-1279. <https://doi.org/10.1017/S003329170999153X>
- Chambers, D., Bagnall, A. M., Hempel, S., & Forbes, C. (2006). Interventions for the treatment, management and rehabilitation of patients with chronic fatigue syndrome/myalgic

- encephalomyelitis: an updated systematic review. *Journal of the Royal Society of Medicine*, 99(10), 506-520. <https://doi.org/10.1177/014107680609901012>
- Cheshire, A., Ridge, D., Clark, L., & White, P. (2018). Guided graded Exercise Self-help for chronic fatigue syndrome: patient experiences and perceptions. *Disability and rehabilitation*, 1-10. <https://doi.org/10.1080/09638288.2018.1499822>
- Chew-Graham, C., Brooks, J., Wearden, A., Dowrick, C., & Peters, S. (2011). Factors influencing engagement of patients in a novel intervention for CFS/ME: a qualitative study. *Primary health care research & development*, 12(2), 112-122. <https://doi.org/10.1017/S146342361000037X>
- Clark, L. V., McCrone, P., Ridge, D., Cheshire, A., Vergara-Williamson, M., Pesola, F., & White, P. D. (2016). Graded exercise therapy guided self-help trial for patients with chronic fatigue syndrome (GETSET): protocol for a randomized controlled trial and interview study. *JMIR research protocols*, 5(2). <https://doi.org/10.2196/resprot.5395>
- Deary, V., & Chalder, T. (2010). Personality and perfectionism in chronic fatigue syndrome: a closer look. *Psychology and Health*, 25(4), 465-475. <https://doi.org/10.1080/08870440802403863>
- Denmark, B. (2017). Patient perspectives on mental health therapy for myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS). *Theses, Dissertations, and Projects*. 1887. Retrieved from: <https://scholarworks.smith.edu/theses/1887>
- Dennison, L., Stanbrook, R., Moss-Morris, R., Yardley, L., & Chalder, T. (2010). Cognitive behavioural therapy and psycho-education for chronic fatigue syndrome in young people: Reflections from the families' perspective. *British journal of health psychology*, 15(1), 167-183. <https://doi.org/10.1348/135910709X440034>

- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British journal of clinical psychology, 38*(3), 215-229. <https://doi.org/10.1348/014466599162782>
- Elliott, R., Slatick, E., & Urman, M. (2001). Qualitative change process research on psychotherapy: alternative strategies. *Psychological Test and Assessment Modelling, 43*(3), 69.
- Flo, E., & Chalder, T. (2014). Prevalence and predictors of recovery from chronic fatigue syndrome in a routine clinical practice. *Behaviour research and therapy, 63*, 1-8. <https://doi.org/10.1016/j.brat.2014.08.013>
- Friedberg, F. (2016). Cognitive-behavior therapy: why is it so vilified in the chronic fatigue syndrome community? *Fatigue: biomedicine, health & behavior, 4*(3), 127–131. <https://doi.org/10.1080/21641846.2016.1200884>
- Friedberg, F., Adamowicz, J., Caikauskaitė, I., Seva, V., & Napoli, A. (2016). Efficacy of two delivery modes of behavioral self-management in severe chronic fatigue syndrome. *Fatigue: Biomedicine, Health & Behavior, 4*(3), 158-174. <https://doi.org/10.1080/21641846.2016.1205876>
- Friedberg, F., Coronel, J., Seva, V., Adamowicz, J. L., & Napoli, A. (2016). Participant attributions for global change ratings in unexplained chronic fatigue and chronic fatigue syndrome. *Journal of health psychology, 21*(5), 690-698. <https://doi.org/10.1177/1359105314535458>
- Friedberg, F., & Sohl, S. J. (2009). Longitudinal change in chronic fatigue syndrome: what home-based assessments reveal. *Journal of behavioral medicine, 32*(2), 209. <https://doi.org/10.1007/s10865-008-9189-9>

- Fukuda, K., Straus, S. E., Hickie, I., Sharpe, M. C., Dobbins, J. G., & Komaroff, A. (1994). The chronic fatigue syndrome: a comprehensive approach to its definition and study. *Annals of Internal Medicine*, *121*(12), 953–959. https://doi.org/10.1300/J092v01n02_06
- Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC medical research methodology*, *13*(1), 117. <https://doi.org/10.1186/1471-2288-13-117>
- Geraghty, K., Hann, M., & Kurtev, S. (2017). Myalgic encephalomyelitis/chronic fatigue syndrome patients' reports of symptom changes following cognitive behavioural therapy, graded exercise therapy and pacing treatments: analysis of a primary survey compared with secondary surveys. *Journal of health psychology*, 1-16. <https://doi.org/10.1177/1359105317726152>
- Gladwell, P. W., Pheby, D., Rodriguez, T., & Poland, F. (2014). Use of an online survey to explore positive and negative outcomes of rehabilitation for people with CFS/ME. *Disability and rehabilitation*, *36*(5), 387-394. <https://doi.org/10.3109/09638288.2013.797508>
- Glaser, B. G., & Strauss, S. A. (1967). *Discovery of grounded theory. Strategies for qualitative research*. New York: Aldine.
- Goudsmit, E. M., & Howes, S. (2008). Pacing: A strategy to improve energy management in chronic fatigue syndrome. *Health Psychology Update*, *17*(1), 46.
- Guy, W. (1976). ECDEU assessment manual for psychopharmacology. *US Department of Health, and Welfare*, 534-537.
- Harrison, N. A., Brydon, L., Walker, C., Gray, M. A., Steptoe, A., Dolan, R. J., & Critchley, H. D. (2009). Neural origins of human sickness in interoceptive responses to inflammation. *Biological psychiatry*, *66*(5), 415-422.

- Heins, M. J., Knoop, H., & Bleijenberg, G. (2013). The role of the therapeutic relationship in cognitive behaviour therapy for chronic fatigue syndrome. *Behaviour research and therapy*, *51*(7), 368-376. <https://doi.org/10.1016/j.brat.2013.02.001>
- Holmes, G. P., Kaplan, J. E., & Schonberger, B. (1993). Definition of the chronic fatigue syndrome. *Annals of Internal Medicine*, *109*, 993–998.
- IOM (Institute of Medicine). (2015). *Beyond myalgic encephalomyelitis/chronic fatigue syndrome: Redefining an illness*. Washington, DC: The National Academies Press.
- Jameson, D. (2016) Persistent Burnout Theory of Chronic Fatigue Syndrome. *Neuroscience & Medicine*, *7*, 66-73. <http://dx.doi.org/10.4236/nm.2016.72008>
- Jason, L. A., Corradi, K., Torres-Harding, S., Taylor, R. R., & King, C. (2005). Chronic fatigue syndrome: the need for subtypes. *Neuropsychology review*, *15*(1), 29-58. <https://doi.org/10.1007/s11065-005-3588-2>
- Jason, L. A., Richman, J. A., Rademaker, A. W., Jordan, K. M., Plioplys, A. V., Taylor, R. R., ... & Plioplys, S. (1999). A community-based study of chronic fatigue syndrome. *Archives of internal medicine*, *159*(18), 2129-2137. <http://dx.doi:10.1001/archinte.159.18.2129>
- Keller, B. A., Pryor, J. L., & Giloteaux, L. (2014). Inability of myalgic encephalomyelitis/chronic fatigue syndrome patients to reproduce VO₂ peak indicates functional impairment. *Journal of translational medicine*, *12*(1), 104. <https://doi.org/10.1186/1479-5876-12-104>
- Kennedy, G., Abbot, N. C., Spence, V., Underwood, C., & Belch, J. J. (2004). The Specificity of the CD C-1994 criteria for chronic fatigue syndrome: comparison of health status in three groups of patients who fulfill the criteria. *Annals of epidemiology*, *14*(2), 95-100. <https://doi.org/10.1016/j.annepidem.2003.10.004>

- Kerr, J. R., Petty, R., Burke, B., Gough, J., Fear, D., Sinclair, L.I., Matthey, D.L., Richards, S.C.M., Montgomery, J., Baldwin, D.A. and Kellam, P., 2008. Gene expression subtypes in patients with chronic fatigue syndrome/myalgic encephalomyelitis. *The Journal of infectious diseases*, 197(8), 1171-1184. <https://doi.org/10.1086/533453>
- Komaroff, A. L. (2000). The physical basis of CFS. *The CFIDS Research Review*, 1(2), 1-11.
- Larun, L., Brurberg, K. G., Odgaard-Jensen, J., & Price, J. R. (2016). Exercise therapy for chronic fatigue syndrome. *Cochrane Database of Systematic Reviews*, (2). <https://doi.org/10.1192/apt.23.3.144>
- Larun, L., & Malterud, K. (2007). Identity and coping experiences in Chronic Fatigue Syndrome: A synthesis of qualitative studies. *Patient education and counseling*, 69(1-3), 20-28. <https://doi.org/10.1016/j.pec.2007.06.008>
- Lian, O. S., & Lorem, G. F. (2017). "I Do Not Really Belong Out There Anymore" Sense of Being and Belonging Among People With Medically Unexplained Long-Term Fatigue. *Qualitative health research*, 27(4), 474-486. <https://doi.org/10.1177/1049732316629103>
- Lorusso, L., Mikhaylova, S. V., Capelli, E., Ferrari, D., Ngonga, G. K., & Ricevuti, G. (2009). Immunological aspects of chronic fatigue syndrome. *Autoimmunity reviews*, 8(4), 287-291. <https://doi.org/10.1016/j.autrev.2008.08.003>
- Maes, M., Berk, M., Goehler, L., Song, C., Anderson, G., Gałeckki, P., & Leonard, B. (2012). Depression and sickness behavior are Janus-faced responses to shared inflammatory pathways. *BMC medicine*, 10(1), 66.
- ME Association. (2015). ME/CFS illness management survey results: No decisions about me without me. *Patient Survey*, May. Retrieved from:

<https://www.meassociation.org.uk/wp-content/uploads/2015-ME-Association-Illness-Management-Report-No-decisions-about-me-without-me-30.05.15.pdf>

McHorney, C. A., Ware, J. E., & Raczek, A. E. (1993). The MOS 36-Item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. *MEDICAL CARE-PHILADELPHIA-*, *31*, 247-247.

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & Prisma Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS medicine*, *6*(7). <https://doi.org/10.1016/j.jclinepi.2009.06.005>

Nater, U. M., Maloney, E., Lin, J. M. S., Heim, C., & Reeves, W. C. (2012). Coping styles in chronic fatigue syndrome: findings from a population-based study. *Psychotherapy and psychosomatics*, *81*(2), 127-129. <https://doi.org/10.1159/000329996>

NICE. (2007). *Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management of CFS/ ME in adults and children*. [cited April 2019]. Available from: <https://www.nice.org.uk/guidance/cg53>

Parker, P. (2018). *Lightning Process*. Retrieved from: <https://lightningprocess.com/>

Picariello, F., Ali, S., Foubister, C., & Chalder, T. (2017). 'It feels sometimes like my house has burnt down, but I can see the sky': A qualitative study exploring patients' views of cognitive behavioural therapy for chronic fatigue syndrome. *British journal of health psychology*, *22*(3), 383-413. <https://doi.org/10.1111/bjhp.12235>

Pinxsterhuis, I., Strand, E. B., Stormorken, E., & Svein, U. (2015a). From chaos and insecurity to understanding and coping: experienced benefits of a group-based education programme for people with chronic fatigue syndrome. *British Journal of Guidance & Counselling*, *43*(4), 463-475. <https://doi.org/10.1080/03069885.2014.987725>

- Pinxsterhuis, I., Strand, E. B., & Sveen, U. (2015b). Coping with chronic fatigue syndrome: a review and synthesis of qualitative studies. *Fatigue: Biomedicine, Health & Behavior*, 3(3), 173-188. <https://doi.org/10.1080/21641846.2015.1035519>
- Price, J. R., Mitchell, E., Tidy, E., & Hunot, V. (2008). Cognitive behaviour therapy for chronic fatigue syndrome in adults. *The Cochrane Library*. <https://doi.org/10.1002/14651858.CD001027.pub2>.
- Reme, S. E., Archer, N., & Chalder, T. (2012). Experiences of young people who have undergone the Lightning Process to treat chronic fatigue syndrome/myalgic encephalomyelitis—a qualitative study. *British journal of health psychology*, 18(3), 508-525. <https://doi.org/10.1111/j.2044-8287.2012.02093.x>
- Reyes, M., Dobbins, J. G., Nisenbaum, R., Subedar, N. S., Randall, B., & Reeves, W. C. (1999). Chronic fatigue syndrome progression and self-defined recovery: evidence from the CDC surveillance system. *Journal of Chronic Fatigue Syndrome*, 5(1), 17-27. https://doi.org/10.1300/J092v05n01_03
- Spencer, L., & Ritchie, J. (2002). Qualitative data analysis for applied policy research. In *Analyzing qualitative data* (pp. 187-208). Routledge.
- Roberts, A. D. L., Charler, M. L., Papadopoulos, A., Wessely, S., Chalder, T., & Cleare, A. J. (2010). Does hypocortisolism predict a poor response to cognitive behavioural therapy in chronic fatigue syndrome? *Psychological medicine*, 40(3), 515-522. <https://doi.org/10.1017/S0033291709990390>
- Roche, L., Dawson, D. L., Moghaddam, N. G., Abey, A., & Gresswell, D. M. (2017). An Acceptance and Commitment Therapy (ACT) intervention for Chronic Fatigue Syndrome (CFS): a case series approach. *Journal of Contextual Behavioral Science*, 6(2), 178-186. <https://doi.org/10.1016/j.jcbs.2017.04.007>

- Rossberg-Gempton, I., & Poole, G. (1992). The relationship between body movement and affect: From historical and current perspectives. *The Arts in Psychotherapy*, 19, 39–46. [http://dx.doi.org/10.1016/0197-4556\(92\)90062-S](http://dx.doi.org/10.1016/0197-4556(92)90062-S)
- Salit, I. E. (1997). Precipitating factors for the chronic fatigue syndrome. *Journal of Psychiatric Research*, 1(31), 59-65. [https://doi.org/10.1016/S0022-3956\(96\)00050-7](https://doi.org/10.1016/S0022-3956(96)00050-7)
- Sharpe, M. C. (1991). A report—chronic fatigue syndrome: guidelines for research. *Journal of the Royal Society of Medicine*, 84(2), 118-121.
- Song, S., & Jason, L. A. (2005). A population-based study of chronic fatigue syndrome (CFS) experienced in differing patient groups: An effort to replicate Vercoulen et al.'s model of CFS. *Journal of Mental Health*, 14, 277-289. <https://doi.org/10.1080/09638230500076165>
- Stanton Jones, K. (1992). Movement and meaning. *En: Payne H, editor. Dance Movement Therapy in Psychiatry. Londres, Routledge*, 59-80.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research*. Sage publications.
- Sunnquist, M., & Jason, L. A. (2018). A reexamination of the cognitive behavioral model of chronic fatigue syndrome. *Journal of clinical psychology*, 74(7), 1234-1245. <https://doi.org/10.1002/jclp.22593>
- Surawy, C., Hackmann, A., Hawton, K., & Sharpe, M. (1995). Chronic fatigue syndrome: a cognitive approach. *Behaviour research and therapy*, 33(5), 535-544. [https://doi.org/10.1016/0005-7967\(94\)00077-W](https://doi.org/10.1016/0005-7967(94)00077-W)
- Urquhart, C. (2013). *Grounded Theory for qualitative research: A practical guide*. London, UK: Sage Publications
- Van Houdenhove, B., Neerinckx, E., Onghena, P., Lysens, R., & Vertommen, H. (2001). Premorbid “overactive” lifestyle in chronic fatigue syndrome and fibromyalgia: an

etiological factor or proof of good citizenship?. *Journal of psychosomatic research*, 51(4), 571-576. [https://doi.org/10.1016/S0022-3999\(01\)00247-1](https://doi.org/10.1016/S0022-3999(01)00247-1)

Van Ravenzwaaij, J., Olde Hartman, T. C., Van Ravesteijn, H., Eveleigh, R., Van Rijswijk, E., & Lucassen, P. L. B. J. (2010). Explanatory models of medically unexplained symptoms: a qualitative analysis of the literature. *Mental Health in Family Medicine*, 7(4), 223.

Vercoulen, J. H. M. M., Swanink, C. M. A., Galama, J. M. D., Fennis, J. F. M., Jongen, P. J. H., Hommes, O. R., ... & Bleijenberg, G. (1998). The persistence of fatigue in chronic fatigue syndrome and multiple sclerosis: development of a model. *Journal of psychosomatic research*, 45(6), 507-517. [https://doi.org/10.1016/S0022-3999\(98\)00023-3](https://doi.org/10.1016/S0022-3999(98)00023-3)

Ward, T., Hogan, K., Stuart, V., & Singleton, E. (2008). The experiences of counselling for persons with ME. *Counselling and Psychotherapy Research*, 8(2), 73-79. <https://doi.org/10.1080/14733140801972760>

Wearden, A. J., Riste, L., Dowrick, C., Chew-Graham, C., Bentall, R. P., Morriss, R. K., ... & Powell, P. (2006). Fatigue Intervention by Nurses Evaluation—The FINE Trial. A randomised controlled trial of nurse led self-help treatment for patients in primary care with chronic fatigue syndrome: study protocol.[ISRCTN74156610]. *Bmc Medicine*, 4(1), 9. <https://doi.org/10.1186/1741-7015-4-9>

Wearden, A. J., Dowrick, C., Chew-Graham, C., Bentall, R. P., Morriss, R. K., Peters, S., ... & Dunn, G. (2010). Nurse led, home based self help treatment for patients in primary care with chronic fatigue syndrome: randomised controlled trial. *Bmj*, 340, c1777. <https://doi.org/10.1136/bmj.c1777>

- Wearden, A. J., Dunn, G., Dowrick, C., & Morriss, R. K. (2012). Depressive symptoms and pragmatic rehabilitation for chronic fatigue syndrome. *The British Journal of Psychiatry*, 201(3), 227-232. <https://doi.org/10.1192/bjp.bp.111.107474>
- White, P. D., Goldsmith, K. A., Johnson, A. L., Potts, L., Walwyn, R., DeCesare, J. C., ... & Bavinton, J. (2011). Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. *The Lancet*, 377(9768), 823-836. [https://doi.org/10.1016/S0140-6736\(11\)60096-2](https://doi.org/10.1016/S0140-6736(11)60096-2)
- Wiborg, J. F., Knoop, H., Stulemeijer, M., Prins, J. B., & Bleijenberg, G. (2010). How does cognitive behaviour therapy reduce fatigue in patients with chronic fatigue syndrome? The role of physical activity. *Psychological medicine*, 40(8), 1281-1287. <https://doi.org/10.1017/S0033291709992212>
- Yardley, L., & Marks, D. F. (2004). *Research methods for clinical and health psychology*. London: Sage.

CATHERINE. E. CLARK BSc Hons MSc

INVESTIGATION INTO COGNITIVE BEHAVIOURAL THERAPY FOR
CHRONIC FATIGUE SYNDROME/ MYALGIC ENCEPHALOMYELITIS

Section B: "A life I can cope with." A grounded theory exploration of
CBT for CFS/ME.

Word Count: 7999 (167)

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

APRIL 2019

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

Abstract

Background: In the UK, CBT is currently recommended as an intervention for CFS/ME. Physical and psychological outcomes of CBT for CFS/ME vary across studies, as does the CBT model adopted. There is some evidence to suggest that some participants experience improved psychological and physical outcomes post CBT. However, the specific nature of these changes and the factors facilitating them is not well understood. This was therefore the focus of the current study.

Methodology: Semi-structured interviews were conducted with 13 service users who had engaged in CBT aimed at improved management of their condition. Interviews were analysed using a grounded theory methodology, in order to build a theory of participants' experiences.

Results: The theory suggests that CBT led to participants feeling more able to cope with CFS/ME. This was due to both a shift in perspective arising from the therapy room and taking a more adaptive approach to daily life. The theory also suggested that participants experienced increased acceptance of the condition, which facilitated further adaptive changes.

Discussion: Findings extend existing literature in suggesting that CBT aimed to improve management of CFS/ME may result in improved coping and reduced distress, independently of changes in fatigue. Clinical and research implications are discussed.

Keywords: Chronic Fatigue Syndrome/ME; cognitive behavioural therapy/CBT; coping; acceptance; grounded theory.

Introduction

Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) has been described as a chronic condition for which there is currently no cure and, as highlighted in the most recent review, a poor prognosis without intervention (Cairns & Hotopf, 2005).

In the UK, NICE (2007) recommends that people with CFS/ME of all severities be offered Cognitive Behavioural Therapy (CBT), incorporating gradual increases in activity, reducing over-vigilance about symptoms, learning problem-solving skills, and supporting adjustment to the diagnosis (NICE, 2007).

A Cochrane meta-analysis (Price, Mitchell, Tidy, & Hunot, 2008) found that CBT was more effective than usual care and other psychological therapies for reducing fatigue symptoms in adults with CFS/ME, with 40% of participants showing improvement in symptoms after CBT compared with 26% in usual care. More recently, the large scale PACE randomised controlled trial (RCT) reported that 22% of participants had 'recovered' from CFS/ME following CBT (White, Goldsmith, Johnson, Chalder, & Sharpe, 2013). This study elicited a strong negative reaction from patient and professional communities who held concerns about the generalizability of the findings, the definition of "recovery" and the finding that the 'objective' outcomes, such as a fitness step test, failed to suggest recovery (Davis, Edwards, & Jason, 2015). Wilshire et. al (2018) re-analysed the data from the PACE trial using the definitions and procedures set out in the original PACE protocol and reported that CBT did not outperform the control group for symptom improvement or recovery rates, which they reported to be consistently low. This is in line with a recent large patient survey conducted by the ME Association, open to anyone with CFS/ME, in which only 8% of participants reported symptom improvement after CBT and 18% reported adverse effects

(Geraghty, Hann, & Kurtev, 2017). Yet there has been considerable publicity on how effective CBT is for CFS/ME. Friedberg (2016) suggests that this may underpin the considerable backlash against CBT from patients, much of which has been on social media.

It has been highlighted that the fundamental treatment goals for CBT for CFS/ME vary across studies (Van Houdenhove, 2006). Some CBT interventions, such as those investigated in the PACE trial (White et al., 2011), adopt a model which aims to increase activity to improve symptoms. This is based on the 'Cognitive Theory of CFS' (Surawy, Hackmann, Hawton, & Sharpe, 1995), which suggests that CFS/ME is maintained by unhelpful beliefs about exercise and illness (e.g. "This activity will make me feel worse" (p. 537)), which result in activity avoidance and subsequent changes in physiology such as loss of muscle strength, collectively known as "deconditioning". The Cognitive Theory suggests that re-conditioning can lead to recovery from the condition. Another model of CBT for CFS/ME aims to support people to live with the condition and find an optimal level of activity to minimise exacerbation in symptoms (e.g. Bleijenberg, Prins, & Bazelmans, 2003). Many CFS/ME patients do not believe that their illness is psychogenic and can be cured by increasing their activity (Geraghty & Blease, 2018; Deale and Wessely, 2001). The M.E. Association (2015) has advocated that interventions focused on better management of the condition are more useful for CFS/ME than interventions whose primary goal is an increase in activity. Yet despite this, many people with CFS/ME are offered the former rather than the latter CBT intervention model (Geraghty, 2016). There remains much more to understand about how and why CBT interventions for CFS/ME, in their varying forms, may be useful.

There is only one qualitative study solely examining CBT for CFS/ME in adults (Picariello, Ali, Foubister, & Chalder, 2017) and one in children (Dennison, Stanbrook, Moss-Morris, Yardley & Chalder, 2010). Both interventions aimed to increase activity by challenging

cognitions. A theme in both studies was that it was inappropriate for CFS/ME to be framed as a psychiatric illness, and this was a barrier to engagement “That’s a lovely idea but it doesn’t work like that” (Dennison et al., 2010, p. 176).

Studies suggest that people with CFS/ME experience high rates of anxiety and depression (Afari & Buchwald, 2003; Short, McCabe, & Tooley, 2002). Jackson and MacLeod (2017) found that people with CFS/ME had significantly lower Psychological Well-being (PWB) (Ryff, 1989), particularly on the personal growth, environmental mastery and self-acceptance scales. Poppe, Crombez, Hanouille, Vogelaers and Petrovic (2012) found that poorer mental health-related quality of life [MHQL] was associated with a lack of “acceptance” (acknowledging symptoms as insoluble and adapting goals accordingly) in people with CFS/ME.

NICE (2007) highlights that CBT should aim to reduce the “distress associated with CFS/ME”. Yet CFS/ME intervention studies have typically focused on fatigue and functioning as primary outcome measures, rather than changes in distress. The available evidence on psychological outcomes for CBT for CFS/ME is mixed. Price et al. (2008) found that CBT failed to reduce distress in comparison to usual care. However, a meta-analysis by Castell, Kazantzis and Moss-Morris (2011) showed that following CBT participants experienced a significantly greater reduction in depression and anxiety than controls. As yet, there are no studies exploring factors mediating a reduction in psychological distress following CBT for CFS/ME. Brooks, Rimes, and Chalder (2011) found that after CBT patients showed significantly increased acceptance and reductions in two aspects of perfectionism (concern over mistakes and doubts about actions). It was found that increased acceptance post CBT was significantly correlated with improvement in fatigue, physical functioning and work and social adjustment. Again, acceptance was defined as recognition that avoidance and control of symptoms was

often not viable. Authors highlighted that it “may be useful for CBT to properly address acceptance” (p.414). Recently, two non-controlled trials (Jacobsen, Kallestad, Landrø, Borchgrevink, & Stiles, 2017; Jonsjö, Wicksell, Holmström, Andreasson, & Olsson, 2019) and one case series study (Roche, Dawson, Moghaddam, Abey, & Gresswell, 2017) have explored outcomes of acceptance and commitment therapy (ACT) for CFS/ME. Results suggested improvement in quality of life and reduced fatigue.

Qualitative research has suggested that after both CBT and other psychosocial interventions (Pinxsterhuis, Strand, Stormorken, & Sveen, 2015a; Reme, Archer, & Chalder, 2012) participants report feeling more able to manage their condition and a greater sense of control and confidence. They can also experience increased acceptance of their symptoms leading to reduced distress and more adaptive coping (Chew-Graham, Brooks, Wearden, Dowrick, & Peters, 2011; Denmark, 2017). However, research exploring psychological change following CBT for CFS/ME is in its infancy and the specific relationships between coping, acceptance, fatigue and other factors are yet to be explored. The grounded theory approach can generate a richer understanding of a phenomenon and the relationships between its components and processes (Urquhart, 2013).

This study therefore sought to build a preliminary model of therapeutic change in the context of CBT for CFS/ME, and specifically to explore the following questions:

1. What are service users’ experiences of CBT for CFS/ME?
2. What changes, if any, do service users experience following CBT for CFS/ME? And to what do they attribute these changes?
3. What are the perceived conditions required for participants to undergo these changes?

Methodology

Design

This study used a grounded theory design (Glaser, 1978), which was considered appropriate due to several issues in the area including contradictory findings between empirical studies and patient surveys, high levels of patient dissatisfaction and questioning of the usefulness of the dominant model of CBT (Geraghty et al., 2017; ME Association, 2015), limited qualitative research and gaps in the understanding of psychological outcomes and processes associated with CBT for CFS/ME. A theoretical sampling strategy (Glaser, 1978) was adopted, with interview questions adapted according to emerging categories within the data. The study was undertaken from a critical realist position in which reality is assumed to exist but can never be perfectly understood due to the flawed nature of the human mind (Guba & Lincoln, 1994). A key tenet of this is the need for claims about reality to be subjected to extensive critical examination.

Recruitment

Participants were recruited through a specialist community CFS/ME service in the South East of England ('the service'). In contrast to the NICE guidelines, the model of CBT delivered in this service was not one with the primary aim of increasing activity in order to facilitate 'reconditioning' and a reduction in fatigue. Instead the primary goal was increased quality of life by better adjustment to and management of CFS/ME. A reduction in fatigue was a secondary 'hope' for the intervention. The service provides assessment and treatment within a multidisciplinary team including doctors, occupational therapists, physiotherapists and two CBT therapists. CBT was delivered by two CBT therapists who had been qualified for seven

and eleven years and worked in specialist CFS/ME services for three and nine years, respectively.

Participants

Participants (n=13) all had a diagnosis of CFS or 'CFS/ME'. The median age of participants was 49 (range 19-72). As shown in table 1, six participants were in full or part time work, one in education, five retired or unemployed and one was a home-maker. Ten participants had experienced only one episode of CBT for CFS/ME, at the service. Three participants had previously undertaken specialist CBT for CFS/ME and reported that the goal of the CBT had been positioned as better management of CFS/ME. Data relating to these experiences was included in the analysis. Participants reported having undergone between 6 and 10 sessions of CBT (median=6).

Table 1. Participant demographic information

Pseudonym	Age	Gender	Ethnicity	Employment Status when starting CBT	Episodes of CFS/ME CBT for
George	57	M	White British	Medically retired	One episode
Sarah	51	F	White British	Home-maker	Three episodes: 'CBT 1' at another specialist service 'CBT 2' at another specialist service (ended after 3 sessions) 'CBT 3' at 'the service'
John	42	M	White British	Unemployed	One episode
Jean	45	F	White British	Unemployed	One episode
Charlie	56	M	White British	Full-time work	Two episodes: 'CBT 1'- at another specialist service 'CBT 2' at 'the service'
Eva	29	F	White British	Full-time work	One episode
Susan	53	F	White British	Medically retired	One episode
Judith	72	F	White British	Retired	One episode
Layla	19	F	Mixed African, Asian & White European	In education	One episode
Will	35	M	White British	Part-time work	One episode
Sebastian	56	M	Caribbean British	Full-time work	Two episodes: 'CBT 1'- at another specialist service 'CBT 2' at 'the service'
Rachel	29	F	White British	Part-time work	One episode
Fiona	49	F	White British	Part-time work	One episode

Procedure

All service users who had completed CBT at the service within the last two years were contacted about the study by a letter (Appendix D) accompanied by a participant information sheet (Appendix E). Those who expressed interest in participating returned a questionnaire containing questions on demographic details and participants' experience of CFS/ME and CBT (Appendix F). This was designed to allow theoretical sampling based on participant characteristics. However due to insufficient recruitment, this was not possible.

Individual semi-structured interviews were conducted and lasted between 52 and 93 minutes. Six interviews were conducted in person and seven over Skype. Immediately prior to interview, participants were encouraged to ask further questions about the study and formal consent to participate was taken (see Appendix G). Interviews were audio-recorded and transcribed. Analysis began after the first interview and continued concurrently with data collection. This enabled interview questions to be slightly modified in a form of within-participant theoretical sampling (Strauss & Corbin, 1998).

An end of study summary was sent to participants following assessment and review of the study (Appendix R).

Ethical Considerations

This study received ethical approval from the Health Research Authority (Appendix H for approval documents). The researcher met with a representative from the university's service user advisory group, who had lived experience of CFS/ME. They provided advice on ways in which ethical issues specific to CFS/ME could be considered, for example prevention of harm. The researcher checked if participants wished to continue talking at several intervals during the interview and suggested taking a break after 25 minutes.

The participant information sheet contained information about confidentiality, risk and the right to withdraw from the study at any time (Appendix E). Participants were advised to take at least 24 hours to consider their participation before expressing interest and were given the opportunity to ask questions prior to and on the day of the interview.

Data Analysis

The grounded theory analysis was informed by the approach described by Strauss and Corbin (1998). Constant comparison was used throughout the analysis to look for similarities and differences between data and emerging categories. Memoing (see Appendix I) was used to record analysis throughout.

Analysis began with open coding aimed at identifying concepts within the data. This involved detailed line-by-line coding (Strauss & Corbin, 1998). See Appendix V for an example transcript. Analytic techniques such as asking questions of the data were used to explore the meaning of the data. Analysis then progressed to axial coding, exploring the properties and dimensions of categories. Theoretical sampling, in the form of adapting interview questions, was used to facilitate conceptual saturation. For initial and adapted topic guides, see Appendices J and K. Data were then analysed for context, holding in mind the concept of conditional/consequential matrices (Strauss & Corbin, 1998). Relationships between categories were explored by creating maps of each participant's experience (for examples see appendix L). The later stages of analysis involved selective coding and broader theoretical integration (see appendix M for iterations of the overall model). In the final stages of analysis constant comparison highlighted that new data reflected existing major categories in the model, and that these categories were dense in terms of properties and well-integrated, suggesting theoretical saturation (Strauss & Corbin, 1998). Whilst they also demonstrated

dimensional variation, this was more limited due to the absence of participants who reported poorer outcomes from the intervention.

Quality assurance

Elliott, Fischer and Rennie's (1999) quality guidelines were used to increase the credibility of the research (Appendix A). A research diary was maintained (Appendix N), a bracketing interview was conducted and a positioning statement created (Appendix O). This increased awareness of researcher preconceptions and facilitated the 'bracketing' of biases prior to data analysis (Creswell & Miller, 2000), for example around attitudes to CBT. Two line-by-line coded transcripts, memos around emerging categories and integrative maps were shared with the researcher's first supervisor, who has extensive experience in qualitative research. The supervisor offered comments, challenges, and elaborations, which were discussed and incorporated into the analysis. Finally, respondent validation was undertaken to ascertain the credibility of the analysis to participants (Mays & Pope, 2000). A proposed draft of the theory was sent to participants and discussed via phone or email (see Appendices P and Q).

Results

As shown in tables 2.1 to 2.9, ten categories and 24 sub-categories were identified in the data. The categories are illustrated in the model in Figure 1. The principal context of the therapy experience was *dealing with ongoing symptoms*. Four categories described experiences in the therapy room (illustrated in the top circle in Figure 1) and three categories describe experiences in daily life (illustrated in the bottom circle in figure 1). As illustrated by the shaded circles in Figure 1, there was often interaction between the different experiences within each context. Experiences in the therapy room and daily life seemed to lead to changes in the meaning participants held around their lives with CFS/ME, as reflected in the categories '*A life I can cope with*' and '*Accepting the reality of CFS/ME.*' Each of the categories and their sub categories will now be discussed, with emphasis on relationships between them. Additional quotes to demonstrate categories are included in table 3 (Appendix U).

Table 2.1. Categories and sub-categories identified in the data

Context	Category	Sub-category
Not specific to one context	Dealing with ongoing symptoms	Lack of improvement from prior interventions
		Minimal changes over CBT
Therapy room	Feeling safe and understood	
	Seeing myself and CFS/ME differently	CFS/ME is real and not my fault
		CFS/ME is manageable
		Lowering expectations of myself
		It's ok to put myself first
	Finding ways to move forwards	Understanding what was happening
		Separating what we can and cannot control
		Learning tools and problem solving
		Finding opportunities for enjoyment
	Lightening the load	Resolving broader issues
		Getting things off my chest
	Not specific to one context	A life I can cope with
Getting my confidence back		
Living beside CFS/ME		
Making peace with CFS/ME		
Not specific to one context	Accepting the reality of CFS/ME	
Daily life	Having tools	Taking a different perspective
		Control over my responses
		More able to communicate
	Putting less pressure on myself	Cutting back on demands
		Re-prioritising my needs
		Being more open about my needs
	Doing more of what I value	More courage to do things
		Having more capacity

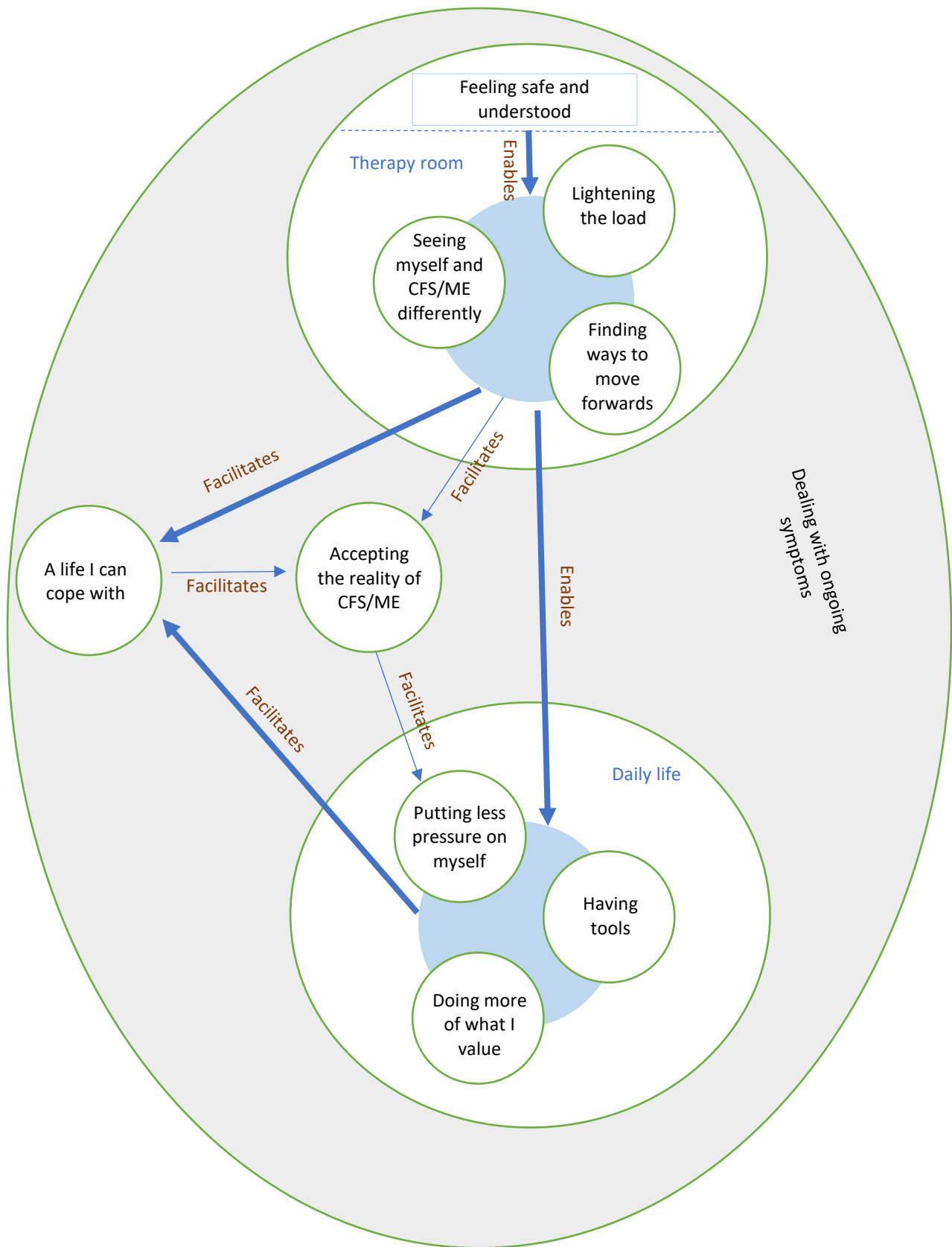


Figure 1. Model of theory (Words in blue represent contexts not categories)

Categories

Dealing with ongoing symptoms (Not specific to one context)

Table 2.2. Subcategories within category 'dealing with ongoing symptoms'

Category	Sub-category
Dealing with ongoing symptoms	Lack of improvement from prior interventions
	Minimal changes over CBT

Lack of improvement from prior interventions.

Participants had engaged in a range of interventions prior to CBT. However all but one participant continued to experience significant CFS/ME symptoms. Jean was an exception as she felt "85% back to normal" when starting CBT, which she attributed to graded exercise:

"The weird thing about ME is that the only cure seems to be, you know, the graded exercise." (Jean).

Minimal changes over CBT.

Most participants experienced no change in their symptoms over CBT:

"I don't think in any way it helped my ME, but it did help my mind." (Sarah)

And those who experienced improvement did not return to pre-illness levels:

"A sort of gradual decline of the fatigue and getting nearer to being back to normal. But I mean I still feel as though I couldn't possibly imagine going back to my full-time job." (George)

Typically, this manifested as fewer relapses:

"I don't want to say reduced the symptoms, but probably have slightly fewer relapses and maintain a slightly better level quality of life" (Susan)

Improvement was typically attributed to better management of energy and being driven less by emotions:

“I think movement, the taking emotional control over your life, seem to have been quite important.” (Jean)

Feeling safe and understood (occurs in therapy room context)

Feeling safe, contained and believed in the therapy room allowed participants to open up:

“I cried quite a lot, quite a lot in the therapy room and it felt like it was okay to do that.” (Sarah CBT 1)

Making progress was more likely when participants felt the therapist understood their unique difficulties:

“Because she connected with me in the area that I wanted to be connected in, which was a nasty manager at work, then it all fell into place.” (Charlie, CBT 2)

This was facilitated by a holistic approach:

“It wasn’t just focused on ME. It was looking at my whole body or mind and seeing how I was coping with things, so I was actually really pleased.” (Susan)

Participants were consistently told that the goal of therapy was better management of CFS/ME. All participants found this suitable as it fitted with their experience of the condition:

“I felt like she believed what was happening, and kind of respected the fluctuations of the condition.” (Eva)

Seeing myself and CFS/ME differently (occurs in therapy room context)

Table 2.3. Subcategories within category 'seeing myself and CFS/ME differently'

Category	Sub-category
Seeing myself and CFS/ME differently	CFS/ME is real and not my fault
	CFS/ME is manageable
	Lowering expectations of myself
	It's ok to put myself first

CFS/ME is real and not my fault.

For several participants the therapist highlighted that CFS/ME was a real and chronic condition. This could be shocking, but was helpful in making sense of things:

“Being able to define and acknowledge about it and say that this is an actual problem, it’s not just this big amorphous blob.” (Will)

Feeling believed by the therapist increased the validity of the illness:

“You weren’t questioned. And so it’s just, you know there is people out there that believe you, and you know you are right.” (Charlie, CBT 2)

For some validation was unique:

“I sort of had somebody else say, “well no you are quite right, you shouldn’t be doing that” because I didn’t have anybody in my life to do that for you know.” (George)

Some participants explored the causes of CFS/ME which reduced frustration and guilt:

“I think it stopped me using energy that I don’t have, being angry about it and looking “why has this happened” and you know, not knowing.” (John)

CFS/ME is manageable.

Therapists describing other people managing CFS/ME was a first step towards hope and reduced fear of the diagnosis, particularly for recently diagnosed participants:

“About like, some people do get better and some people, with help have been able to work more or just work in general or things like that. So, I think, you know, there’s that kind of practical hope” (Rachel)

Therapist positioning of the condition was reassuring:

“She made me realise that it’s just something in my back pocket, it doesn’t have to be something that completely controls my life.” (Layla)

Lowering expectations of myself.

Many participants realised that they placed high expectations on themselves, and were able to find more realistic standards at work:

“Like realising that I put a lot of emphasis on professional competence.” (Eva)

“I think it was, it’s the, you’re only human, a human makes mistakes.” (Sebastian, CBT 2)

And perceive it as acceptable to take on less pressured roles in their personal lives:

“Saying like, put yourself, if you went to somebody’s house, would it matter if you saw them, or would it matter if they produced loads and loads of food?” (Susan)

“How you know you get a different type of mum maybe, but it is still a very valid, valid scenario” (Sarah, CBT 1)

And shifting expectations about coping with the illness:

“When I would say, I don’t know, “I’m a complete failure because I can’t do this, that and the other”, and she’ll make you look at it from the other perspective.” (Fiona)

It’s ok to put myself first.

Participants increasingly recognised that it was valid to prioritise their own needs, often resolving ambivalence and guilt about responsibilities:

“I came away just with that re-focus on putting myself first and not being afraid to do that actually, it is okay to do that when you are not well, it is okay to do that.”

(Sarah, CBT 3)

This was often facilitated by direct therapist advice.

“She basically said, “well just tell them to go away, you don’t have to do anything you don’t want to do” and that was a... I don’t know why I thought I did need to.”

(Jean)

Finding ways to move forwards (occurs in therapy room context)

Table 2.4. Subcategories within category ‘finding ways to move forwards’

Category	Sub-category
Finding ways to move forwards	Understanding what was happening
	Separating what we can and cannot control
	Learning tools and problem solving
	Finding opportunities for enjoyment

Understanding what was happening

Participants found it helpful to identify factors exacerbating their symptoms, which reduced stress and allowed them to respond differently:

“Where everything’s overwhelming and everything’s impossible, just being able to take a look at each piece sort of individually...because there’s so many different aspects to how you end up not being able to do anything.” (Fiona)

Exploring thought patterns and discussing the biological mechanisms of anxiety helped participants better understand their distress:

“All the ways you know that your mind can undermine you...I could see that I was making it worse by upsetting myself.” (George)

Separating what we can and cannot control.

Participants valued separating out problems within their control and those out of their control which resulted in unproductive worrying:

“I think one of the biggest things for me that I remember was talking about what we kind of can and cannot control.” (Rachel)

This helped participants to let go of issues, though this could be challenging:

“And it was sort of learning and accepting that I can’t change things and people involved in my family” (Susan)

“Carry on with life, and then if the next blip hits you, you deal with that when it comes.” (Layla)

Learning tools and problem solving.

Identifying what was within their control could help participants find effective solutions:

“So, then I’ve gone down that avenue, thought about it, what can I control, what can’t I control, yes I can see how much I owe on the mortgage.” (Charlie, CBT 2)

Therapists supported participants to develop problem solving skills:

“I would kind of say that “this has worked” and “that hasn’t” and then we would look at the reasons.” (George)

“I just mean like, dissect things. So, whereas before it’d just be like, “woah, I’m really stressed, and there’s loads of stuff, and I can’t cope.” (Rachel)

Some saw a didactic therapist approach as essential for resolving challenges:

“I felt my first therapist had given me lots of practical ideas, I wanted that, I wanted someone to say, “Right we can sort this out, we can sort that frustration out” and I didn’t get that [in CBT 2 and 3].” (Sarah, CBT 1)

Participants learned tools for communication and managing emotions and energy:

“It gave me strategies to work on. So if you’re really feeling like fatigued or feeling irritable, you need to ask someone to, you need to trust someone to help you.”
(Sebastian, CBT 2)

Finding opportunities for enjoyment.

Planning exercises helped participants look to the future and find opportunities:

“Rather than spending my entire life thinking about getting back to “so called normal” and thinking about all the things I couldn’t do and thinking what can I do and thinking how am I going to do it.” (George)

Exploring timetables helped participants plan their time:

“She’d write it all down and she’d say, “well actually you can do that because you’ve got this and that amount of time every day”. (Fiona)

Lightening the load (occurs in therapy room context)

Table 2.5. Subcategories within category 'lightening the load'

Category	Sub-category
Lightening the load	Resolving broader issues
	Getting things off my chest

Resolving broader issues.

Participants came to experience less anxiety about other issues, such as personal traumas, relationships and identity:

“So it was that sort of, always wanting to be loved, always being, wanted to be accepted, to the point of “I’m really not that fussed with it, you don’t mean nothing to me”” (Sebastian, CBT 2)

For some, this resulted from re-prioritising themselves:

“It was like, if I don’t need these things to affect me and they’re doing me more damage than good then why wouldn’t I just let it go?” (Layla)

This often resulted in feeling less need to change things and more able to step back:

“I think what it’s enabled me to do is deal with this [personal] trauma without involving members of the family, which wasn’t helpful to me.” (Judith)

Resulting in more capacity to focus on managing their condition:

“I do feel that I can clear the way to improvement by dealing with that [personal trauma]” (Judith)

Getting things off my chest.

A space for participants to get things off their chest was often unique:

“It was just a rare opportunity for me to open up to somebody and get things off my chest” (John)

Participants felt less overwhelmed and burdened:

“I got bits off my shoulders about the nasty doctor, the nasty manager, it just felt, you felt lightened, lifted...” (Charlie, CBT 2)

A life I can cope with (Not specific to one context)

Table 2.6. Subcategories within category ‘a life I can cope with’

Category	Sub-category
A life I can cope with	Having ways to take control
	Getting my confidence back
	Living beside CFS/ME
	Making peace with CFS/ME

Having ways to take control.

Participants described a sense of being equipped with understanding, “tools”, solutions, support and an ability to step back, thus feeling more able to manage CFS/ME and life more broadly:

“You can start to see how even if you can’t control it [CFS/ME], you can manage it.”

(George)

“Just kind of being like, you know, understanding what’s going on, it makes such a difference in terms of actually being able to cope with it.” (Will)

“I think it helped because I felt like, it felt like having someone on your team.” (Eva)

Participants also described having more “emotional energy” (Eva) to pursue other interventions after CBT. In this sense, Judith described CBT as “a springboard”.

Feeling equipped allowed participants to regain a sense of control over their illness and lives:

“I think it [saying no to people] made me feel more in control.” (Jean)

“I was very reluctant to do it [say no], but when I started doing it, I started to feel as though I was more in control of my life.” (Sebastian, CBT 1)

This could lead to participants feeling less vulnerable:

“It gave me the controlled focus that, “it doesn’t matter, it’s enough, I don’t care”, because now I’ve got a plan B.” (Charlie, CBT 2)

Feeling equipped, reduced focus on symptoms:

“You focus less on the symptoms of stuff and more on like what you can do.”
(Rachel)

Getting my confidence back.

Participants experienced increased self-esteem, which allowed them to engage more positively in work and personal contexts:

“It also just helped with making me get some more confidence back.” (Layla)

“I’d go back to the pub. I started not to become paranoid, you know?” (Sebastian, CBT 1)

Making sense of their symptoms helped participants be more compassionate to themselves about having the condition and when symptoms intensified:

“I stopped beating myself up, I was knocking myself.” (John)

Some felt more conviction in themselves:

“I did actually write a note to myself of like, this is what I believe and this is who I want to be.” (Will)

Living beside CFS/ME.

Adjustments to their outlook and lifestyle led participants to see CFS/ME as taking less away from their lives:

“just sort of feeling that it was something that wasn’t necessarily going to ruin my life” (George)

“I can live beside it rather than, it doesn’t dominate me in the same way anymore.” (Susan)

Life with CFS/ME could seem more compatible with values and desired roles:

“I remember sort of coming out thinking “yeah okay I can work with that, you know, it is a good thing for them [my children]” (Sarah, CBT 1)

This reduced the need for certainty and seeking further information:

“Just putting it in your back pocket kind of makes it feel okay to know what’s not going to happen in the future.” (Layla)

Despite Judith feeling more able to manage broader issues, her perception of living with CFS/ME did not shift over the CBT:

“At that stage I didn’t have any hope. Now [following further interventions] I have a little bit of hope.” (Judith)

Making peace with CFS/ME.

Most participants felt less distressed about living with the illness, described as “making peace with it” by Layla.

“This life, I am living with it, it’s helped me to be more relaxed with it.” (John)

Feeling more able to manage increased hope for the future:

“I think understanding things also gives a lot of hope, because yeah, I’m more able to deal with stuff.” (Rachel)

Natural adjustment and therapeutic processes contributed to the process:

“CBT has helped me accept frustration and leave frustration to one side.” (Susan)

Frustration about the condition remained for several participants, particularly around limitations imposed by the illness:

“It’s difficult, it’s not the mum I want to be.” (Sarah)

Accepting the reality of CFS/ME (Not specific to one context)

Many participants underwent the process of “accepting” having CFS/ME. This involved acknowledging the extent of their symptoms and absence of an immediate way of curing or controlling them:

“an acceptance or understanding that I might need to stop expecting progress to happen really quickly” (Eva)

But did not mean relinquishing hope of gradual longer-term improvement:

“Just kind of accepting that at least for the time being. Yeah I think not thinking this is forever.” (Will)

For some, acceptance happened prior to CBT, but many described CBT facilitating this:

“Before I was fighting it in every way. This has just made me say, “yeah I am shattered””. (John)

Acceptance could result from participants gaining understanding of their symptoms, via exploratory methods such as diaries, and more didactic therapist approaches:

“To have someone actually saying, “well when are you going to accept that that’s what you’ve got?”, it’s like, oh my god, it’s quite a wake up.” (Fiona)

For some, acceptance depended on participants lowering expectations of themselves or self-criticism:

“not being so hard on myself. That’s what made me accept I’m a CFS person.”
(Sebastian, CBT 2)

“rather than beating myself up in my own head and being angry about it, and just saying “you don’t like it but that is how it is”. (John)

And seeing CFS/ME as less detrimental due to feeling more able to live alongside it:

“Not living with it in terms of accepting it and then being like, “oh I can’t do this or this because I’m ill”” (Layla)

Acceptance was often initially distressing, and involved making adjustments such as reducing activity:

“And it was learning that I can grieve that I can’t do dinner parties for sixteen people anymore, but actually that that doesn’t matter.” (Susan)

Sebastian reported only accepting the nature of CFS/ME after a second set of CBT. Judith did not understand the extent of her symptoms until after CBT, as she reported being encouraged by the therapist to increase her activity:

“I don’t think she was asking me to accept. She was telling me I could push though. I could push through, I could do this extra walking every week” (Judith)

Having tools (occurs in daily life context)

Table 2.7. Subcategories within category ‘having tools’

Category	Sub-category
Having tools	Taking a different perspective
	Control over my responses
	More able to communicate

Participants described using tools learned in therapy in their everyday lives. Experience of doing this contributed to a sense of “having ways to take control” (earlier subcategory).

Taking a different perspective.

Participants became able to take a different perspective on symptoms and broader issues in their daily lives, often using metaphors or images. This reduced distress:

“Just seeing it [symptom worsening] as like waves you know, that occasionally you get three big ones in a row.” (George)

“If I felt I was going into a panic about anything, to ‘catch a train in the other direction.’” (Judith)

This was facilitated by increased awareness of unhelpful thought patterns:

“CBT gave me sort of skills which I will you know probably use forever really you know. Really noticing when I am catastrophising for instance.” (George)

Which allowed people to relate differently to their thoughts:

“and really just able to come out of myself a little bit and just look at it more as an observer really.” (Fiona)

It was harder to challenge thinking when symptoms intensified:

“I know I can generally pick up from these sort of dips but it is still difficult to convince yourself that it is a temporary blip.” (Sarah)

Alternative perspectives led to a reduction in extreme distress:

“It stopped me from spiralling to overwhelmed and despair a lot more.” (Eva)

Control over my responses.

Participants saw tools such as time out and problem solving as ways of gaining control over their emotional responses:

“Just taking a time out made it a lot easier and made the blips less worse. So I wouldn’t be going in a panic attack.” (Layla)

Allowing them to make decisions in a way that was helpful for managing the condition:

“Whereas previously to that, I’d just kind of said yes. I think mostly because I didn’t have the tools to kind of rationalise things and process it and be able to be like, “actually this is unreasonable.”” (Rachel)

Taking control allowed them to do more of what they wanted:

“Just by counting, “one, two, three, four, one, two, three, four”, that’s really helped me be able to get up and take the next steps.” (Will)

More able to communicate.

Several participants felt more able to communicate and negotiate with others, particularly about their needs:

“I could kind of talk about things more. So, if I needed to have a conversation at work, or I needed to say that I couldn’t do something because it was too much, I was able to have that conversation.” (Rachel)

This could be due to feeling less preoccupied, freeing up thinking space:

“It cleared my head. Then helped me think, concentrate on the other side, the arguments we could have” (Charlie, CBT 2)

Or feeling less distressed, having *lightened the load* in the therapy room:

“It meant I suppose that I could save the emotional stuff and dump it there and then be more choosy and more selective about what I ran past him [my husband].”

(Sarah, CBT 1)

Or having better understanding and a language to explain their difficulties:

“Just going from, “I’m tired all the time”, to having more vocabulary is definitely helpful.” (Rachel)

Which could lead to better support:

“I think with personal understanding comes, your circle become more understanding as well.” (Rachel)

Putting less pressure on myself (occurs in daily life context)

Table 2.8. Subcategories within category ‘Putting less pressure on myself’

Category	Sub-category
Putting less pressure on myself	Cutting back on demands
	Re-prioritising my needs
	Being more open about my needs

Cutting back on demands.

Almost all participants cut back the demands placed on themselves in work and social contexts. This was typically due to better understanding and acceptance of their condition and re-evaluating their expectations of themselves:

“Trying to actually have rest properly if you want to rather than waiting until you’re just so wrecked you can’t do anything. So, it is feeling, and I know it’s what everyone says, but I never understood the whole meaning of “try to be kind to yourself”.”
(Fiona)

“I just have given up trying to achieve as much.” (Susan)

Some initially required implicit “permission” (Rachel) from the therapist to cut back.

Others found it necessary to use strict boundaries:

“It’s now got different boxes, different sections. That’s my work box, that’s it, gone, nine to five.” (Sebastian, CBT 2)

Cutting back was less likely for those who had not reached an understanding of the condition:

“It wasn’t long enough for me, myself, to reach an understanding of what I needed to do to protect myself.” (Judith)

Lack of acceptance of the chronic nature of the condition could result in reverting to old habits:

“I thought I was cured. You know, and I carried on, I thought “yeah, it’s back to going to events and weekends away.” (Sebastian, CBT 1)

Re-prioritising my needs.

Re-evaluating their responsibilities led several participants to re-prioritise their own needs, often by letting go of responsibilities or relationships:

“I am being more selfish about making those decisions and if I can throw money at the issue I will throw money at the issue and if I can’t then someone else has to help out.” (Sarah, CBT 3)

“I definitely remember thinking, “I’m going to do what I want now and I’m going to tell this person I’m not seeing them again” (Jean)

Participants became more willing to say no:

“Generally, I’m better at putting my foot down and saying, “no, I’m sorry, I can’t do that”. (Susan)

This shift was often uncomfortable:

“For her [my wife] to be told that she was impacting on my health was quite a difficult conversation.” (Sebastian, CBT 1)

This became increasingly easier with experience:

“Once I started to actually say something, it wasn’t negative, I haven’t lost my job, I haven’t gone down the ladder.” (Rachel)

Participants often introduced new forms of self-care, often based on therapist advice:

“I’ll go make myself a cup of tea or something. So yeah, I more sort of made myself a bit more important.” (Layla)

Being more open about my needs.

Many participants became more open about their physical and emotional needs. This could become easier after therapist validation which provided a language with which to discuss it:

“I suppose because someone else has validated it, rather than feeling like, it’s very difficult to say to someone “actually I just feel really really shit”.” (Fiona)

Some were encouraged by the therapist to test out fears about talking:

“She would say “just push a little bit more, just open up a little bit more and see what happens”.” (John)

Others felt more comfortable after a positive experience of talking in therapy:

“Once I have said it to someone it’s okay sort of thing, it’s already out there in the ether, it’s maybe easier to say it again to someone.” (Sarah, CBT 1)

Increased openness typically led participants to feel more supported:

“They are a little bit more aware and a little bit more understanding.” (John)

Doing more of what I value (occurs in daily life context)

Table 2.9. Subcategories within category ‘Doing more of what I value’

Category	Sub-category
Doing more of what I value	More courage to do things
	Having more capacity

More courage to do things.

Having tools and *Being more open about my needs* led to situations seeming more manageable and less avoidance:

“I didn’t let it kind of stop me doing things as much...” “it [the CBT] did just give me more motivation and more positivity and courage I guess to actually think, “okay, fine, I’m going to be tired today, and I can tell my friends that.”” (Will)

And being able to relax and engage more fully during activities:

“Rather than doing it and questioning whilst I’m doing it, if I can do it. It’s more like I’m doing it because I actually know I can do it.” (Layla)

Understanding their fears allowed participants to respond differently and face difficult situations:

“I’m more able to kind of like go back to the source [of fear] rather than just living in that perpetual cycle of, “I’m just going to be really tired, so I can’t do it, can’t do it, can’t do it”. (Rachel)

Having more capacity.

Participants felt less preoccupied and stressed, which made space for valued activities and topics of conversation:

“Being able to kind of like sort things out from a work perspective and push back there, I was kind of able to go back to singing.” (Rachel)

“If I got it out of my system I would be more likely to talk about other stuff” (George)

Participants had more time and energy:

“Being able to take time to maybe go to the travel agent with my wife or go on the website. Before I would be too tired to do that, I would just drop in bed.” (Sebastian, CBT 1)

Planning and goal setting exercises helped participants re-engage in active planning:

“I suddenly started thinking, “okay I’ve got to maybe get my brain working again and start thinking for myself” (Jean)

Discussion

This study aimed to explore service users’ experiences of CBT for CFS/ME. Specifically it examined what changes, if any, service users experienced, to what they attributed these changes and what conditions were required for participants to undergo these changes. These will each be discussed in the context of extant literature, considering limitations of the study alongside implications for clinical practice and future research.

Fatigue outcomes

In line with Geraghty et al. (2017) in this study, participants described either experiencing no change in their symptoms over CBT or some reduction in relapses but ongoing regular symptoms. This was not unexpected given that the CBT model adopted by the service aimed to improve quality of life, rather than eliminate symptoms via reconditioning.

Psychological outcomes

Turning to psychological outcomes, overall the results highlighted two key reported changes after CBT. Firstly, intervention components from the therapy room, alongside subsequent changes made in daily life, seemed to result in participants feeling more able to cope with life with CFS/ME. This echoes previous studies (Picariello et al., 2017; Dennison et al., 2010). Secondly, in line with studies of other psychosocial interventions for CFS/ME (Chew-Graham et al., 2011; Denmark, 2017; Pinxsterhuis et al., 2015a), including CBT (Brook et al., 2011), several participants reported greater 'acceptance' post intervention, which meant acknowledgement that there was no immediate way of curing or controlling their symptoms. This contributed to making adjustments in daily life, which in turn further increased participants' belief that they could cope, which in turn increased further acceptance of the condition. This suggests a 'cycle' of accepting and coping. The processes facilitating these changes will be addressed in turn.

A life I can cope with

The study suggested that CBT led to participants perceiving life with CFS/ME as more manageable. As found in Dennison et al. (2010), facets of this included participants feeling more in control and developing greater belief that it was possible to live alongside the condition. Factors facilitating this in the therapy room seemed to include making sense of the

illness, finding ways to solve problems and meet values, and the therapist providing hope. In line with the survey results presented in Geraghty (2017), participants particularly valued learning how to manage their energy or 'pace' and tools for managing emotions. Results suggested that it was helpful for the therapist to take a holistic approach allowing understanding and validation of participants' unique difficulties. This allowed participants to process and resolve broader issues such as traumas, relationships, roles, identity and unrealistic expectations of themselves. This often then reduced barriers to managing their condition.

Together these facilitated participants taking a more adaptive approach to managing daily life. This then also contributed to participants starting to view life with CFS/ME as manageable. Participants described lowering expectations of themselves and prioritising their own needs. This echoes Brooks et al. (2011), who found reduced perfectionism and fatigue after CBT. Brooks et al. questioned whether the reduction in perfectionism in fact reflected a reduction in 'goal discrepancy' (being unable to achieve a valued goal) due to improved fatigue. This study suggests otherwise, as participants described lowering expectations of themselves often without any associated improvement in fatigue. In fact, data suggested that it was a lowering of standards that led to better management of symptoms, both directly and via increased acceptance of the condition.

Pinxsterhuis, Strand and Sveen (2015b) found that outside of interventions, the use of adaptive coping strategies in CFS/ME, such as pacing, was facilitated by participants rebuilding their identities. This involved letting go of a past sense of self and looking to future sources of fulfilment. This current study extends this to suggest that interventions can facilitate this process, leading to more adaptive coping. Of particular importance were

discussions around expectations of self, roles and identity, as well as problem solving new ways of meeting values.

Acceptance

The study echoes the findings of Pinxsterhuis et al. (2015b) in suggesting that accepting the nature of CFS/ME in the short term did not mean giving up hope of gradual longer-term improvement. The study extended existing knowledge by identifying several factors that facilitated this. For some, acceptance resulted from reduced guilt and anxiety after receiving information and/or validation that CFS/ME was not their 'fault.' For many, it was facilitated by participants lowering the expectations they had of themselves and thus re-building an identity which could accommodate a representation of the illness. Initially the acceptance process could feel like 'grieving'. Acceptance often led to participants re-prioritising their needs and putting less pressure on themselves, which allowed better management of CFS/ME. This may explain the findings of Brooks et al. (2011) that following CBT increased acceptance was correlated with improvements in self-reported fatigue and functioning. Notably, results suggested a cycle in which adapting approaches to daily life resulted in seeing life with CFS/ME as more manageable, which in turn facilitated increased acceptance of the condition. In their study of CBT, Brooks et al. (2011) suggested that acceptance may have been driven by improvements in fatigue which resulted in the condition 'interfering' less in their lives. The cycle highlighted in this study extends this by suggesting that acceptance may be driven by a perceived improvement in *functioning*, even if participants do not perceive improved *fatigue*.

Limitations

Although the study was guided by grounded theory methodology, its use of theoretical sampling was limited. Although the development of the interview schedule was influenced by the ongoing analysis, due to limitations resulting from recruitment, the selection of participants did not allow the testing of specific hypotheses.

Another limitation is that most participants seemed to have benefited from CBT to some extent. This may be a consequence of opportunity sampling via the service in which the intervention was delivered and participants who benefitted wanting to 'give back.' It was not possible to use purposive sampling to capture a breadth of experience, which would have been desirable, as those with poorer outcomes from CBT may have provided more data around barriers to therapeutic change. A wider range of ethnic variation amongst participants would also have been desirable. In addition, it was not possible to ascertain data on when precisely participants completed CBT within the previous two years, which limits conclusions which can be drawn on follow up effects. Due to these limitations, the findings may not be applicable to all individuals with the condition.

Although a strength of this study is the various 'credibility checks' that were put in place, participants' responses both during the interviews and respondent validation may have been influenced by a social desirability bias.

Implications

Clinical

This study suggests that CBT in which the primary aim is improving quality of life, rather than increasing activity and reducing fatigue, can be experienced by service users as very beneficial

and result in reduced distress about life with CFS/ME. CFS/ME remains a poorly understood area and this study highlights that services may be faced with the dilemma of whether to adhere strictly to NICE guidelines and deliver interventions aimed at increasing activity, despite relatively poor outcomes and high levels of patient dissatisfaction. Alternatively, based on clinical judgement, services may wish to deviate slightly from guidelines, adopting more novel approaches with less of an evidence base, as was the case in this study. As demonstrated, this can create opportunities for innovation, advancing understanding and broadening thinking about the range of ways in which service users can be helped. It is important to note that all participants in this study found it appropriate that the goal of therapy was positioned as better management of CFS/ME and quality of life rather than physical recovery. This model of CBT may not be suitable for service users who view the goal as recovery.

Results suggest that interventions should identify and address barriers to service users managing their CFS/ME, explore ways of helping service users meet their values and increase their acceptance of the nature of the condition. Interventions might include exploration of service users' expectations of themselves, identities, roles and relationships. Clinicians should be aware of the value of addressing holistic issues in service users' lives. Results suggest the value of interventions providing skills in pacing, as well as problem solving, a recommended component of CBT for CFS/ME in the NICE guidelines (2007) and cognitive tools to manage distress, which is a hallmark of CBT more generally. These skills not only appear to reduce distress but allow for greater engagement in valued activities.

Research

Research exploring psychological outcomes and processes in CBT for CFS/ME is in its infancy. It may be appropriate to explore aspects of the model developed here through quantitative research. For instance, measuring changes in distress or quality of life using a sample only

receiving this specific model of CBT. It may be useful to conduct mediation analysis of this model of CBT; measures might include self efficacy/sense of control, perfectionism/self compassion, acceptance or denial of having a chronic illness and valued living. It may also be useful to identify the active components of this CBT model using component analysis (Cooper, Heron, & Heward, 2007).

Future research might also consider whether the current model could be extended to service users with more severe fatigue, for example those who are homebound.

Conclusion

The study produced several novel findings. Firstly, CBT aimed at improved management of CFS/ME, rather than increased activity, was viewed as acceptable by participants and led to reduced distress about living with the condition. Secondly, this was not dependent on improvements in fatigue. This was facilitated by exploring and resolving issues around CFS/ME and identity and learning tools such as problem solving and pacing, which together facilitated taking a more adaptive approach to daily life and becoming able to do more of what they valued. A common part of the therapeutic process was increased acceptance of the reality of having CFS/ME. Again, this occurred independently of improvement in fatigue and led to more adaptive coping, in turn reducing distress about the condition. Results suggest the need for interventions addressing the above factors. However, it is unclear to what extent these apparent improvements in daily living may be maintained in the long term, and whether they may lead to less experience of fatigue and activity-restriction. Further research is needed to test out the model suggested in this study.

References

- Afari, N., & Buchwald, D. (2003). Chronic fatigue syndrome: A review. *American Journal of Psychiatry, 160*, 221–236. <https://doi.org/10.1176/appi.ajp.160.2.221>
- Bleijenberg, G., Prins, J., & Bazelmans, E. (2003). Cognitive Behavioural Therapies. In Jason, L.A., Fennell, P.A., Taylor, R.R., *Handbook of Chronic Fatigue Syndrome* (pp. 493-526). Hoboken, New Jersey: John Wiley and Sons.
- Brooks, S. K., Rimes, K. A., & Chalder, T. (2011). The role of acceptance in chronic fatigue syndrome. *Journal of psychosomatic research, 71*(6), 411-415. <https://doi.org/10.1016/j.jpsychores.2011.08.001>
- Cairns, R., & Hotopf, M. (2005). A systematic review describing the prognosis of chronic fatigue syndrome. *Occupational medicine, 55*(1), 20-31. <https://doi.org/10.1093/occmed/kqi013>
- Castell, B. D., Kazantzis, N., & Moss-Morris, R. E. (2011). Cognitive behavioral therapy and graded exercise for chronic fatigue syndrome: A meta-analysis. *Clinical Psychology: Science and Practice, 18*(4), 311-324. <https://doi.org/10.1111/j.1468-2850.2011.01262.x>
- Chew-Graham, C., Brooks, J., Wearden, A., Dowrick, C., & Peters, S. (2011). Factors influencing engagement of patients in a novel intervention for CFS/ME: a qualitative study. *Primary health care research & development, 12*(2), 112-122. <https://doi.org/10.1017/S146342361000037X>
- Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory into practice, 39*(3), 124-130. https://doi.org/10.1207/s15430421tip3903_2

- Davis, R. W., Edwards, J. C. W., & Jason, L. A (2015). *An open letter to Dr. Richard Horton and the Lancet*. Virology blog: about viruses about viral disease 2015. Available from: <http://www.virology.ws/2015/11/13/an-open-letter-to-dr-richard-horton-and-the-lancet/>.
- Deale, A., & Wessely, S. (2001). Patients' perceptions of medical care in chronic fatigue syndrome. *Social science & medicine*, 52(12), 1859-1864. [https://doi.org/10.1016/S0277-9536\(00\)00302-6](https://doi.org/10.1016/S0277-9536(00)00302-6)
- Denmark, B. (2017). Patient perspectives on mental health therapy for myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS). *Theses, Dissertations, and Projects*. 1887. Retrieved from: <https://scholarworks.smith.edu/theses/1887>
- Dennison, L., Stanbrook, R., Moss-Morris, R., Yardley, L., & Chalder, T. (2010). Cognitive behavioural therapy and psycho-education for chronic fatigue syndrome in young people: Reflections from the families' perspective. *British journal of health psychology*, 15(1), 167-183. <https://doi.org/10.1348/135910709X440034>
- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British journal of clinical psychology*, 38(3), 215-229. <https://doi.org/10.1348/014466599162782>
- Friedberg, F. (2016). Cognitive-behavior therapy: why is it so vilified in the chronic fatigue syndrome community? *Fatigue: biomedicine, health & behavior*, 4(3), 127-131. <https://doi.org/10.1080/21641846.2016.1200884>
- Geraghty, K. J. (2017). 'PACE-Gate': When clinical trial evidence meets open data access. *Journal of Health Psychology*, 22(9), 1106-1112. <https://doi.org/10.1177/1359105316675213>

- Geraghty, K. J., & Blease, C. (2018). Cognitive behavioural therapy in the treatment of chronic fatigue syndrome: A narrative review on efficacy and informed consent. *Journal of health psychology, 23*(1), 127-138. <https://doi.org/10.1177/1359105316667798>
- Geraghty, K., Hann, M., & Kurtev, S. (2017). Myalgic encephalomyelitis/chronic fatigue syndrome patients' reports of symptom changes following cognitive behavioural therapy, graded exercise therapy and pacing treatments: analysis of a primary survey compared with secondary surveys. *Journal of health psychology, 1-16*. <https://doi.org/10.1177/1359105317726152>
- Glaser, B. (1978) *Theoretical sensitivity: Advances in the methodology of Grounded Theory*. Mill Valley, CA: Sage.
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. *Handbook of qualitative research, 2*(163-194), 105.
- Cooper, J. O., Heron, T. E., & Heward, W. L. (2007). Applied behavior analysis.
- IOM (Institute of Medicine). (2015). *Beyond myalgic encephalomyelitis/chronic fatigue syndrome: Redefining an illness*. Washington, DC: The National Academies Press.
- Jacobsen, H. B., Kallestad, H., Landrø, N. I., Borchgrevink, P. C., & Stiles, T. C. (2017). Processes in acceptance and commitment therapy and the rehabilitation of chronic fatigue. *Scandinavian journal of psychology, 58*(3), 211-220. <https://doi.org/10.1111/sjop.12363>
- Jonsjö, M. A., Wicksell, R. K., Holmström, L., Andreasson, A., & Olsson, G. L. (2019). Acceptance & Commitment Therapy for ME/CFS (Chronic Fatigue Syndrome)—a feasibility study. *Journal of Contextual Behavioral Science*. <https://doi.org/10.1016/j.jcbs.2019.02.008>

Mays, N., & Pope, C. (2000). Assessing quality in qualitative research. *Bmj*, 320(7226), 50-52.

<https://doi.org/10.1136/bmj.320.7226.50>

ME Association. (2015). ME/CFS illness management survey results: No decisions about me

without me. *Patient Survey*, May. Retrieved from:

<https://www.meassociation.org.uk/wp-content/uploads/2015-ME-Association-Illness-Management-Report-No-decisions-about-me-without-me-30.05.15.pdf>

Poppe, C., Crombez, G., Hanoulle, I., Vogelaers, D., & Petrovic, M. (2012). Mental quality of

life in chronic fatigue is associated with an accommodative coping style and neuroticism: a path analysis. *Quality of life Research*, 21(8), 1337-1345.

<https://doi.org/10.1007/s11136-011-0048-8>

Picariello, F., Ali, S., Foubister, C., & Chalder, T. (2017). 'It feels sometimes like my house has

burnt down, but I can see the sky': A qualitative study exploring patients' views of cognitive behavioural therapy for chronic fatigue syndrome. *British journal of health psychology*, 22(3), 383-413. <https://doi.org/10.1111/bjhp.12235>

Pinxsterhuis, I., Strand, E. B., Stormorken, E., & Sveen, U. (2015a). From chaos and insecurity

to understanding and coping: experienced benefits of a group-based education programme for people with chronic fatigue syndrome. *British Journal of Guidance & Counselling*, 43(4), 463-475. <https://doi.org/10.1080/03069885.2014.987725>

Pinxsterhuis, I., Strand, E. B., & Sveen, U. (2015b). Coping with chronic fatigue syndrome: a

review and synthesis of qualitative studies. *Fatigue: Biomedicine, Health & Behavior*, 3(3), 173-188. <https://doi.org/10.1080/21641846.2015.1035519>

Price, J. R., Mitchell, E., Tidy, E., & Hunot, V. (2008). Cognitive behaviour therapy for chronic

fatigue syndrome in adults. *The Cochrane Library*. <https://doi.org/10.1002/14651858.CD001027.pub2>.

- Reme, S. E., Archer, N., & Chalder, T. (2012). Experiences of young people who have undergone the Lightning Process to treat chronic fatigue syndrome/myalgic encephalomyelitis—a qualitative study. *British journal of health psychology, 18*(3), 508-525. <https://doi.org/10.1111/j.2044-8287.2012.02093.x>
- Roche, L., Dawson, D. L., Moghaddam, N. G., Abey, A., & Gresswell, D. M. (2017). An Acceptance and Commitment Therapy (ACT) intervention for Chronic Fatigue Syndrome (CFS): a case series approach. *Journal of Contextual Behavioral Science, 6*(2), 178-186. <https://doi.org/10.1016/j.jcbs.2017.04.007>
- Ryff, C. D. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of personality and social psychology, 57*(6), 1069.
- Short, K., McCabe, M., & Tooley, G. (2002). Cognitive functioning in chronic fatigue syndrome and the role of depression, anxiety, and fatigue. *Journal of psychosomatic research, 52*(6), 475-483. [https://doi.org/10.1016/S0022-3999\(02\)00290-8](https://doi.org/10.1016/S0022-3999(02)00290-8)
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research techniques*. Thousand Oaks, CA: Sage publications.
- Surawy, C., Hackmann, A., Hawton, K., & Sharpe, M. (1995). Chronic fatigue syndrome: a cognitive approach. *Behaviour research and therapy, 33*(5), 535-544. [https://doi.org/10.1016/0005-7967\(94\)00077-W](https://doi.org/10.1016/0005-7967(94)00077-W)
- Urquhart, C. (2013). *Grounded Theory for qualitative research: A practical guide*. London, UK: Sage Publications
- Van Houdenhove, B. (2006). What is the aim of cognitive behaviour therapy in patients with chronic fatigue syndrome?. *Psychotherapy and psychosomatics, 75*(6), 396-397. <https://doi.org/10.1159/000095448>

White, P. D., Goldsmith, K. A., Johnson, A. L., Potts, L., Walwyn, R., DeCesare, J. C., ... & Bavinton, J. (2011). Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. *The Lancet*, *377*(9768), 823-836. [https://doi.org/10.1016/S0140-6736\(11\)60096-2](https://doi.org/10.1016/S0140-6736(11)60096-2)

White, P. D., Goldsmith, K., Johnson, A. L., Chalder, T., & Sharpe, M. (2013). Recovery from chronic fatigue syndrome after treatments given in the PACE trial. *Psychological medicine*, *43*(10), 2227-2235. <https://doi.org/10.1017/S0033291713000020>

Wilshire, C. E., Kindlon, T., Courtney, R., Matthees, A., Tuller, D., Geraghty, K., & Levin, B. (2018). Rethinking the treatment of chronic fatigue syndrome—a reanalysis and evaluation of findings from a recent major trial of graded exercise and CBT. *BMC psychology*, *6*(1), 6. <https://doi.org/10.1186/s40359-018-0218-3>

Section C: Appendices

Appendices for Section A

Appendix A: Guidelines taken from Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields.

A. Publishability guidelines shared by both qualitative and quantitative approaches

Although qualitative researchers often design their studies from a different philosophy of science than that followed by experimentalists, they generally share the following traditional guidelines for publishability of their research

1. *Explicit scientific context and purpose.* The manuscript specifies where the study fits within relevant literature and states the intended purposes or questions of the study.

2. *Appropriate methods.* The methods and procedures used are appropriate or responsive to the intended purposes or questions of the study.

3. *Respect for participants.* Informed consent, confidentiality, welfare of the participants, social responsibility, and other ethical principles are fulfilled. Researchers creatively adapt their procedures and reports to respect both their participants' lives, and the complexity and ambiguity of the subject matter.

4. *Specification of methods.* Authors report all procedures for gathering data, including specific questions posed to participants. Ways of organizing the data and methods of analysis are also specified. This allows readers to see how to conduct a similar study themselves, and to judge for themselves how well the reported study was carried out.

5. *Appropriate discussion.* The research data and the understandings derived from them are discussed in terms of their contribution to theory, content, method, and/ or practical domains, and are presented in appropriately tentative and contextualized terms, with limitations acknowledged.

6. *Clarity of presentation.* The manuscript is well-organized and clearly written, with technical terms defined.

7. *Contribution to knowledge.* The manuscript contributes to an elaboration of a discipline's body of description and understanding.

B. Publishability guidelines especially pertinent to qualitative research

The following guidelines are either specific to qualitative research, or are specifications of how more general principles apply to qualitative research. These guidelines are not intended to be all-inclusive or definitive. Authors should be able to address how they meet the intentions of these guidelines for reporting qualitative research, or their rationales for meeting alternative standards.

1. *Owning one's perspective.* Authors specify their theoretical orientations and personal anticipations, both as known in advance and as they became apparent during the research. In developing and communicating their understanding of the phenomenon under study, authors attempt to recognize their values, interests and assumptions and the role these play

in the understanding. This disclosure of values and assumptions helps readers to interpret the researchers' data and understanding of them, and to consider possible alternatives.

2. *Situating the sample.* Authors describe the research participants and their life circumstances to aid the reader in judging the range of people and situations to which the findings might be relevant.

3. *Grounding in examples.* Authors provide examples of the data to illustrate both the analytic procedures used in the study and the understanding developed in the light of them. The examples allow appraisal of the fit between the data and the authors' understanding of them; they also allow readers to conceptualize possible alternative meanings and understandings.

4. *Providing credibility checks.* Researchers may use any one of several methods for checking the credibility of their categories, themes or accounts. Where relevant, these may include (a) checking these understandings with the original informants or others similar to them; (b) using multiple qualitative analysts, an additional analytic 'auditor', or the original analyst for a 'verification step' of reviewing the data for discrepancies, over-statements or errors; (c) comparing two or more varied qualitative perspectives, or (d) where appropriate, 'triangulation' with external factors (e.g. outcome or recovery) or quantitative data.

5. *Coherence.* The understanding is represented in a way that achieves coherence and integration while preserving nuances in the data. The understanding fits together to form a data-based story} narrative, 'map', framework, or underlying structure for the phenomenon or domain.

6. Accomplishing general vs. specific research tasks. Where a *general* understanding of a phenomenon is intended, it is based on an appropriate range of instances (informants or situations). Limitations of extending the findings to other contexts and informants are specified. Where understanding a *specific* instance or case is the goal, it has been studied and described systematically and comprehensively enough to provide the reader a basis for attaining that understanding. Such case studies also address limitations of extending the findings to other instances.

7. Resonating with readers. The manuscript stimulates resonance in reader/reviewers, meaning that the material is presented in such a way that readers/reviewers taking all other guidelines into account, judge it to have represented accurately the subject matter or to have clarified or expanded their appreciation and understanding of it.

Appendix B: Table 4. Studies evaluated against quality criteria

Study	Aim	Owning one's perspective	Situating the sample	Grounding in examples	Providing credibility checks	Coherence	Accomplishing general vs. specific research tasks	Resonating with readers	Comments
Adamowicz et al (2017)	To identify change attributions offered by patients to explain changes in their overall condition following a home self management intervention for severe CFS.	No No reflection on this.	Yes Information provided on age, gender, illness duration, illness severity and disability status. Upper and lower age limit unclear. Intervention well described.	No None included Including quotes is best practice for framework analysis (Gale, Heath, Cameron, Rashid, & Redwood, 2013)	Partly Multiple researchers used in main coding of themes. However, no information about how themes were categorised into 'active' or 'passive' styles.	Partly 20 themes were grouped into two categories: active and passive coping.	Yes Aim was to understand a specific intervention, for a specific group of patients. Analysis covers comprehensive range of factors relating to the phenomenon including factors intrinsic and extrinsic to the intervention. Authors note limits to extending findings beyond patients with severe CFS/ME.	Partly Clear and assessable language and concepts. Themes presented as single phrases without quotes or further detail, reducing meaning and resonance.	LOW QUALITY (for the qualitative component of the study) This was an interesting study, with useful quantitative data but the qualitative data lacked depth. The majority of themes were developed from a previous study, which could result in researchers not remaining open to new themes in the data.

Blazquez et al (2010)	To evaluate the influence of dance movement therapy (DMT) on the perception of well-being and functional capacity in women with CFS and understand personal responses to the intervention.	No No reflection on this.	No Gender and age provided with vague detail on duration of CFS. Precise recruitment method was unclear. Intervention not well described.	Partly The three main themes are reported as one-word headings each followed by a series of quotes, without further analysis. As themes are abstract in nature, it is not clear how they closely reflect the meaning of the quotes.	Yes Coding of raw data was carried out by two investigators and discrepancies discussed and resolved.	No As the themes are not explained in any detail, nor broken down into subthemes, the results lack structure and coherence.	Partly Aim was to understand a specific intervention. Only positive comments were reported. Analysis of the experience was not comprehensive. Authors note that results cannot be extended to other contexts.	No The English is poor at times and the meaning of some sentences and quotes is unclear. Due to lack of analysis of quotes, the results lack sufficient detail.	LOW QUALITY
Cheshire et al (2018)	Explore the experiences of patients who have completed Guided graded Exercise Self-help (GES), and differences between the experiences of those reporting an improvement compared with those reporting a deterioration in their condition.	Partly The professional and personal experience of one researcher (the interviewer) is given, but their orientation and anticipations are not stated. Nor is it clear whether this was the researcher who conducted the initial analysis. The positions of the other three authors/researchers are not stated.	Yes Basic details provided (gender, age and duration of CFS). No details on illness severity or class/ethnicity. Intervention well described.	Yes The basis of themes can be understood from the multiple quotes presented.	Partly The method suggests that only one researcher was involved in coding the raw data. Other authors 'debated higher order concepts'. Analysis was critiqued and contributed to by the other authors, independent researchers, and patient representatives.	Yes	Yes Aim was to understand a specific intervention and authors note that results cannot be extended to other interventions. Themes describe a comprehensive range of aspects of the therapy experience, including barriers and facilitators to engagement and responses to the intervention.	Yes Clear, detailed, meaningful descriptions and multiple quotes, results in high resonance.	HIGH QUALITY A very useful study highlighting in rich detail the challenges encountered during GET and barriers and facilitators to engagement.

Chew-Graham et al (2011)	To establish participants' perspectives on the factors which are important for patient engagement in a Pragmatic Rehabilitation (PR) intervention.	No No reflection on this.	Yes Details provided on gender, age, marital status, duration of CFS. Authors present further descriptive data which is not interpreted (e.g. scores on measures of deprivation and functioning). Intervention well described.	Yes Many quotes provided to demonstrate themes.	Yes Interpretation and coding of the data were undertaken by all five authors and themes were agreed upon through discussion. Authors were from different professional and academic backgrounds, to increase the trustworthiness of the analysis.	Yes Themes are grouped into 3 overarching categories.	Yes Aim was to understand a specific intervention and authors note the limitations to extending findings to other contexts. Sample was purposively selected to achieve mix of gender, age, postcode, illness duration, functioning level and beliefs about suitability of treatment model.	Yes Clear language with many quotes led to high resonance.	HIGH QUALITY
Denmark (2017)	To explore experiences of people living with ME/CFS related to psychotherapy, their opinions about their treatment and recommendations for psychotherapists working with people living with ME/CFS.	No No reflection on this.	Partly Details provided on gender, age, ethnicity, duration of CFS, and country of residence. Details of the psychotherapy interventions received not included.	Yes Lots of examples- feel some of the raw data is not captured in the named theme, but the theme is well demonstrated by the quote/data.	Yes A second reader reviewed themes and subthemes for validity.	Yes Grouped into 3 themes, with subthemes.	Yes Aim was to understand the general experience of a range of psychotherapy interventions. Large sample size and participants recruited from different countries and interventions, capturing a diversity of experiences. Author notes lack of diversity in gender and race of	Yes Simple meaningful language, lots of	HIGH QUALITY Focused on helpful and unhelpful treatment components, but also therapeutic discusses processes such as grief and acceptance.

								participants and implications for extending findings.	
Dennison et al (2010)	To explore in detail adolescent patients' and their parents' experience of both family-focussed CBT and psychoeducation (PE) for CFS.	Partly Acknowledge position as health psychologists and CBT practitioners and the influence of 'biases' but provide no further detail of these or influence on anticipations. Coding blind to group allocation.	Yes Basic details provided on gender, age, ethnicity and self-reported improvement post intervention. No details on duration/severity of CFS. Intervention well described.	Partly Some quotes, but the basis for some themes not provided.	Partly No evidence of a second researcher auditing initial codes. Other researchers were involved at a later stage of analysis. Constant comparison was used.	Yes Grouped into 3 themes, with minor themes. Young person and parent comments subthemes are distinguished.	Yes Aim was to understand specific interventions. Analysis was somewhat comprehensive: significant focus on effectiveness/satisfaction and intervention components, less on therapeutic processes. Authors note limits to extending findings beyond trial participants.	Partly Descriptions sometimes lacked detail and their meaning unclear in some instances.	MEDIUM QUALITY Relies on retrospective accounts of therapy undertaken three years prior to interview.
Friedberg et al (2016)	To identify and classify the types of personal attributions offered by patients to explain changes in their overall condition following a behavioural self management intervention.	No	Yes Information provided on age, gender, illness duration and employment status. Upper and lower age limit unclear. Intervention well described.	No None included	Partly The initial coding of major themes was conducted by one researcher only. Subsequent systematic charting of these themes in the transcripts was carried out by two separate researchers amongst whom inter-rater	No 17 themes were identified but not grouped into broad categories, therefore lacks overall cohesion/structure.	Yes Aim was to understand a specific intervention. Analysis covers comprehensive range of factors relating to the phenomenon including factors intrinsic and extrinsic to the intervention.	Partly Clear and assessable language and concepts. Lack of quotes and detailed explanation of themes reduced resonance.	LOW QUALITY (for the qualitative component of the study) This was an interesting study, with useful quantitative data but the qualitative data lacked depth. Interviews were conducted

					agreement was achieved.		Authors note that participants were all high functioning and implications for extending findings.		by a graduate student, separate from the research term so coders were less close to the data.
Gladwell et al (2014)	To explore the experiences of people with CFS/ME of rehabilitation therapies including GET, Exercise on Prescription (EoP) and Graded Activity Therapy (GAT).	No No reflection on this.	Yes Basic details provided (gender, age bracket and duration of CFS) and self-reported improvement post intervention. No details on class/ethnicity. Upper and lower age limit unclear. Intervention principles described.	Yes A quote to support each reported concept.	Yes Coding of raw data was agreed upon by two researchers, one of whom was a volunteer living with CFS/ME.	Yes	Yes Aim was to understand a range of exercises intervention. Large sample size. Authors analysed data on range of experiences and demographics to confirm sufficient diversity of participant characteristics.	Yes Particularly easy to interpret results as quotes are followed by information about a participant's intervention and self-reported improvement.	HIGH QUALITY A well-grounded and well balanced exploration of GET and other rehabilitation therapies. Provides rich detail around reasons why particular aspects helpful or unhelpful.
Picariello et al (2017)	To explore the experiences of patients with CFS who undertook CBT and in particular why some patients engage in treatment more than others, and to assess whether CBT meets patients' needs.	No	Yes Details provided on gender, age, ethnicity and improvement post CBT and satisfaction with CBT. No details on duration of CFS or level of functioning.	Partly All subthemes supported by quotes. However, quotes do not always clearly demonstrate the construct described.	Yes Data was coded separately by two of the authors and any discrepancies discussed. A coding manual was developed.	Yes Subthemes are grouped into six overarching themes. Results are organised into a thematic diagram.	Partly Aim was to understand experience of CBT. Analysis is systematic but may not be comprehensive as themes are almost entirely positive (responses/helpful elements). Authors note	Partly Some descriptions and terms such as 'change' lack detail and clarity, reducing resonance.	MEDIUM QUALITY

			Intervention well described.				potential bias in sample (e.g. due to 40% response rate, 12 of the 13 participants satisfied with CBT) and implications for extending findings.		
Pinxsterhuis et al (2015a)	To elicit participants' experiences with a multidisciplinary patient education programme and their views regarding the usefulness of the programme.	No No reflection beyond noting that authors worked at the intervention setting.	Yes Details provided on gender, age, illness duration employment status, levels of physical functioning, education and relationship status. Intervention well described.	Yes Most of the analysis is supported by quotes.	No The analysis was primarily conducted by one author, with a second involved in the final step of grouping themes into abstract categories.	Yes Themes grouped into abstract categories and organised in a process model, shown in a simple schematic, highlighting relationships between constructs.	Partly Aim was to understand a specific intervention. Analysis of the intervention was comprehensive, but themes were almost entirely positive. Authors note potential biases in sample which could skew results to be more positive: <50% response rate and one researcher having been involved in delivery of the intervention.	Yes Use of simple, meaningful language and multiple quotes resulted in good resonance and adding to reader's understanding.	MEDIUM QUALITY The researcher who moderated the focus groups taught a session on the programme and had conducted assessments with two participants, which may have introduced bias in participants' responses.

Reme et al (2012)	Explore the experiences of young people with CFS who had undergone the Lightning Process, in particular beneficial and adverse effects of the intervention and participants' attributions of these.	Partly Authors reports that they have been involved in approaches to CFS with elements in common with LP, but not LP itself. Do not comment on their theoretical or research/philosophical orientation. Do not state their anticipations as are 'impartial and do not pre-empt either positive or negative outcomes.'	Yes Basic details provided (gender, age and duration of CFS). No details on class/ethnicity or CFS severity. Intervention principles and components described.	Yes Includes quotes to demonstrate most sub-themes.	Partly No verification of codes by a second rater or participants. Reliability was tested by applying the codes to the same text on two occasions separated by a week.	Yes Themes organized into three broad categories with sub categories. (Some themes in table not discussed in the text e.g. Prepared to work hard)	Yes Aim was to understand the LP specifically. Broad range of elements of the therapy experience discussed. Inclusion of two detailed case studies helpful.	Yes Easy to understand, themes seemed meaningful and relevant. Clear, easy language; an accessible study.	HIGH QUALITY
Roche et al (2017)	To assess the utility, feasibility and acceptability whether Acceptance and Commitment Therapy (ACT) for individuals with CFS and ascertain which aspects of the intervention, if any, had promoted change and/or were useful from the participants' perspectives.	No No reflection on this.	Partly Basic details provided (gender, age and duration of CFS). No details on class/ethnicity or CFS severity. Intervention not described in significant detail.	No No quotes included so challenging to understand the basis for comments.	Partly Triangulation with quantitative data. No evidence of independent checking of themes/codes.	No No structure within the qualitative results.	No Aim was to understand ACT intervention specifically. Qualitative results are not systematic and comprehensive as they lack detail and the predominant focus is on acceptability and adherence.	Partly Ideas and language clear, but lack of detail and in-depth meaning. Adds minimally to reader's understanding.	LOW QUALITY Interviews were conducted by an individual external to the research, which is likely to have resulted in the researchers being less close to the data.
Ward et al (2008)	Explore the perceptions of counselling interventions of people with ME, in	Partly Researchers' professions/stage of training were stated, and the expectation	Yes Basic details provided (gender, age and duration of CFS).	Partly Most themes are demonstrated by quotes.	Yes Transcripts were analysed by multiples authors and compared and	Yes	Yes Aim was to understand the general experience of a range of	Yes	HIGH QUALITY

particular what they found helpful and unhelpful and the kinds of issues which they discussed.	'that a range of both positive and negative experiences would be described.' However, no reflection on researcher orientations or more specific anticipations.	Details on ME triggers, symptoms and impact. No details on class/ethnicity.	discussed until a final agreed thematic structure was agreed.	counselling interventions. Participants had experienced a diverse range of counselling approaches, intervention types and durations and in both private and NHS settings. Analysis was comprehensive, including positive and negative experiences.
--	--	---	---	--

Appendix C: Table 5. Part A additional quotes

Theme	Subtheme	Example quotes
Challenging experiences pre-intervention		“During these years I had no idea what was wrong with my health and did not know anyone with ME/CFS, so was very much alone and without support or credibility.” (Denmark, 2017, p. 23)
Helpful and unhelpful aspects of intervention	Content: explanations, practical approaches and support to grieve	<p>“Told me how to get round the different ones, how to sort of beat the little buggers you know, beat the little nasties, that was ruining my life.” (Chew-Graham et al., 2011, p. 116)</p> <p>“And this is a sensible way to go while people do crystals and wheat grass and very far out alternative things. While I do think this has a type of legitimacy.” (Dennison et al., 2010, p. 174)</p> <p>“She's very practical and gives me skills/advice on self-talk.” (Denmark, 2017, p. 28)</p> <p>“I think I have a lot more understanding of the illness and all these strange symptoms I had that scared me to death” (Pinxsterhuis et al., 2015, p. 468)</p> <p>“When you have been ill for so many years, you want to know what the hell is going on, and nobody has any idea...and I wouldn't say that definitely his ideas and reasoning is 100%, because I'm not a medical person, I wouldn't know, but it made so much sense that that was actually important to sort of say, ok, now I understand why we have had these horrible horrible symptoms, and I can understand why the process might work” (Reme et al., 2012 p. 11)</p> <p>“The practice in session was helpful- sort of practically standing up and walking through the process was the helpful bit” (Reme et al., 2012, p. 11)</p>

		<p>“Even if I could only do one thing in the day because it was a bad day, y’know, without some kind of routine I wouldn’t have even been able to do that. And that’s the one that stayed with me. They helped rebuild that” (Dennison et al., 2010, p. 176, [CBT])</p> <p>“As a person with ME the challenges for me are grieving the loss of who I was, recognising the beauty of who I am now (both before and after contain the beautiful essence of me!)” (Denmark 2017, p. 26)</p>
	<p>Format: lack of adjustments and inappropriate setting but groups supportive</p>	<p>“the [psychiatric hospital] was somewhere where people went when they were seriously ill. . . I felt very ashamed” (Picariello et al., 2017, p. 391)</p> <p>“And it was very great to be together with people that understand the condition, finally being at a place where it feels normal.” (Pinxsterhuis et al., 2015, p. 470)</p> <p>“the feeling of being involved, no need to talk” (Blazquez et al., 2010 2010, p. 287)</p>
<p>Facilitators and barriers to engagement</p>	<p>Practitioner: understanding versus dismissive and client-led versus controlling</p>	<p>“[She] was the first person that I spoke to whom I could be honest with.” (Denmark, p. 25)</p> <p>“. . .only person I have seen in 20 years who has a real understanding of this condition” (Gladwell et al., 2014, p. 390, [GET])</p> <p>“It made me feel safe to come to a group and health care professionals that understand my condition and respect it.” (Pinxsterhuis et al., 2015, p. 470)</p> <p>“That was what I needed to hear... I needed somebody who had an official title who was actually interested in what I was going through to actually say ‘you are not mad’” (Dennison et al., 2010, p. 175 [psychoeducation])</p>

“it makes you feel like you didn’t spend years of your life making this up and it makes you feel normal and . . . human” (Picariello et al., 2017, p. 390 [CBT])

“She validated the spectrum of feel[ings] I went through. She truly believed me and helped me to learn how to live within my small envelope of energy” (Denmark, 2017, p. 27 [psychotherapies])

“They push you to do more without listening to what you are telling them. I have had ME for years; I know where my body is tired!” (Gladwell et al., 2014, p. 391, [Exercise on prescription])

“The therapist wasn’t listening. Just patted out the same old lines” (Gladwell et al., 2014, p. 391, [GET])

“Therapist refused to accept my comments that GET was not working for me” (Gladwell et al., 2014, p. 391, [GET])

“I was told to continue with the session no matter what” (Gladwell et al., 2014, p. 392, [GET])

“But activity/ exercise cannot harm you, I think it can harm you, if you are not good and you really, really push yourself you can relapse, definitely. And I did try to tell her that, but I think she was, rigid to the book and she thought that was exact, I didn’t.” (Chew-Graham et al., 2011, p. 118)

Fit between
intervention
and client
illness models

“Well I am like 17 years on so I have already learnt I have to get on with it and live with it really.” (Chew-Graham et al., 2011, p. 118)

“Overall it felt like the course was being run as a cure for false illness beliefs” (Denmark, 2017 p. 33)

“Here in the UK the emphasis is still on CBT and GET. And not just the kind of CBT that simply helps you come to terms with chronic illness but the sort that

pushes you to improve your health as if you have false illness beliefs. Sometimes the psychiatrist would say 'we do believe in your illness' but went on to talk as if it could be improved or even cured by changing the way I approach it. Yes, that may help me come to terms with it, but it definitely will not cure ME and may even make it worse." (Denmark, 2017, p. 33)

"I was insulted by the idea that we would do anything to impair our recovery – we fight for it." (Ward et al., 2008, p. 77)

"I used to do triathlon. And I knew about sort of pushing myself a little bit extra each time I trained to accomplish a little bit more. ... It sort of made perfect sense to me that there would be similar approach with the therapy." (Cheshire et al., 2018, p. 6)

Overcoming hurdles: getting worse, slow progress and individual differences	"I did do it sporadically but at the time it wasn't something that I could commit to fully." (Cheshire et al., 2018, p. 4)
---	--

External life circumstances	"I haven't got children so, married but I haven't got children, and so I think that makes a big difference too because I haven't got to be running around after them." (Cheshire et al., 2018, p. 4)
-----------------------------	--

Responses to intervention	Satisfaction and symptoms	"I suffered a major relapse and am now more poorly than I ever was" (Gladwell et al., 2014, p. 392, [GET]) "It gave me something to work with which is something I haven't had since I was in school. And that was the absolute starting block of getting my life back and being able to live in any way" (Dennison et al., 2010, p. 176 [CBT])
---------------------------	---------------------------	--

Positive: accepting, managing	"the Sunday I had what I felt was a real CFS symptom day, it felt exactly like I felt right back in the beginning.
-------------------------------	--

wellbeing and . . . So I thought “no stop it, I am not going to go nuts”
less distress (Picariello et al., 2017, p. 396)

“It helped me to deal with all the emotional stuff that was coming up” (Ward et al., 2008, p. 77)

“it [validation] did give me strength and remind me I really was not crazy but certainly very ill” (Denmark, 2017 p. 27)

“It brought out my inner feelings which I hadn’t noticed for a very long time and which I missed very much.” (Blazquez et al., 2010 2010, p. 288)

“I leave your classes like a new person, not at all tired and in a good mood” (Blazquez et al., 2010 2010, p. 288)

“It’s nice to have someplace to vent about my disease without stressing the listener” (Denmark, 2017, p. 23)

Negative: “I think that the general impression that is being given
feeling is that once you have been doing the Lightning
blamed and Process, the lightning is quick, you will feel better and
false promises can do whatever, whereas I don’t think that is the right
impression. I think that stamina and strength is
something that has to be built up gradually.” (Reme et
al., 2012, p. 12)

“I just think that the way they go about it is awful, blaming people that if it doesn’t work then, you know, it’s your own fault. I think that is absolutely awful” (Reme et al., 2012, p. 12)

“I couldn’t do what was asked of me, the therapist said I wasn’t trying” (Gladwell et al., 2014, p. 392, [GET])

Appendices for Section B

Appendix D: Recruitment letter [Name of service and NHS trust removed]

Name
Address

date

Dear xxx,

You are being invited to take part in a research study to explore people with Chronic Fatigue Syndromes' (CFS) experiences of Cognitive Behavioural Therapy (CBT). The study aims to understand peoples' experiences of attending CBT for CFS. It aims to understand when and in what ways CBT can be helpful for people with CFS, in what circumstances it may not be helpful and what else, if anything, people may have found helpful. Participating in the research would involve being interviewed in person or via telephone or Skype.

There are several items included with this letter.

- 1) A detailed Patient Information Sheet, which explains why you are being invited to participate and what the study involves, as well as your rights during the study. Taking part, or deciding not to take part, will not affect the care you receive at the hospital.
- 2) A one page flyer providing a simple overview of the study.
- 3) A Participant Questionnaire with 15 questions on demographic information (age, gender, ethnicity), information about your health and your experience of CBT.
- 4) A consent form where you can indicate that you consent to be contacted to discuss participating in the research.
- 5) A prepaid addressed envelope in which to return the consent form to us.

Please read the enclosed Patient Information Sheet carefully and take some time to consider whether you are interested in participating in the study. If you are interested in participating in the study or wish to seek further information please contact the researcher directly on 01227 927070 (telephone) or c.clark711@canterbury.ac.uk (email). If you are leaving a voice message please state that the message is for Catherine Clark. Alternatively, you can express interest in participation by post: if so please complete 1) *Participant consent form: consent to be contacted to discuss participation* and 2) *Participant Questionnaire* and return it to us in the prepaid addressed envelope provided. You will be contacted as soon as possible following this.

With kind regards,

Name of treating clinician



Information about the research for participants

Project Title: Understanding the experiences of people who have attended Cognitive Behavioural Therapy for Chronic Fatigue Syndrome.

Hello. My name is Catherine Clark and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide whether you would like to participate, it is important that you understand why the research is being done and what it would involve for you. Please feel free to talk to others about the study if you wish.

Part 1 of this information sheet gives you a general outline of the purpose of this study and what will happen to you if you take part. You may also wish to refer to the 1 page flyer included with this sheet for a simple overview of the project.

Part 2 of this information sheet gives you more detailed information about the study.

Details on what to do if you are interested in taking part in the study are at the end of this information sheet (on page 5).

Part 1 of the information sheet

What is the purpose of the study?

Some evidence suggests that cognitive behavioural therapy (CBT) may be helpful for reducing fatigue symptoms in some patients. However, often only a minority of people seem to benefit from CBT and many report they have not. This study aims to understand people's experiences of attending CBT for chronic fatigue syndrome. It aims to understand what changes, if any, occurred for you during and after the therapy. It also aims to understand your experience of particular elements of the therapy. Finally, your individual circumstances might have contributed to changes during or after therapy, and we are interested in this too.

Why have I been invited?

You have been invited to participate in this study as you have attended at least six sessions of CBT for CFS. Anyone who attended CBT at the [name of service] over the last two years could be invited to participate and the study aims to recruit around 15 participants in total.

Do I have to take part?

It is up to you to decide whether to join the study. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. If you are currently receiving care from [name of service] or another medical centre, then participating in this study (or deciding not to) would not affect the standard of care you receive.

What will happen to me if I take part?

You have been sent a questionnaire in the post with 15 items asking about demographic information (age, gender, ethnicity) and about your health and experience of CBT.

You will be asked to participate in one interview with myself, lasting around 1 hour. This will be conducted either face to face at the [name of service] or if this is not possible, the interview may be conducted via Skype if you can access this, or telephone.

The interview will be audio-recorded and transcribed. Transcription will either be completed by myself or outsourced to a professional transcriber, who would be required to sign a confidentiality agreement. I will send you a copy of your transcript. If you wish to comment on it you can then discuss it with me over the telephone. I will then analyse your responses, along with those from other participants, in order to draw out ideas and form a theory about how people with CFS experience CBT.

You will also have the opportunity to be sent a user-friendly summary of the final theory and conclusions of the study.

If you are receiving ongoing treatment from a medical service, none of this treatment will be withheld for all or part of the study.

Expenses and payments

You will be offered up to £10 towards travel if you have to travel to an interview.

What will I be asked to do?

During the interview you will be asked to answer questions about your experiences – mainly concerning what CBT was like for you, and a little about your experience of CFS before, during and after CBT. Both positive and less positive experiences of CBT are of interest.

What are the possible disadvantages and risks of taking part?

Whilst I will make every effort to be sensitive in asking questions about your experience of CBT, it is possible that you may find it uncomfortable or distressing discussing your experiences during the interview. This is especially possible if you have had negative experiences of CBT, but also if we touch on distressing things about having CFS. You may

find yourself thinking about distressing issues at home after the interview has been completed. If you become distressed during the interview I will ask whether you would like to take a break or finish the interview. I will check how you want to go on from there. It is important that you feel comfortable as far as is possible.

There is also the risk that if you currently experience symptoms of CFS, participating in the interview could result in increased fatigue or a worsening of these symptoms in the days following the interview. The impact of the interview will vary between individuals.

What are the possible benefits of taking part?

You may find it useful or interesting having the opportunity to reflect on your experiences. We cannot promise the study will help you but the information we get from this study is intended to help improve the treatment of people with CFS.

What if I become distressed as a result of talking about my experiences?

If you become distressed, the interview will be paused so you that you can consider whether you would like to take a break from the questions, continue or end the interview. I, as the interviewer, would provide time to talk about your responses to the interview and 'de-brief.' I would also ask about any strategies which can help you when you feel distressed. I would also ask about ways in which you might look after yourself following the interview. If the interview takes place over Skype or telephone I would recommend that a friend or family member is at home with you as you might find it useful to speak to someone you know afterwards. If you remained distressed, I might ask you whether you thought it would be helpful to be referred to the psychology service at the Chronic Fatigue Service. Lastly, if I was concerned about any risk of harm to you, I might request that a clinician linked with the Chronic Fatigue Service also speak with you to assess this risk. I would inform you if I was considering this.

What if there is a problem or I want to make a complaint?

Any complaint about the way you have been dealt with during the study will be addressed. The detailed information on this is given in Part 2.

Will information from or about me from taking part in the study be kept confidential?

Yes, except in specific circumstances (see Part 2). We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

This completes part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2 of the information sheet

What will happen if I don't want to carry on with the study?

If you choose to withdraw from the study you do not have to provide a reason for doing so. If you are currently receiving care from the [name of service] or another medical centre, then participating in this study (or deciding not to) would not affect the standard of care you receive. You will be offered the opportunity to be sent a user-friendly summary of the final

theory and conclusions of the study. You will also be offered the opportunity to discuss the findings of the study with me over the telephone.

What if there is a problem?

You can raise a complaint or concern with myself or the Research Director at my university (see below). These will be investigated and the outcome of this communicated to you.

Complaints or requests for further information

If you have a concern about any aspect of this study, you should ask to speak to me on 01227 927070 and I will do my best to address your concerns. If you remain unhappy and wish to complain formally, you can do this by contacting either:

Professor Paul Camic, Research Director, Salomons Centre for Applied Psychology,
Canterbury Christ Church University – paul.camic@canterbury.ac.uk, tel: 01227 927114

Or:

The UCLH Patient Advisory Liaison Service (PALS) on- 020 3447 3042 - address: PALS, Ground Floor Atrium, University College Hospital, 235 Euston Road, London NW1 2BU.

Will information from or about me from taking part in the study be kept confidential?

Yes. The only circumstances in which investigators would be obliged to pass on information to a third party would be in the event that there were concerns that either you or someone else may be at risk of harm.

All information which is collected from or about you during the course of the research will be kept strictly confidential. Any information about you which leaves the hospital will be kept separate from details of your name and address so that you cannot be recognised.

Any identifying information about you such as your personal and contact details will be stored on a password protected memory stick. Data from interviews will be recorded on a dictaphone and then transferred and stored on a password protected computer. Audio Data will be erased after the final write-up of the study has received feedback from the university's examiners, and corrections have been made and re-submitted. This is most likely to be in mid-late 2019. The anonymised transcripts of interviews will be stored for 10 years at Canterbury Christ Church University, after which they will be destroyed.

Any identifying data will be removed in the write up of the project. It will be ensured that participants' comments are not stored on the same database as where their names are, so that the comments cannot be seen to be linked to named individuals. In order to differentiate between different participants in the write up, a participant code will be allocated to each participant.

Involvement of the General Practitioner/Family doctor (GP)

It is not necessary that your GP (or other health care practitioner) be notified of your participation in this study.

What will happen to the results of the research study?

Investigators intend to publish the results of this study in a scientific journal. Participants will not be identified in any report/publication unless they have given their consent. Signing the consent form accompanying this information does not constitute consent to be named. Anonymised quotes from the interviews will be used in published reports.

A user-friendly copy of the final results of the study will be sent to participants in the post if they wish.

Who is organising and funding the research?

Canterbury Christ Church University with support from [name of service]

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Bromley Research Ethics Committee

Further information and contact details

You will be given a copy of this information sheet and a signed consent form to keep.

You may wish to gain further information around research in general, this research project, advice as to whether you should participate and who you should approach if you are unhappy with the study. You may be able to gather information on some of the above from documents or websites. However if you would like to speak to me and find out more about the study or have questions about it answered, you can leave a message for me on a 24-hour voicemail phone line at 01227 927070 . Please say that the message is for me [Catherine Clark] and leave a contact number so that I can get back to you. You can also use this contact number if you have any concerns during the study.

I will always try to handle your query myself in the first instance. If appropriate after we have talked, I may forward your query onto a colleague in the research team or at [name of service] with your permission.

What to do if you think you might be interested in taking part in the study:

There are 2 ways in which you can express interest in finding out further information about the study:

1) Please return 'Participant consent form: consent to be contacted to discuss participation' included in this information pack, in the prepaid envelope provided. On the slip please indicate if you would be willing to be contacted by me (the researcher), to discuss participation in the research. Please also complete the short questionnaire included in this information pack and also enclose it in the same prepaid envelope.

2) Alternatively, please contact me, Catherine Clark, to discuss participation or ask further questions about the research. You can do this either by telephone on 01227 927070 or by email on c.clark711@canterbury.ac.uk. If leaving a voice message please state that the message is for Catherine Clark. I will contact you as soon as possible following this. In this option, you will be able to complete the questionnaire over the phone.

Appendix F: Participant questionnaire

CONFIDENTIAL

Participant questionnaire– all answers will be treated in the strictest confidence

1. What is your age in years and months? _____
2. How would you describe your gender? _____
3. How would you describe your ethnicity? _____

The following questions relate to your CFS and the CBT you received at [name of service]

4. Other than CFS, have you received a diagnosis of any other physical or mental health condition during your life? If so please specify _____
5. For how long a period did you receive CBT for CFS? How many CBT sessions did you attend?

6. How would you describe your employment/education/training status at the time when you began attending CBT? (Please circle one answer)
Full time work Part time work Unemployed Home-maker
Full time education or training Part time education or training
7. At the time you began attending CBT to what extent did your physical health or emotional problems interfere with your normal social activities with family, friends, neighbours, or groups? (Please circle one answer)
1 Not at all 2 Slightly 3 Moderately 4 Quite a bit 5 Extremely

8. Were you taking any medication regularly at the time you attended CBT?

Yes/ No

If yes, what for? _____

9. Did you find CBT beneficial?

Yes

Partly

No

10. Before starting CBT, did you feel hopeful that it might bring about changes that would improve your quality of life?

Yes

Partly

No

11. Have your activity levels increased since the time you started CBT?

Yes

To some extent

No

12. Over the course of receiving CBT, did you notice a change in your self esteem?

Yes- increase

Yes-decrease

No change

13. To what extent were the people in your life (family, friends, partners or others) talked about in your therapy sessions?

A lot

Quite often

Sometimes

Occasionally

Never

End of questionnaire. Thank you.

Please return this questionnaire in the prepaid addressed envelope provided. If you need any advice or further information, please contact the researcher Catherine Clark (tel. 01227 927070; email: c.clark711@canterbury.ac.uk).

Appendix G: Consent form for participation

Participant consent form: consent to participate in the research

Title of Project: Understanding the experiences of people who have attended Cognitive Behavioural Therapy (CBT) for Chronic Fatigue Syndrome (CFS).

Name of Researcher: Catherine Clark

Please initial the box next to each statement to indicate agreement.

1. I confirm that I have read and understand the information sheet dated 06.07.18 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by the researcher [Catherine Clark] and those supervising the research [name of external supervisor removed and Sue Holttum], individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

4. I agree to the use of audio recording of my interviews.

5. I agree that anonymous verbatim quotes from my interview may be used in published reports of the study findings.

6. I agree to take part in the above study.

Name of Participant _____ Date _____

Signature _____

Name of Person taking consent _____ Date _____

Signature _____

Appendix H: Project approval documents

Health Research Authority

This has been removed from the electronic copy

This has been removed from the electronic copy

This has been removed from the electronic copy

This has been removed from the electronic copy

This has been removed from the electronic copy

This has been removed from the electronic copy

This has been removed from the electronic copy

Research Ethics Committee

This has been removed from the electronic copy

This has been removed from the electronic copy

This has been removed from the electronic copy

This has been removed from the electronic copy

This has been removed from the electronic copy

Trust Research and Development Team (email approval)

This has been removed from the electronic copy

Appendix I: Example memo on 'acceptance'

26/10/18

In the first few interviews several participants have talked about the therapy resulting in 'acceptance'. I've been thinking about the word acceptance. The first word that comes to my mind is 'acceptable' which to me means making a judgement that something is aligned with my values or tolerable to me. But so far, I think the participants are using it to mean what I might think of as 'acknowledging'; that is, facing up to rather than denying the reality of a situation and therefore accommodating for it in behaviour. E.g. in today's interview with John when I explored the meaning of the word acceptance he said: "just saying "you don't like it but that is how it is". I'm curious about variation in how people use the word; if the word acceptance comes up again in future interviews I think it is going to be important to explore the unique meaning to each participant.

What's not clear to me is how the concept of accepting/acknowledging (which for now I might think of being consciously aware of a situation) relates to the meaning and emotional responses people have about that situation. Are the two processes inextricably linked? i.e. I feel better about the idea of CFS, so I can tolerate acknowledging it. Or are they separate constructs? Can you become more aware of something without the meaning you attach to it necessarily changing first?

So far, the data suggests that often changes in meaning have facilitated greater 'acceptance':

Me: How do you make sense of what helped you with that acceptance process?

George: 'I think it was partly seeing people who dealt with this all day made it feel relatively kind of normal.' 'Well I think that the other thing was just sort of feeling that it was something that wasn't necessarily going to ruin my life or get worse.'

John attributed acceptance to exploring causes of CFS and realising it wasn't his fault, which changed the meaning of CFS for him, and made it easier to acknowledge/accept having the condition: "it is just about saying "oh well that's how it is" rather than beating myself up in my own head and being angry about it"

I've been surprised that participants have not talked about acceptance as a distressing process. The interviews have suggested that this is because acknowledging the diagnosis brought about an overriding feeling of relief because acceptance meant that something could

now change going forwards e.g. John- “This [CBT] has just made me say, “yeah I am shattered”. But I wonder if accepting the reality of CFS is more distressing for other participants? I should try to explore this in other interviews.

Another property of acceptance seems to be how it changes over time; for some participants there was a significant increase over the short time span of CBT. Others have described it happening naturally over a longer timespan prior to CBT: e.g. Sarah: “you fight that initially you know, I was a very active, very sporty woman, busy with three kids at home you know. That’s taken a long time, that acceptance”

Participants have suggested that acceptance resulted in some significant changes for them and was very valuable. John said it was the ‘only’ thing he got out of therapy. It seems like a gateway to making changes; if other interviews reflect this, I think this could be a major category in the model. At the moment I’m focusing on understanding the experience of ‘acceptance’ but I’m mindful that when it comes to axial coding I’ll want to know what acceptance facilitated, so I’m keeping a record of the changes people have suggested. I can see it on their individual maps (e.g. George described shifting from ‘carrying on as normal’ and thinking about going back to normal’ to looking to the future and finding different ways of doing what he liked, in ways that accommodated his CFS/ME. John described making adjustments such as cutting back on activities).

25/11/19

I’ve had an interesting interview with Eva. She also described increased ‘acceptance’ following CBT but that this was an ongoing process that had started before the CBT. To her acceptance meant “an acceptance or understanding that I might need to stop expecting progress to happen really quickly”. So, a property of acceptance seems to be a change in the meanings people have about possible recovery or improvement, and specifically the possible timescale which people associate with this. So, for some acceptance is not about giving up hope of longer-term recovery. This echoes the way Charlie talked about acceptance; he said he accepted that there was no quick cure but had hopes that under the right circumstances he might be able to make gains (e.g. if he retired and could fully control his activities). Another interesting property of acceptance seems to be whether it is ‘whole’ or ‘parts’ of a situation that are accepted. Eva said, “you reach a happy medium where, “I kind of need to accept

some of this but I need to not give up completely”. I’m interested to see if there is dimensional variation of this with other participants.

6/12/18

Interesting interview with Susan who also described reaching greater acceptance of the nature of her symptoms and limitations the illness imposed on her. It was interesting because Susan’s comments suggested that a property of acceptance may be the extent or degree of accepting the most recent/most extreme/worst part of the illness. Susan: “So it’s very much about acceptance of where you are *now* with the illness”. This reminded me of what Eva said about accepting parts of the situation, but not the whole situation.

Susan’s interview suggested that there is extreme dimensional variation in how distressing acceptance is, depending on the meaning the illness has to the individual; she described it like ‘grieving’ a loss- “And it was learning that I can grieve that I can’t do dinner parties for sixteen people anymore, but actually that that doesn’t matter.” For her acceptance seemed to be a step in a larger process of re-forming an identity which accommodated her CFS (mainly via lowering her expectations of herself). She described this re-forming or re-building as helping her feel like a ‘whole person’ again.

There are now multiple codes relating to acceptance and the model has a major category ‘accepting the reality of CFS/ME.’ On the map of the model I’ve just moved it from the therapy room context to occurring across all contexts as the data suggests it occurs and is influenced by experiences in the therapy room and taking more control of daily life.

14/12/18

Following my interview with Judith, she seems to be an exception in that she was the only participant so far who felt she did not understand or accept her limitations, following CBT. She attributed this to the approach of the therapist: “I don’t think she was asking me to accept. She was telling me I could push through. I could push through, I could do this extra walking every week”. She said she therefore did not make helpful adjustments to her daily life until after the CBT when she started other interventions which led to her acknowledging her limitations. This highlighted that lack of acceptance was a barrier to making changes to better manage the condition in daily life.

7/2/19

Within the main category 'seeing CFS as more manageable', a sub-category has emerged currently named 'making peace with CFS', which is about feeling less distressed about the condition. This speaks to the question I had early on about whether acceptance (awareness) can occur separately to feeling less negatively about the condition. The data suggests they are separate as some participants have described acceptance being facilitated simply by the therapist taking a very didactic approach providing information about CFS/ME described by Fiona as "quite a wake up."

Another facilitator of acceptance can be changes in identity; Sebastian suggested he had to stop being so hard on himself before he could accept having CFS/ME, otherwise the condition was too dissonant with the image he had of himself. He suggested that it was exploring a wide range of issues about his identity (e.g. race, professional competence) that allowed him to regain his confidence and accept the nature of CFS/ME. This really brought home for me how complex and varied the processes are which have facilitated greater acceptance for each participant. He also suggested that after his first set of sessions of specialist CBT he made adjustments such as cutting back at work, but still did not 'accept' that he had a chronic condition and felt he was 'cured'. This led to him returning to working long hours, not managing his energy well, and eventually leading to relapse. This further highlighted the significant role of acceptance in taking an adaptive approach to managing the condition.

Given these factors, the model must have a line directly from the therapy room to acceptance. However, the data continues to suggest that perceiving CFS/ME less negatively is also a significant facilitator of acceptance, suggesting an arrow is needed between these two as well.

Appendix J: Initial topic guide

Scene setting:

- If you don't mind could you tell me a bit about yourself? (prompts: people in your support network, where you live, interests you have)
- Can you tell me a little bit about your journey with CFS and how it has impacted your life? (prompts: when diagnosed, course of severity since then, other treatments)

Pre-therapy:

- 1) What led to you starting CBT?
- 2) Before starting CBT, how were you expecting it to be? (Prompts: what it would involve and whether/in what ways it might be useful)

Therapy:

- 3) What feels significant for you when you think about your experience of CBT?
- 4) How were the sessions for you? (prompts: thoughts/feelings)
- 5) What do you remember from it?
- 6) Were there any particularly significant moments you can remember?
- 7) Do you feel like anything changed for you over the CBT? If so what?
 - a. Prompt on what might have led to these changes? (prompt: Could the changes have been due to anything else, for example other things that happened in your life at the time?)
 - b. Were there any knock-on effects of that?
- 8) What was your therapist like? How do you think this impacted the therapy?
- 9) Which elements of the sessions were particularly helpful? In what ways?
- 10) Was there anything which you think made it easier to do the CBT?
- 11) Which elements of the sessions were unhelpful? In what ways?
- 12) Was there anything which you think made it harder to do the CBT?
- 13) Are there any other aspects of the therapy that were helpful or unhelpful but we have not yet discussed?

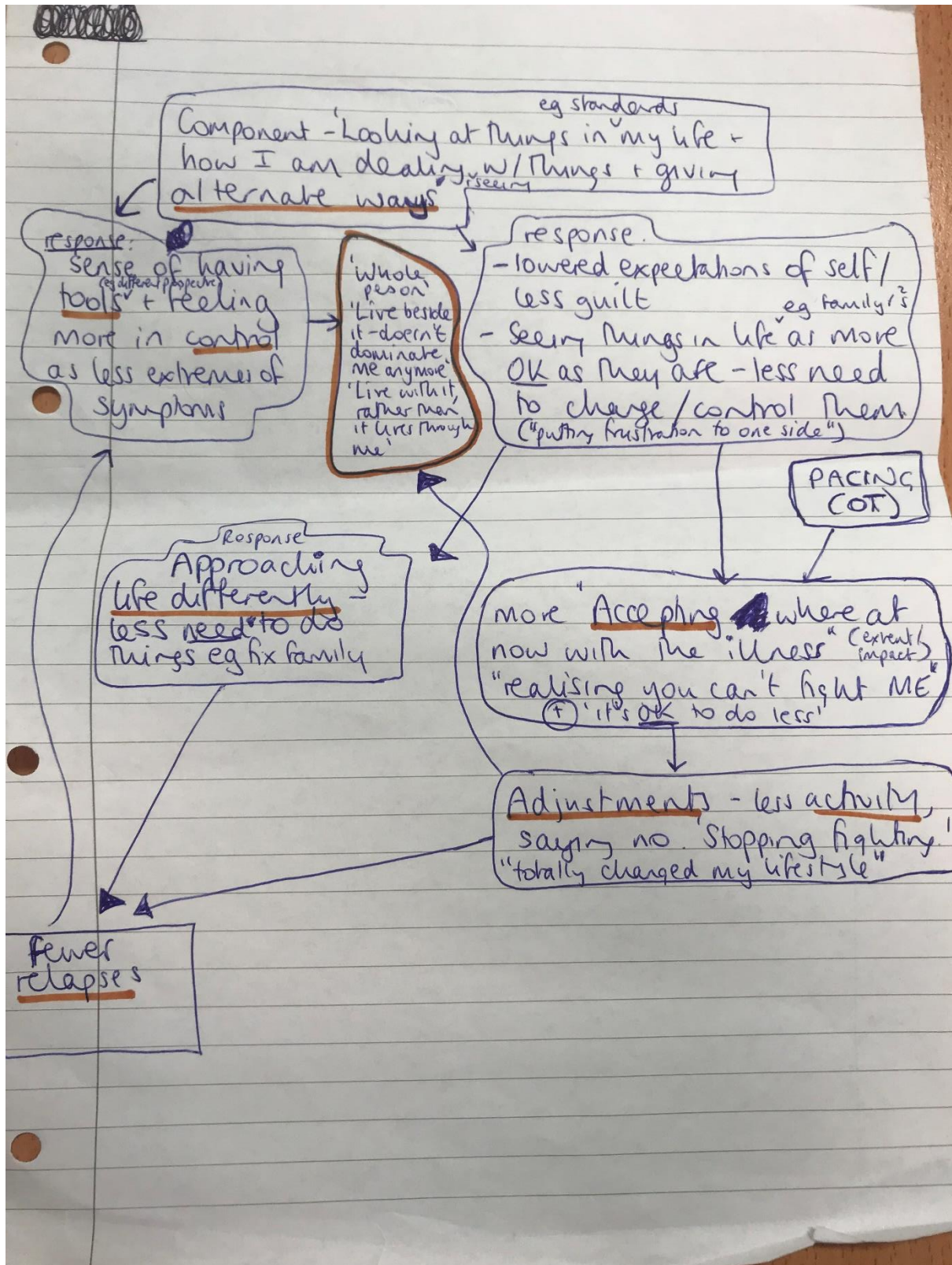
- 14) Did you notice any differences in your relationships with friends and family during or after your therapy? Or how they appeared to you? If so, what do you think caused that?
- 15) Did anything make it easier to do the CBT? Harder to do the CBT? (Prompt- the sessions themselves and the work at home in between sessions)
- 16) Is there anything else that you would like to tell me about your experiences of engaging in CBT for CFS?

Appendix K: Questions added to topic guide to facilitate theoretical sampling

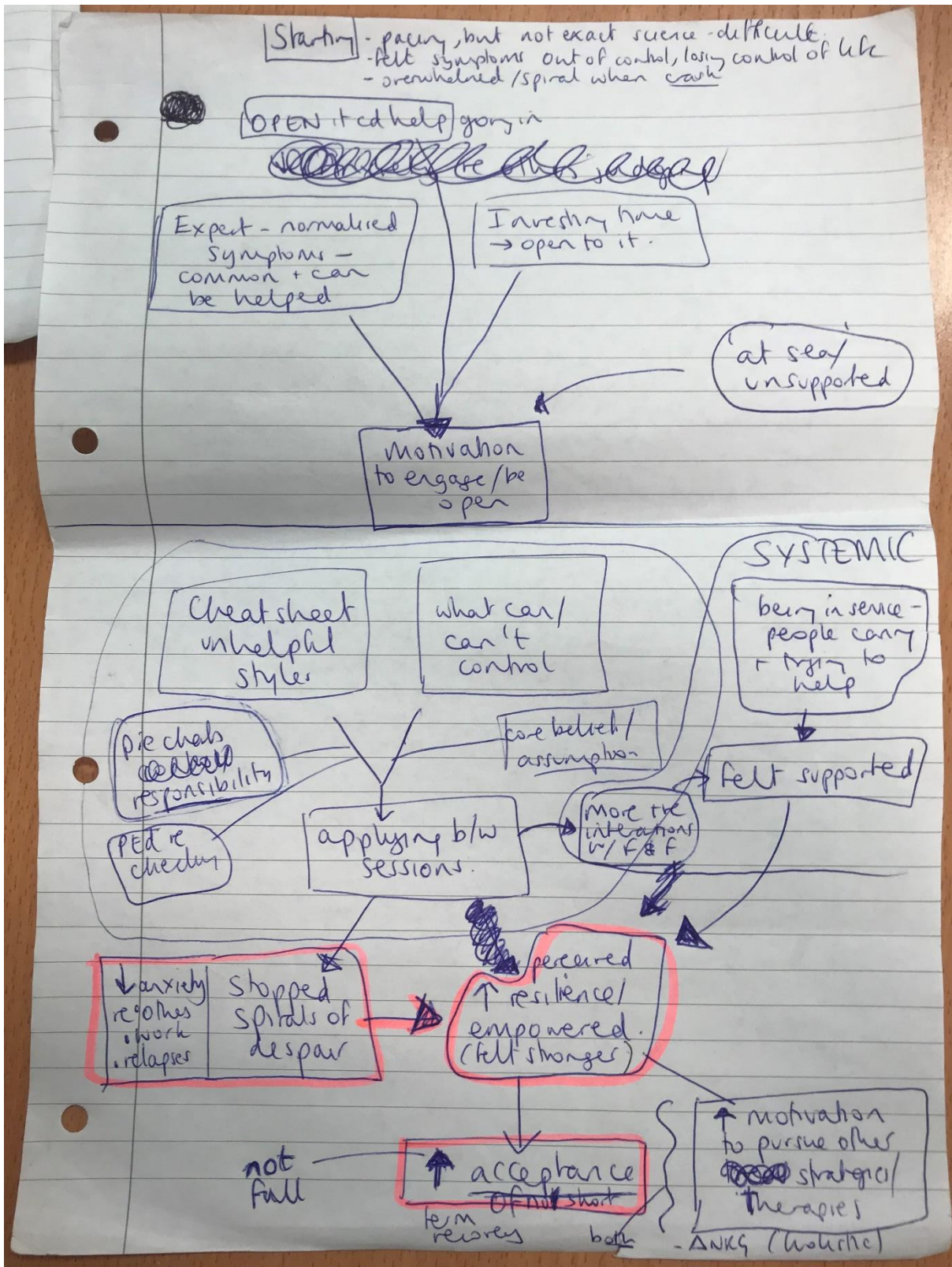
- 1) Did your experiences in the therapy room lead to you making any changes in your approaches to daily life? If so what specifically do you think led to this? (if they answered that they adopted better ways of coping, ask what might have been barriers to them doing this prior to therapy)
- 2) Did your experiences in the therapy room lead directly to any changes in your feelings or mindset? If so in what way? What specifically do you think led to this?
- 3) What felt like the most important topic you discussed in therapy? Why was this significant? What was the result of discussing this topic? What made it possible to discuss this topic?
- 4) Did you talk about what was important to you during the therapy? (prompt: sometimes people refer to this as their values). Was this helpful? If so why? Was there a knock-on effect of discussing this?
- 5) More generally, do you feel you did more of what was valuable to you following the therapy?
- 6) Did the way you viewed life with CFS/ME change over the course of the therapy? If so what do you think led to that?
- 7) Some people have said that they felt they 'accepted' or acknowledged the full extent of their symptoms more as a result of the therapy. What does 'acceptance' of CFS/ME mean to you? Was this the case for you? If so what do you think led to that? What might have prevented that from happening before CBT? What was the knock-on impact of that? Was acceptance a difficult/distressing process? What did acceptance involve for you?

Appendix L: Maps of participants' experiences created to help understand the relationships between constructs as part of axial coding

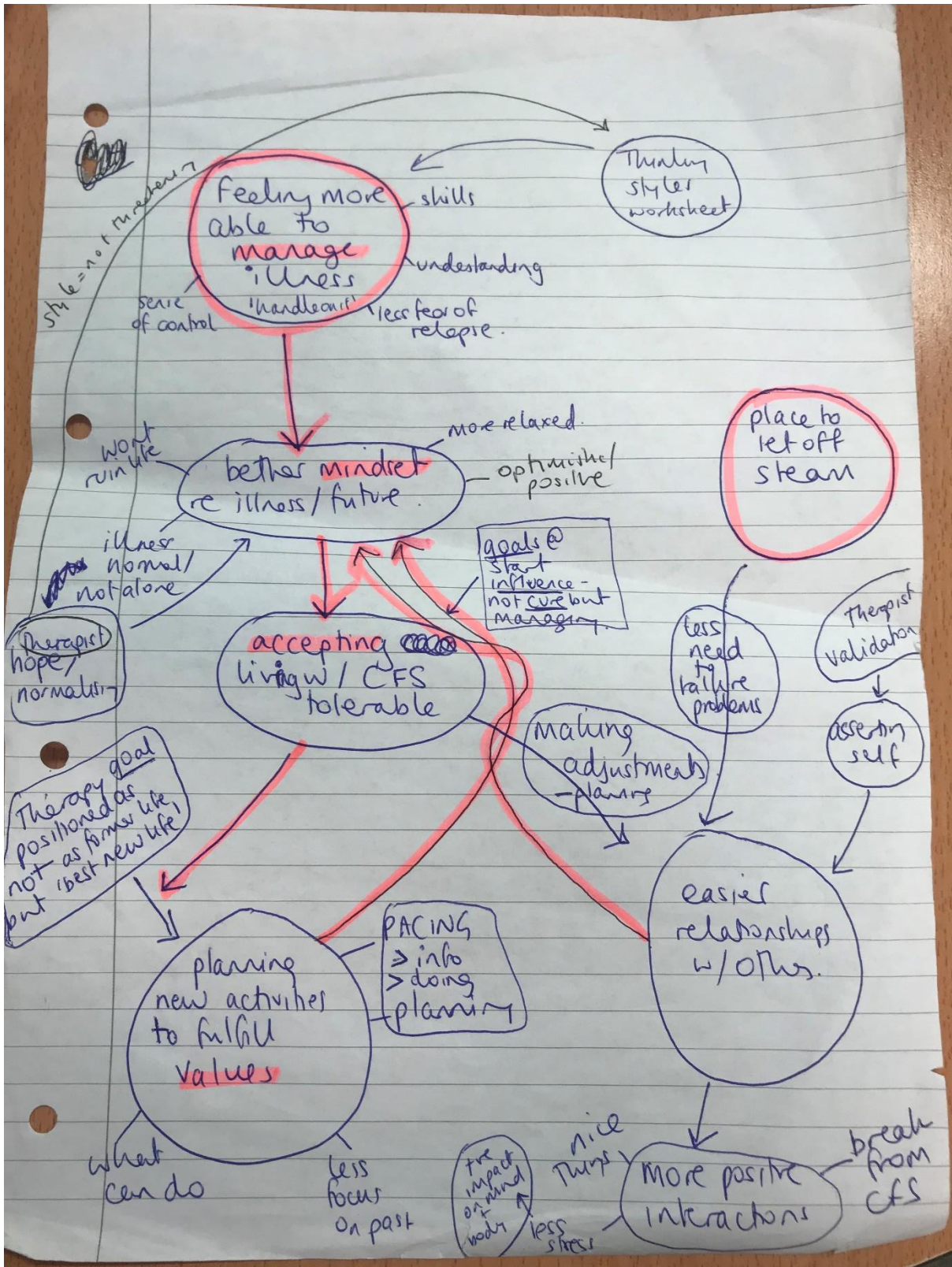
Map for participant Susan



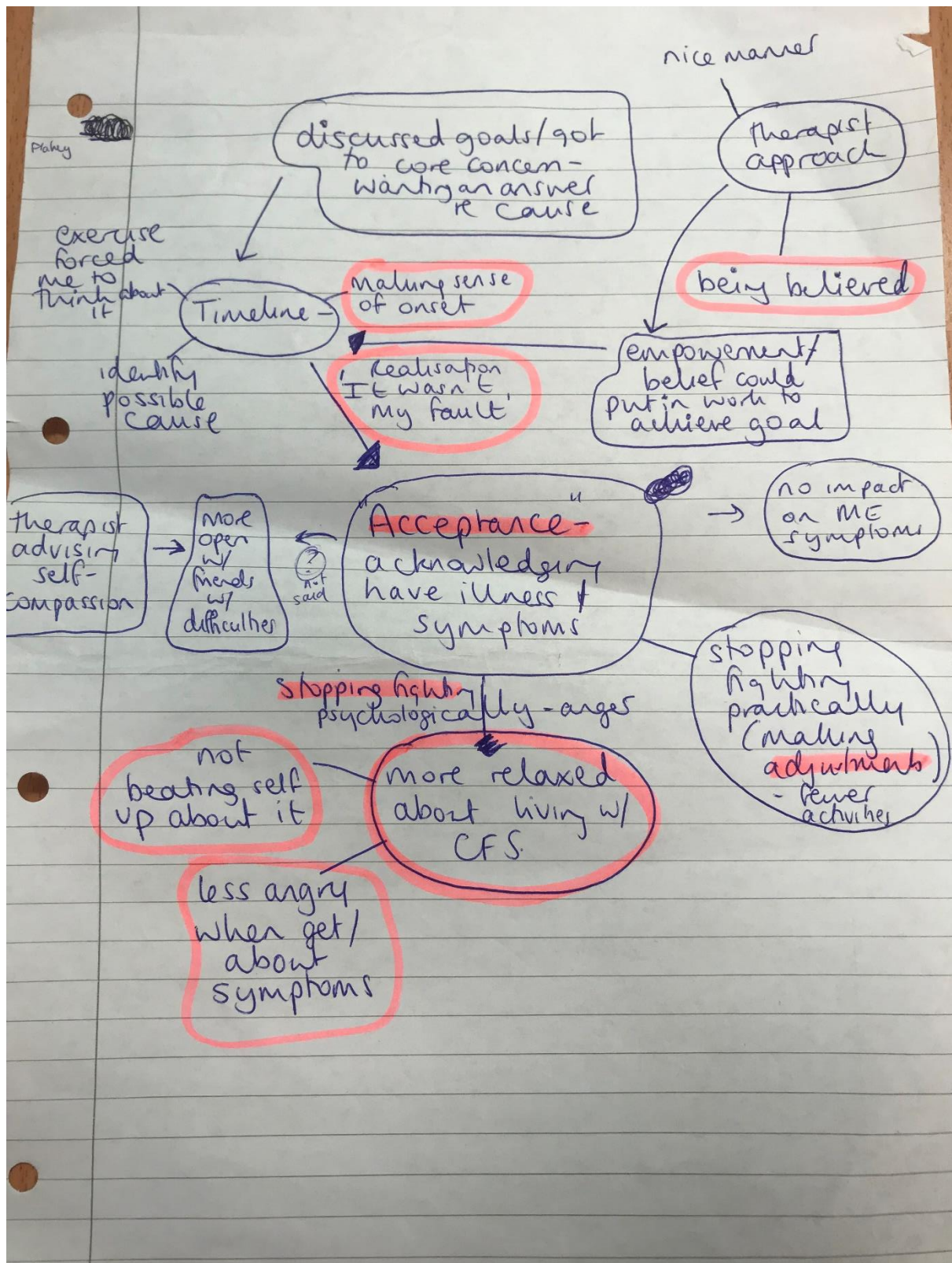
Map for participant Eva



Map for participant George

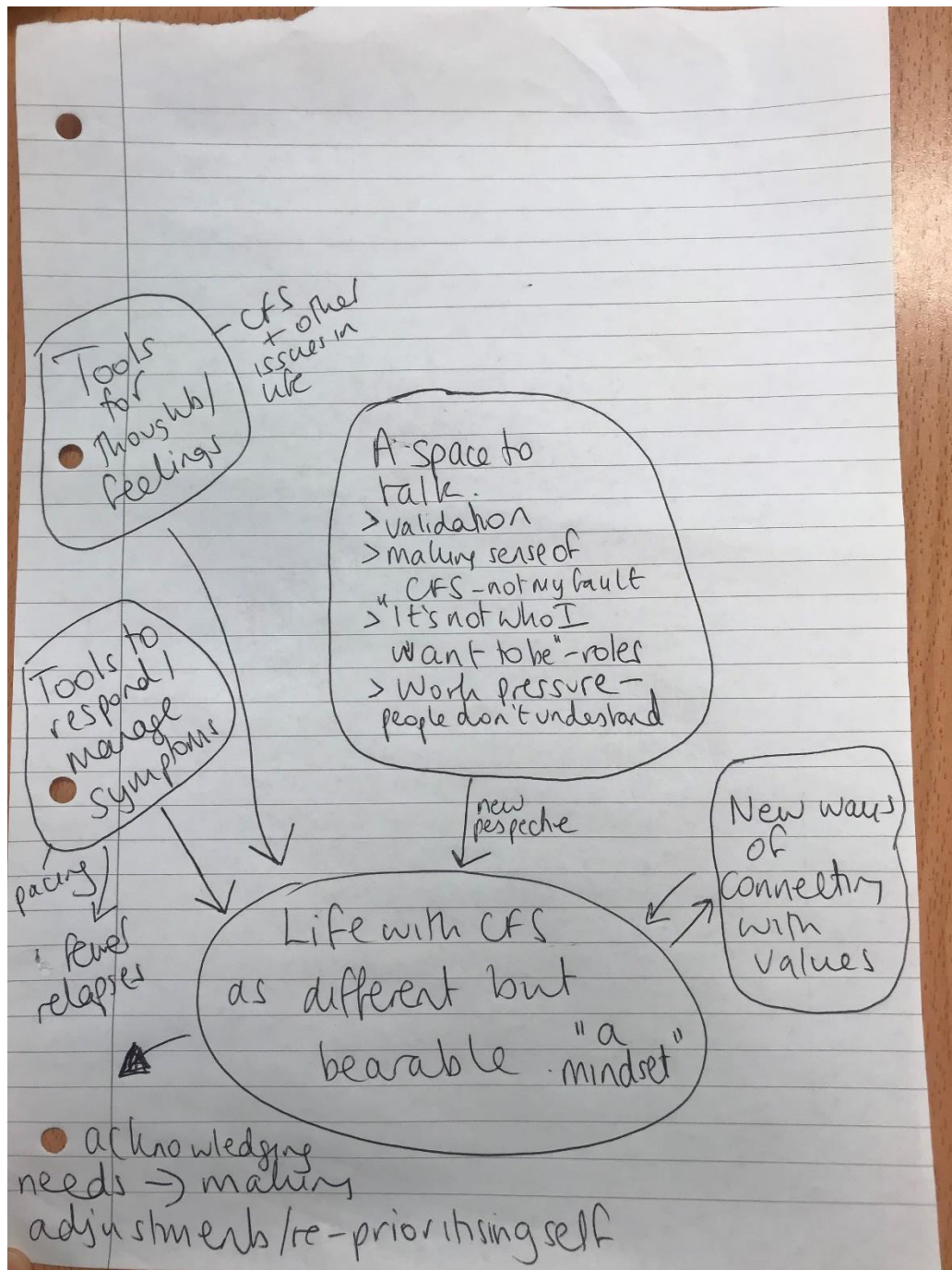


Map for participant John

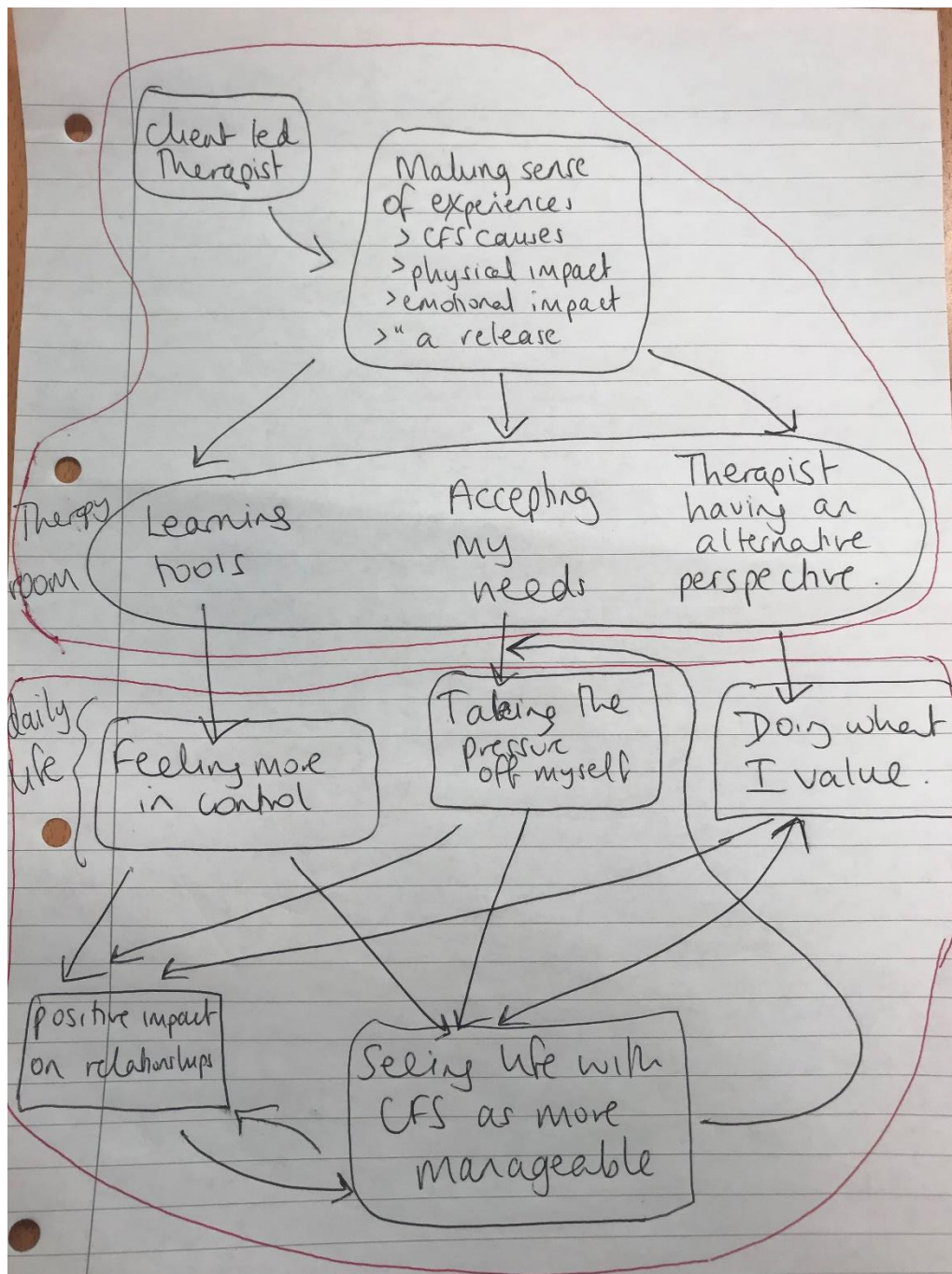


Appendix M: Iterations of the model undertaken as part of the process of theoretical integration

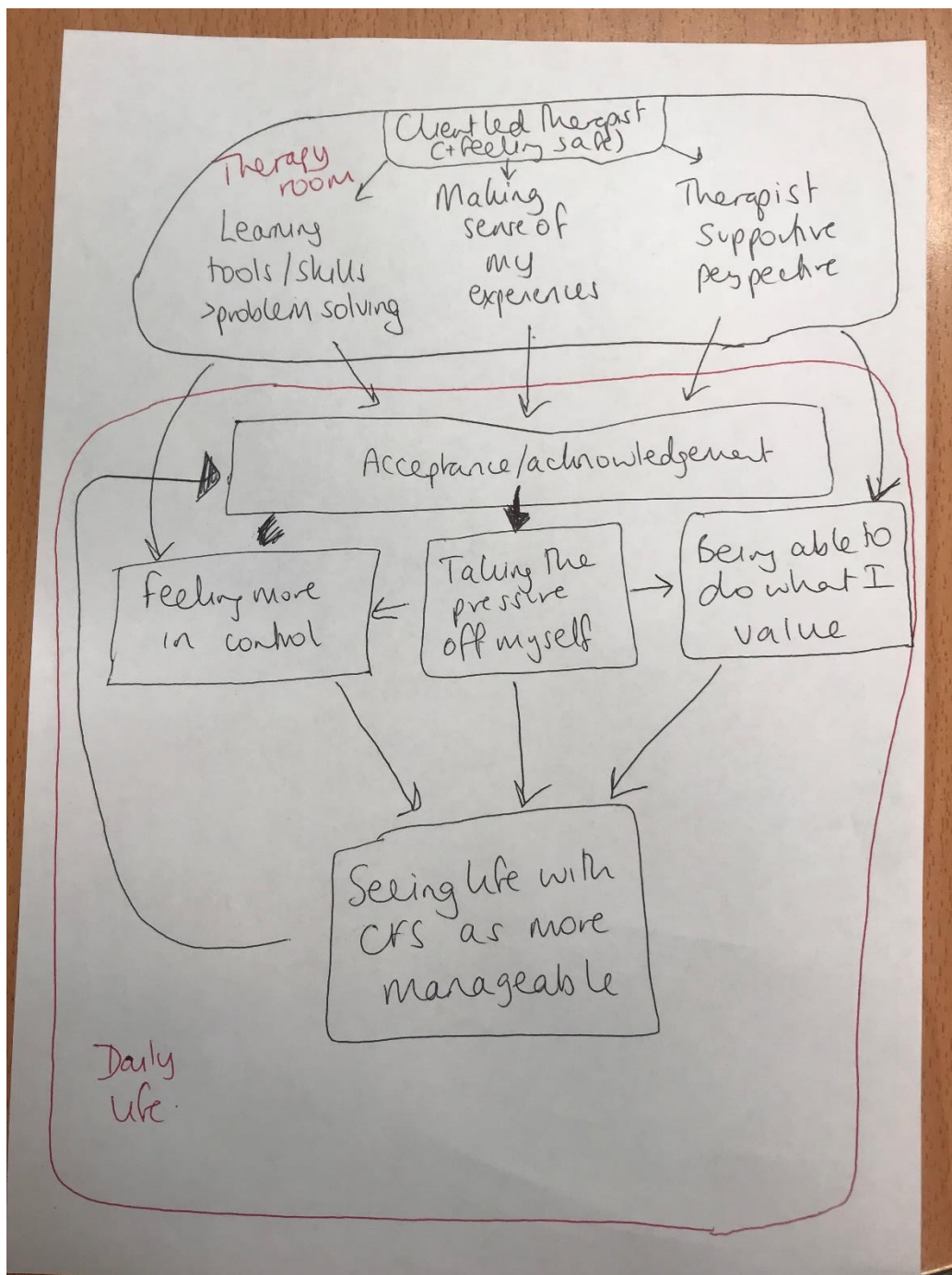
A map of the model at an early stage of analysis. It was clear after the first few interviews that a core category involved participants experiencing a shift to seeing life with CFS/ME as more manageable. It had also emerged that this made it easier for some participants to acknowledge their needs and symptoms. It had emerged that feeling less distressed about the diagnosis helped people to think about new ways of connecting with values, which in turn reinforced the belief that life with the condition was bearable. Participants were talking about some significant changes occurring; what wasn't clear at this stage was the specific processes that facilitated these.



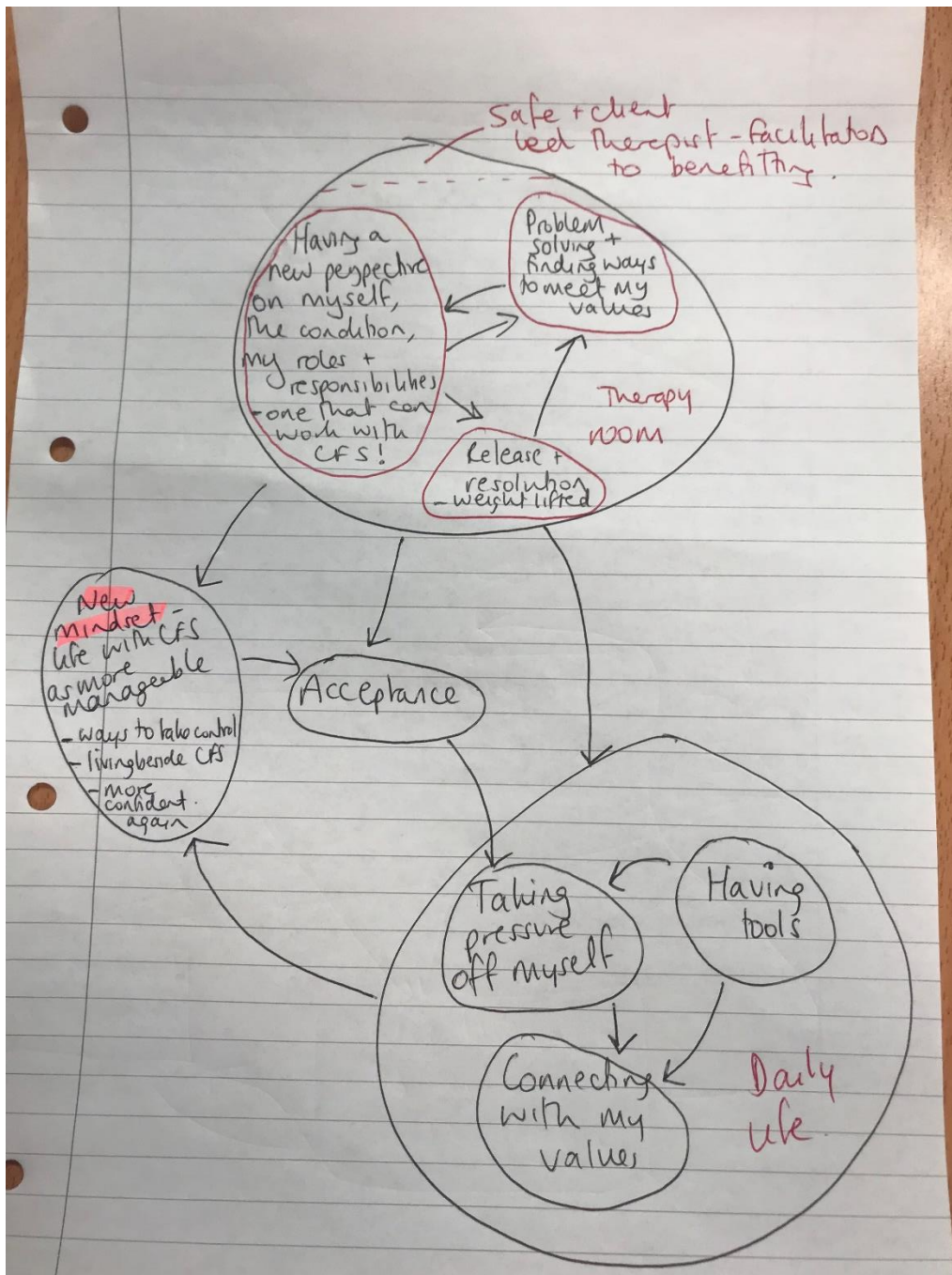
At a later stage in analysis it was clear that changes in the therapy room led participants to make changes in their daily lives and I tried to capture this in the model by introducing the two contexts (in red circles). It was also clear that participants felt that the therapy had led to positive changes in their personal relationships for lots of different reasons, and this was feeding into seeing life with CFS as more manageable. Later 'impact on relationships' was merged into being more able to communicate and open about needs and having more capacity for personal life due to 'lightening the load' in the therapy room. At this stage, I felt like I didn't have enough arrows on the model as the data was suggesting that many factors facilitated each change. Later shaded circles were introduced to highlight that the factors within each context all influenced each other.



After gathering more data around the concept of acceptance during interviews, it was clear that acceptance was facilitated both by conversations in the therapy room and by making changes in daily life which resulted in a mindset shift towards seeing life as more manageable. Thus, it was moved out of the 'therapy context' in the model. At this stage the category 'making sense of my experiences' included resolving broader life issues like trauma and breaking down challenges arising in life around roles and responsibilities (in order to problem solve these). This category was later merged into 'lightening the load', 'understanding what was happening' and 'separating what we can and cannot control'.



A map of the model in the late stages of analysis. Theoretical sampling, via adapting interview questions, highlighted that participants' experiences in the therapy room had a broader impact than participants only adopting different approaches to daily life. Participants experienced reduced distress about the condition and their lives, due to releasing distress, resolving issues and having solutions. This led to participants seeing life as more manageable. Thus, an arrow was added directly from the therapy room to the category 'seeing life as more manageable'. The category learning tools became a subcategory of 'problem solving and tools' (later re-named finding ways to move forwards). 'Having a new perspective' and 'release and resolution' emerged as categories (later names were slightly adjusted to match participants' words).



Appendix N: Research diary extracts

March 2017

I have decided to do a study looking at psychological interventions for a chronic health condition, as I am interested in the mind-body relationship and ways of working with this clinically. I have started looking at the academic and grey literature for a few conditions and found an area that seems to have generated a lot of controversy, disputes and disagreements between academics, clinicians and service users: CFS/ME. The literature suggests the condition is poorly understood, there is no test or cure for it, prognosis and intervention outcomes are bad. And there are big discrepancies between the RCT outcomes and those of patient surveys. This feels like an area that needs more research. And I have been looking for an area where I could do a truly exploratory qualitative study of a poorly understood area; this seems to be the case here. The service offering projects to Salomons trainees doesn't offer GET, so I think I'll do CBT; these are the two most common interventions offered in the UK, and both have been a source of controversy.

20th April 2018

I have just received the informal decision from the NHS Ethics committee; they have asked me to 'Revise the Protocol demonstrating equipoise and uncertainty of current treatment.' They feel that I have overstated the benefits of CBT. I am surprised by this as I thought I had made it clear that my rationale for the study was that there was disagreement amongst studies about CBT outcomes and even the most favourable studies suggested that outcomes were poor for most people. I noticed that when I attended the ethics panel, the committee were not friendly and had lots of questions about my views on CBT for CFS/ME. I thought I perceived some anger at my proposal. I wondered if this mirrors the frustration expressed by professionals and service users about CFS interventions in the literature and on social media. I noticed I felt angry about the committee's responses to me both in person and in their decision letter. However, it is incredibly important to me to attempt to approach both part A and part B of my study with clear vision, as unclouded as possible by emotions and alternative agendas. I have returned to the literature and added further meta-analyses to the protocol to support my assertion that CBT has resulted in some self-reported improvements in fatigue for some participants. But I have also added further criticisms of the RCTS to the protocol. I think what that does more than anything is highlight the dissatisfaction with CBT for CFS/ME, which is an important context to the study and demonstrates that it is one of which I am aware.

3rd October 2018

I met with the two CBT therapists in the service today, with the aim of understanding the aims and model of the CBT they deliver. The service does not possess any written documents describing the model used, for example a protocol or manual. The therapists highlighted that they couldn't provide much general information about the approaches they used as they tailored the intervention to each service user. They did say that they often used components of pacing. I asked if they aimed to support participants to increase their activity and they responded that is helpful for some service users but not others. I asked what they thought about the model of CBT used in the PACE trial; they said they had copies of the manual from the trial and found some components of it useful from but that the model was not suitable for many service users. They reflected that the service may hold more complex service users than participants in the PACE trial. In general, I was heartened by the emphasis the therapists put on individualised care. But I didn't feel I had come out with a good understanding of the aims and scope of the CBT delivered (particularly whether or not they aimed to support service users to increase activity, or just to exist within their energy limits, which is how I understand pacing). I did however have a sense that the broad aim of the CBT was to help service users better manage their physical and emotion needs. The nice thing about grounded theory is that I feel it is ok not to have understood everything before starting interviews; in fact it may mean that I am more open to participants' words and meanings. But I will have to go back and clarify the treatment model with the service before I write up the study for submission.

26th October 2018

I have completed my first interviews. During the interviews I felt conflicted about how much to slow people down and probe for more details on issues they had raised. I was conscious that I wanted the conversation to evolve naturally so that participants had the opportunity to talk about what felt most relevant. But after the first interview I realised that conversations tended to jump around a lot, meaning that it was hard to explore issues raised in depth. I found it helpful to keep track of issues I wanted to come back to by writing these down as participants spoke. I also found it helpful at the start of each interview to provide a brief explanation of the aims of the study and the style which I might adopt in the interview (e.g. asking about conditions and consequences). This way when I slowed people down and asked these questions later in the interview, I felt less worried that participants might feel they had not initially provided enough detail. I noticed that when I started providing this explanation at the start of the interview, participants appeared less concerned by this style of questioning later on.

Open coding is really time consuming. I am coding all content relating to the illness, including past interventions, participants' conceptualisation of the condition, and find myself questioning if this is necessary and at worst could result in me not focusing my thinking on a small enough area. Sue looked at a whole transcript and agreed the scope was very wide and it might be helpful to focus more on the CBT specifically, given that is the focus of the project. I don't feel the coding was wasted though, as for those first few participants I have a detailed understanding of the wider context of their lives. Sue said she thought my interviewing technique was good for grounded theory which was very reassuring; everything feels very unfamiliar, so it was nice to be told my style was appropriate. And there were very few discrepancies between our codes for the two transcripts she reviewed. Some of her initial thoughts made me realise that particularly at this early stage of analysis it is important to capture the meaning of individual words and phrases in order to sensitise to the data.

1st November 2018

I have now completed two interviews over Skype. I cannot see any major differences between the dynamics or content of these interviews and those conducted face to face. If anything, during the Skype interviews I personally felt more relaxed as I was less worried about participants' physical welfare, knowing they had not travelled to the interview. In the face to face interviews I was conscious of whether the lighting in the room was overstimulating and whether people needed a rest after arriving, as some mentioned having got lost on route to the interview. I had wondered whether only having a "head shot" provided by webcam would prevent me from being able to read participants' non-verbal cues such as body language. But in the skype interviews so far, participants have positioned the cameras in such ways that I could see much more than just their heads. I'd also wondered whether participants would generally appear more or less relaxed and forthcoming over skype; positions on this in the academic literature are mixed. So far, I feel that participants appear more relaxed in the Skype interviews.

In terms of the content of interviews, I am finding myself feeling surprised and uplifted by how beneficial the participants have reported finding the CBT. I am wondering if my sample might be biased towards people who have had a good experience and want to 'give back' to the service. I am hoping I might be able to use the participant questionnaire to identify and selectively interview someone who did not find CBT beneficial.

It seems clear that the goal of therapy was positioned as helping people to manage their fatigue, not increase their activity and all the participants so far found this satisfactory. I can start to see a coherent model emerging already with the core category that life was perceived as more manageable by the end of therapy. On saying that, the range of issues people discussed in therapy ranges widely; this fits with the therapists describing their approach to therapy as very individualised. I feel quite lucky that I am coding data relating to such positive experiences.

22nd November 2018

I have only just completed the 5th interview. Recruitment has been slower than I anticipated, although it is understandable given the difficulties participants face. I don't think I will be able to select participants based on certain characteristics, to facilitate theoretical sampling, as I had hoped. I have already adapted the topic guide based on emerging topics, so I will have to concentrate on this as a means of theoretical sampling.

7th December 2018

I have started axial coding: I am finding it useful to write memos about emerging categories to think about conditions and consequences. I find I am constantly re-jigging categories due to constant comparison. I am finding it quite emotionally exhausting to be undertaking the constant cycle of settling on a model or set of categories which seem coherent and to fit the data, only to find that each new interview results in a re-arrangement. On the upside, every time this happens the model does feel richer, with the categories more saturated with properties and the overall model more coherent; I know from Strauss and Corbyn that these are hallmarks of theoretical saturation, so I am holding this in mind for motivation.

20th December 2018

I am completing a quality analysis of the studies in part A and it is certainly sensitising me to factors which increase the robustness of qualitative research. I'm going to ask Sue to look at line by line coding for the part A data subjected to thematic analysis, and for her to review broader themes. In generally, part A is suggesting that the quality of existing qualitative data is OK but there are consistent methodological flaws across studies, particularly researcher reflexivity. This has made me very aware of the need to monitor my assumptions and biases as they emerge and evolve through part B. It has

really highlighted to me how important it feels to leave enough time at the end of the study to conduct respondent validation as another form of credibility check.

17/2/19

All interviews completed, and transcripts coded. Now finalising the theory, which mainly involves thinking about relationships between the categories. I am looking back and forth between the model and the raw data, but the most useful tool has been the maps of each participant's individual experience, highlighting conditions and consequences. And the memos. I am really glad I invested time doing this after each interview.

22/3/19

Just had an interesting discussion with Sue about the Part B model, thinking about Jean and Judith who seem to be in some ways exceptions or 'negative cases'. Jean was the only participant who had experienced significant symptom improvement prior to CBT and Judith was the only participant who didn't feel more able to manage her CFS/ME post CBT. I had incorporated Jean's experiences prior to CBT in the model by highlighting her as an exception in the category 'Lack of improvement from prior interventions' and Judith's experiences as an exception in 'Acceptance' and 'Living beside CFS/ME'. I had also highlighted that she felt CBT was a 'springboard' as therapeutic gains in other personal issues allowed her to feel more able to pursue further interventions for her CFS/ME. Sue, however, wondered if an additional dimension should be added to the model, such as 'stage in journey of interventions'. The implication would be that where someone is on their journey through therapies affects how much the latest one is experienced as helpful. And a hypothesis might be that it can take several years before people are able to fully benefit from even the most evidence-based therapies for CFS.

I thought this was a very interesting idea and initially thought that it might fit the data. I went back to the transcripts and the maps I had for each participant's journey to reflect on whether the data spoke to this potential additional category. But on further reflection I don't think participants do consistently experience a progressive 'journey' with interventions, in which there is a shift in the extent to which CBT can be helpful. Several participants had tried many other things prior to CBT and their symptoms and capacity to benefit from CBT had not shifted; which is why I think Jean is an exception. Likewise, many participants were in Judith's position of this being their first intervention, yet found it really helped them manage CFS. The data suggests that 'stage' in journey effects how

participants engaged with more basic interventions like pacing (as they either do or do not have the knowledge of this already). But the data suggests that this didn't seem to be a consistent predictor of engagement with CBT, so for Judith other factors were more likely to have been barriers.

Sue had expected that her suggestion might not fit the data; this discussion really highlighted that for qualitative research to be robust, researchers must be constantly re-exploring the meaning in the data, testing out emerging hypotheses.

Appendix O: Positioning statement created following bracketing interview

I am a 30-year-old female third year trainee clinical psychologist at the time of starting data collection for this study. I have never experienced significant long-term health problems but often describe feeling 'tired', which I attribute to the high work load and intensity of my job. Nobody in my close friends and family has experienced a long-term health condition during their adult life. One friend of mine was diagnosed with CFS/ME as a teenager and has reported experiencing full recovery after a significant period spent on sick leave from school. I have no previous experience working in health settings. I chose to complete research on CBT for CFS/ME for three reasons. Firstly, I am interested in the relationship between mind and body. Secondly, it became apparent to me from academic literature and social media that CFS/ME is not well understood, intervention outcomes are poor and there are inconsistencies in the research. Lastly, CBT was the only psychosocial intervention provided within the service which offered the CFS/ME project.

The bracketing interview drew to my attention that I feel quite anxious and slightly angry about the power imbalance between people with CFS/ME and clinicians and academics, particularly those in large research groups running RCTS. It is important service users' voices are heard, and qualitative research facilitates this, but I'm very aware for the research to be robust I need to remain aware of my biases and which in this case could translate into an unconscious agenda to disprove the existing RCT results.

I have tried to limit the literature I have read on CBT for CFS/ME prior to data collection, beyond that needed to understand the basic context of the issue. I have become aware of the different illness models that have been proposed, and that people with CFS/ME tend not to subscribe to a psychiatric explanation of their difficulties, but that this is the basis of several CBT interventions reported in the literature. In the bracketing interview my opinion about the basis of CFS/ME crystallised: I believe that the term CFS/ME is likely to incorporate a range of illness subtypes, which might explain variation in illness trajectories and intervention outcomes amongst individuals. I noted that attributing variation in intervention processes to physical factors could limit my thinking; I must therefore be careful to consider the role of individual psychological differences when considering facilitators and barriers to benefitting from intervention components.

I have used CBT with between 5-10 clients on my clinical placements during my clinical psychology doctorate. I see CBT as useful for some clients, in some contexts, but not others. Generalising from my experience of CBT, I can imagine some ways in which certain cognitive and behavioural components of the intervention could be beneficial to people with CFS/ME. However, currently I do not feel convinced that CFS/ME is maintained by inactivity.

I noted in the bracketing interview that I often thought in a CBT framework, categorising factors as thoughts, feelings or behaviours. I acknowledged that it would be important to keep my questions open to understand how participants perceive experiences using their own conceptual frameworks. I wondered if participants might use a CBT conceptual framework themselves, possibly because of undergoing the therapy and adopting the language of the therapists. I noticed my assumption that the CBT therapists had used traditional CBT terminology like 'core beliefs' and 'unhelpful assumptions'. It is however widely acknowledged that the delivery of CBT by qualified therapists varies widely, with some preferring to use less of the terminology typically associated with application of the model.

Appendix P: Respondent validation covering email

Dear [name of participant]

I hope you are well. Firstly, I wanted to say thank you again for participating in the research study exploring the experiences of engaging in CBT (Cognitive Behavioural Therapy) for CFS/ME.

Altogether 13 participants were interviewed for the study. I have analysed the data from the interviews and used this to create a model or 'theory' explaining peoples' experiences of the CBT. The model is explained in a 1 page illustration followed by 3 pages of text (see attached).

Please note that each participant was assigned a pseudonym in the write up of the results. Yours was [pseudonym of participant]. Verbatim quotes from your interview have been included in the full results, [then either:

- but you will not see your name in the attached summary, as it is a condensed version.
OR
- you will also see your pseudonym in the attached summary.]

Next steps: It would be extremely valuable to ask your opinion of the proposed model. Specifically, I would like to ask you 5 questions:

- a. What are your thoughts on the model?
- b. Is there anything in the model that particularly fits with your experiences of CBT for CFS/ME and what you spoke about during the interview?
- c. Was there anything you expected the model to contain that is not there?
- d. The arrows in the model represent factors influencing each other. Do any of these fit particularly well with your experience? Would you expect to see different arrows on the model?
- e. Is there anything about the model that you feel could be useful?

There are two ways in which you could share your responses with me. One option is to respond by email. Alternatively, you might find it easier to have a brief phone call with me (around 15 minutes); this would allow you to provide further detail. Would you be able to let me know if this option would be suitable for you?

After feedback from yourself and other participants has been gathered, a full report of the study will be finalised and sent to you at a later date.

Many thanks again for your participation, it is very much appreciated.

With best wishes,

Catherine Clark

Trainee Clinical Psychologist

Appendix Q: Respondent validation findings sent to participants and participants' responses

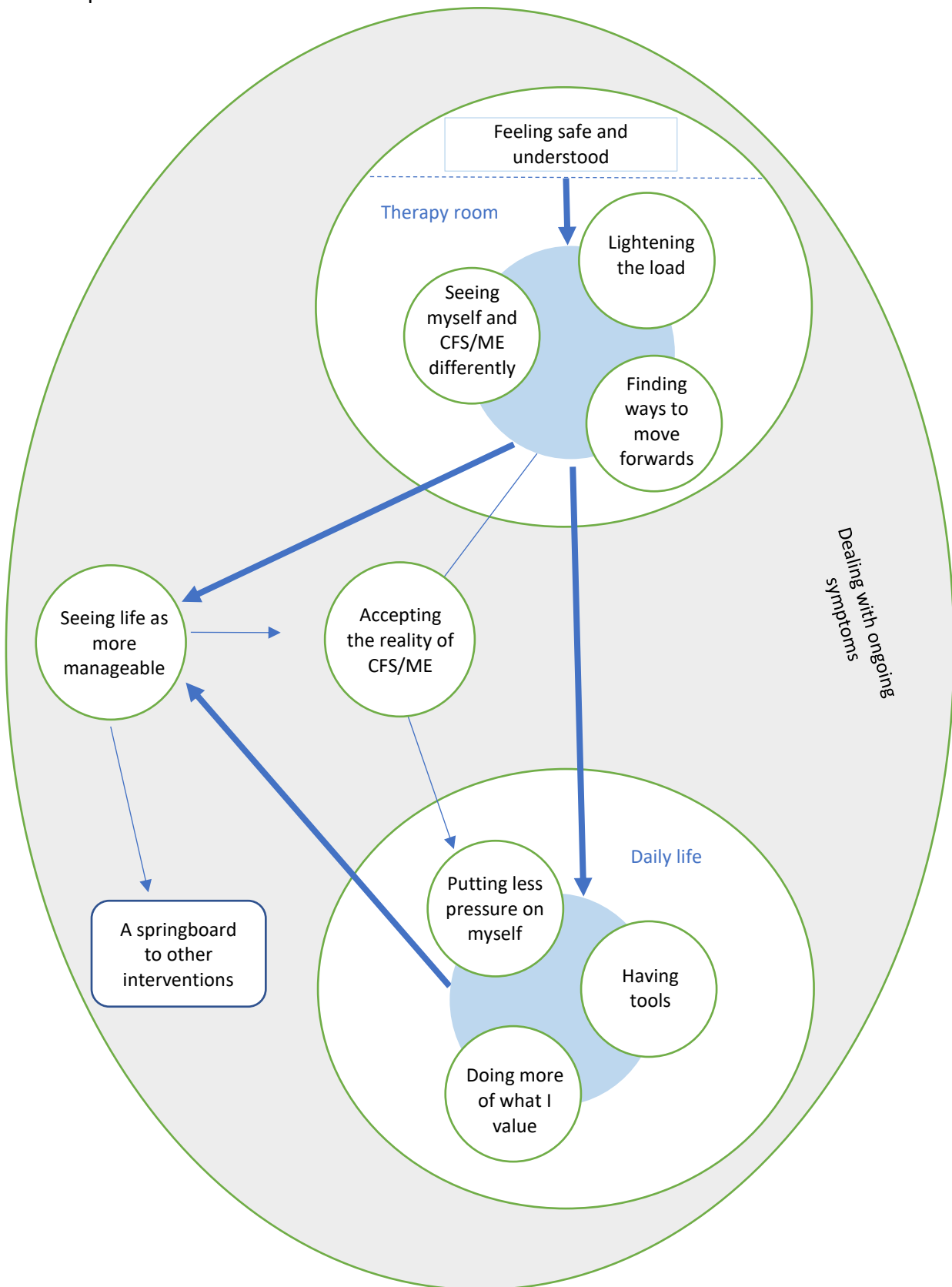


Figure 1. Model of the theory. Blue writing represents locations. Arrows represent factors influencing each other. The shaded circles represent the idea that the different experiences within each context influence each other.

A theory of engaging in Cognitive Behavioural Therapy (CBT) for CFS/ME

(Please note this is not the final version of the study results. The full report will be sent to you at a later date.)

Summary of theory

The diagram above displays a model of a theory of how people experience CBT for CFS/ME. The theory comes from analysis of the data gathered from my interviews with you and the other 12 participants in the study. Words in circle represent the key elements of the experience; these are written in italics below and each elaborated on in detail.

The theory suggests that throughout CBT people are typically '*Dealing with ongoing symptoms*'. Experiences in the therapy room (illustrated in the top circle) enable people to make changes in their daily life (illustrated in the bottom circle). Discussions in the therapy room can also help people in '*Accepting the reality of CFS/ME*'. Changes in mindset arising from the therapy room and changes in approaches to daily life contribute to people '*Seeing life as more manageable*.' For some people this helps further in '*Accepting the reality of CFS/ME*'. This can in turn lead to people making further adjustments such as '*Putting less pressure on myself*.'

Dealing with ongoing symptoms

- **Improvement from prior interventions:** Participants had engaged in a range of interventions prior to CBT, however all but one participant continued to experience significant CFS/ME symptoms. Jean was an exception as she felt "85% back to normal" when starting CBT, which she attributed to a previous intervention.
- **Changes over CBT:** Most participants experienced no change in their symptoms over CBT. Those who experienced improvement continued to experience symptoms but had fewer relapses. Improvement was typically attributed to better management of energy and being more in control of emotions.

Feeling safe and understood

Feeling safe, contained and believed allowed participants to open up. Making progress was more likely when participants felt the therapist understood their unique difficulties.

Seeing myself and CFS/ME differently

- **CFS/ME is real and not my fault:** Therapists highlighted that CFS/ME was a real and chronic condition. Participants could find this shocking but helpful in understanding their situation. Exploring the causes of CFS/ME could reduce frustration and guilt.
- **CFS/ME is manageable:** Therapists describing CFS/ME as manageable and providing examples of others managing the condition, was a first step in increasing hope, particularly for recently diagnosed participants.
- **Lowering expectations of myself:** Many participants had high expectations of themselves, and were able to set more realistic standards about work, home life and coping with CFS/ME.

- **It's ok to put myself first:** Participants came to see it as more acceptable to prioritise their own needs and felt less guilty about sharing responsibilities. This was often based on direct therapist advice.

Finding ways to move forwards

- **Seeing what was making it worse:** Participants found it helpful to identify factors exacerbating their symptoms, which made things clearer and allowed them to respond differently. Exploring thought patterns helped participants better understand their distress.
- **Separating what we can and cannot control:** Participants valued separating out problems within their control and those out of their control. This helped them to let go of unproductive worrying.
- **Problem solving and learning tools:** Therapists supported participants to find solutions and develop problem solving skills, which reduced anxiety. Some participants saw therapist suggestions as essential for moving forwards. Participants learned tools for communication and managing emotions and energy.
- **Finding opportunities for enjoyment:** Practical exercises exploring timetables and planning activities helped participants find opportunities for valued activities and look to the future.

Lightening the load

- **Resolving broader issues:** Discussions around personal traumas, relationships and identity led participants to experience some resolution around these issues. Participants often felt more able to step back from things, allowing them to focus on managing their condition.
- **Getting things off my chest:** A space for participants to get things off their chest was often unique. Participants felt less overwhelmed and burdened.

Seeing life as more manageable

- **Having ways to take control:** Participants described a sense of being equipped with “tools”, solutions, support and an ability to step back. This resulted in feeling more in control of their illness and lives, and less vulnerable. For some this led to focussing less on symptoms.
- **A springboard to other interventions:** Participants also felt they had more “emotional energy” and headspace to pursue other interventions after CBT, which was seen as “a springboard”.
- **Getting my confidence back:** Participants experienced increased self-esteem and were more compassionate to themselves. This led to more positive engagement in work and personal lives.
- **Living beside CFS/ME:** Changes in outlook and lifestyle led participants to view it as possible to “live beside” CFS/ME without the condition ruining their lives. Judith was an exception as she continued to feel unable to manage life with CFS/ME post CBT.
- **Making peace with CFS/ME:** Most participants felt less distressed about CFS/ME after CBT, described as “making peace with it”. This was a result of both therapy and ongoing natural adjustment. Commonly some frustration remained, particularly around limitations caused by the condition.

Accepting the reality of CFS/ME

Many participants felt that after CBT they more fully understood and accepted the extent of their symptoms and the nature of CFS as a chronic illness with no immediate cure. This did not mean giving up hope of gradual longer-term improvement. Acceptance could result from participants learning that ‘*CFS/ME is real and not my fault*’. For others, it came after ‘*Lowering expectations of myself*’ and reducing self-criticism. Acceptance was also more likely after ‘*Making peace with*

CFS/ME. Acceptance was often initially distressing. It typically led to *'Putting less pressure on myself.'* Sebastian reported only accepting the nature of CFS/ME after a second set of CBT sessions. Judith felt that the approach in the CBT sessions did not allow her to acknowledge the extent of her symptoms.

Having tools

Participants described using tools learned in therapy in their everyday lives. Experience of doing this contributed to a sense of *'Having ways to take control'* (within *Seeing life as more manageable* above).

- **Taking a different perspective:** Participants became able to notice unhelpful thoughts and take a different, less distressing perspective on symptoms and broader issues in their daily lives, often using metaphors or images. It was harder to challenge thinking when symptoms intensified.
- **Control over my responses:** Participants saw tools such as time out and problem solving as ways of gaining control over their emotional responses, actions and decision making. Participants also felt more able to let go of worrying.
- **More able to communicate:** Several participants felt more able to communicate and negotiate with others, particularly about their needs. This could be due to feeling less preoccupied, distressed or frustrated, and having the understanding and language to explain their difficulties. Better communication led to better support.

Putting less pressure on myself

- **Cutting back on demands:** Almost all participants cut back the demands they placed on themselves in work and social contexts. This was typically due to *'Acceptance of the reality of CFS/ME'* and *'Lowering expectations of myself'*. Some required "permission" from the therapist to cut back. Others found it necessary to use strict boundaries such as leaving their laptop at work.
- **Re-prioritising my needs:** Re-evaluating *'It's ok to put myself first'* led several participants to re-prioritise their own needs. Although this was often uncomfortable, it became easier with experience. Participants became more willing to say no to others and introduced new forms of self-care, often on therapist advice.
- **Being more open about my needs:** Many participants became more open about their physical and emotional needs. This was easier after the therapist provided validation and a language to discuss difficulties. Others felt more comfortable after a positive experience of talking in therapy. Some were encouraged to test out being more open. Increased openness led to feeling more supported.

Doing more of what I value

- **More courage to do things:** *Having tools* and *Being more open about my needs* led to less fear and avoidance of situations, and fuller engagement in activities. Understanding their fears allowed participants to face difficult situations.
- **Having more capacity:** Feeling 'lightened' and more able to manage other areas of their lives increased participants' ability to engage in valued activities. Participants had more time and energy. Goal setting exercises helped participants regain abilities to plan activities for themselves.

Responses from participants (included with their consent)

At the time of submission of this report, five participants had responded with comments about the proposed model. John opted to discuss the model over the phone, and George, Charlie, Jean and Judith responded via email. Four participants broadly endorsed the results. Jean endorsed the results in that she felt that her experiences appeared to be an exception to the model. Interestingly, she recognised processes described in the model as those she experienced when she went on to engage in further interventions following CBT, as reflected in her description of CBT as a 'stepping stone.'

Phone responses:

John:

John felt that the model all made sense and fitted with his experiences; he said I had 'done a great job.' Initially he felt the category 'seeing life with CFS/ME as more manageable' did not fit with his experiences as he still found life with CFS/ME very hard. When we discussed the content of the category, discussing each subcategory in turn, John said that these did fit with his experiences. He suggested that the word manageable did not seem useful for the category and suggested that 'A life I can cope with' would be more fitting. I told him that my initial response to this, was a sense that this indeed might be a more suitable name to reflect the data across participants, but that I would like to return to look at the data and reflect more on the most useful name for the category.

John felt that the areas of the model that best captured his experience were 'accepting' and 're-prioritising myself.' He felt that the all the arrows on the model fitted his experience. In particular, he identified with a 'cycle' in which acceptance led to re-prioritising needs, which led to life feeling more manageable, which in turn led to further recognition of his needs. He said he realised the extent of his needs after making changes as this highlighted that his approach to life prior to therapy had been adding to his problems. He summed it up succinctly as "finding a way that actually works makes you realise that this is how it has to be."

John identified least with the idea of a springboard to other interventions but after discussing the meaning of this, John said he had thought this meant going on to benefit from other interventions which had not been the case for him. He had however been able to attempt other interventions, which is in line with the concept of the springboard.

John suggested that the model could be useful for clinicians, as they could use it to consider at what stage in a service user's journey, CBT would be most valuable. John thought clinicians could give particular consideration to a service user's level of acceptance and the tools which they have and have not yet gained.

Verbatim email responses:

Charlie:

Read through it. Loved the model of the theory, I think that would be a useful handout to show people who are suffering symptoms the potential way forward.

It all relates to how I was and am now.

Recognition, belief and help.

Not sure if it's within this context but legal knowledge, The Disability Act, and how to access and use it. Added security. Cant see anything else to add.

Thanks for letting me help, it was in a good way therapy revision.

Jean:

1. Yes the model reflects the situation. I did not know that was what CBT was trying to achieve.

2. Tow [sic] things - firstly coming to terms with the illness and adapting to your new limits and secondly doing things you love in order to get better.

3. No I don't know if I'd know what could exist under CBT

4. I think all the arrows cover my experiences.

5. Yes in informing people what CBT is and is trying to achieve.

George:

I agree with all your findings except that I would go a bit further in terms of the helpfulness of CBT. I felt supported and increasingly optimistic as I went through the sessions. I also felt that learning to manage the condition was the key to gradually improving it.

Before this I kept having relapses, not realising that I was exacerbating the underlying condition by overdoing it. By rationing my energy, avoiding stress (vital!) and looking for inspiring and uplifting experiences I have made great progress, and CBT is to thank for it.

As someone who has suffered from CFS I feel very strongly that this therapy must be made readily available. Apart from this, the medical profession completely failed to provide me with any help whatsoever and I dread to think how things might have ended up otherwise.

I then clarified via email:

“Can I just clarify when you say ‘go a bit further’ are there particular parts of the results you feel don’t fit with your experience?”

George’s follow up response:

No, it all fits in with my experience. I just meant I would expand what you said a bit as per my enthusiastic comments.

Well done for doing this!

Judith:

It seems to me that most participants benefitted more than I did from CBT. I recognised a lot of their experiences from the work I went on to do with the Optimum Health Clinic but the sessions at [name of service] made me believe that all I needed to do was walk a bit further each week and I would improve.. Maybe we were too focussed on helping me deal with the trauma that was affecting me.

There is no mention of GET in this summary. Because I was being urged to up my walking every week, I felt that M.E./CFS was being treated as purely a psychological illness - not a real and serious condition. It was disheartening for me when I wasn’t able to increase my walking without experiencing payback.

As you present CBT here it is a very helpful intervention on most fronts - but not combined with GET, which can be harmful to some.

Appendix R: End of study summary (participants)

What is the background to the study?

In the UK, it is recommended that people with CFS/ME of all severities be offered Cognitive Behavioural Therapy (CBT), although these guidelines are currently under review. There has been considerable publicity on how effective CBT is for CFS/ME. Yet there have been significant discrepancies between the outcomes of CBT reported in large research trials and those reported in patient surveys.

In addition, it has been highlighted that different models of CBT for CFS/ME exist across settings. One model of CBT primarily aims to support participants to increase their activity in order to improve their fatigue and other symptoms. This is based on the theory that “re-conditioning” can lead to recovery from the condition. Another model of CBT for CFS/ME aims to support people to live with the condition and find an optimal level of activity to minimise exacerbation in symptoms. Research so far has focused almost exclusively on the first “re-conditioning” model of CBT. Furthermore, healthcare guidelines highlight that CBT should aim to reduce the “distress associated with CFS/ME”. Yet CFS/ME studies have almost exclusively examined whether CBT results in changes in fatigue and functioning, rather than changes in distress or quality of life.

Further research is needed to understand the experience of the model of CBT aimed at improved living with the condition. This study therefore aimed to build a model of this experience, focused particularly on understanding any changes underwent.

How was the study carried out?

Interviews were conducted with 13 service users who had completed CBT aimed at supporting them to manage their condition. Interviews were analysed in order to build a theory of the experience of engaging in CBT for CFS/ME. A preliminary theory was sent to participants to gather their feedback. The five participants who responded all reported that the model captured their experience or highlighted when their experience was an exception.

Results

Fatigue

In line with some recent large patient surveys many participants in this study described experiencing no change in their symptoms over CBT. Some participants experienced a reduction in relapses, which they put down to better management of energy and feeling more in control of their emotions. All but one participant still had symptoms at the end of the CBT. This was not unexpected given that the service delivering the CBT aims to support service users to manage life with CFS/ME, rather than eliminate symptoms.

Psychological factors

Firstly, following CBT most participants felt more able to cope with life with CFS/ME. Participants described feeling more in control and thinking that it was possible to live alongside their condition without it getting in the way so much. Partly this resulted from addressing issues that were preventing participants from being able to manage their CFS/ME, such as holding themselves to unrealistic standards. This, together with learning tools such as problem solving and pacing, allowed participants to approach their daily lives in a way that was more helpful in managing their CFS/ME. Seeing life as more manageable also resulted from participants addressing anxieties about how CFS/ME prevented them from being able to fulfil their roles or values.

Secondly, several participants reported greater 'acceptance' of their condition after the CBT, which involved acknowledging that it was not possible to make symptoms go away or control them, at least in the short-term. This acceptance often led to participants making further adjustments in daily life, which in turn made them feel more able to cope with life with CFS/ME. This then made it easier again to accept having the condition. This suggested a 'cycle' in which acceptance led to better coping which led to further acceptance.

What could this research mean in terms of helping people?

This study suggests that CBT in which the primary aim is improving quality of life, rather than increasing activity and reducing fatigue, can be experienced by service users as very beneficial and result in reduced distress about life with CFS/ME.

Firstly, it is important to note that all participants in this study found it appropriate that the goal of therapy was positioned as better management of CFS/ME rather than "recovery". This model of CBT might not be suitable for service users who view the goal of therapy as "recovery".

The study suggested that it might be useful for services to offer interventions incorporating problem solving, cognitive tools to manage distress and pacing. Results suggest that interventions should identify and address barriers to service users managing their CFS/ME, explore ways in which service users can fulfil their roles and meet their values whilst living with CFS/ME and increase their acceptance of the nature of the condition. Interventions might include exploration of service users' expectations of themselves, identities, roles, relationships and values. Results suggested these discussions often changed the way participants saw or approached things which made it easier for them to manage their CFS/ME.

Next steps

This study did not look at the impact of CBT beyond two years after therapy. Further research is needed to test out longer-term changes. More studies are also needed to test out the ideas suggested in this study's model.

Appendix S: End of study notifications

A copy of the following cover letter and summary was sent to the NHS ethics panel and the relevant NHS R&D department

Dear members of Bromley REC committee/[name of host trust] Research and Development Department,

RE: A grounded theory exploration of cognitive behavioural therapy for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis.

I am writing to notify you that the above study has been completed and a thesis has been written to be submitted for partial fulfilment of the degree of Doctor of Clinical Psychology at Canterbury Christ Church University. Please see attached a brief summary of the study. A separate report will be sent to the study participants following examination of the submitted thesis.

.

Yours Sincerely,
Catherine Clark

Trainee Clinical Psychologist
Salomons Institute for Applied Psychology
Canterbury Christ Church University

Summary

Background

In the UK, NICE (2007) recommends that people with CFS/ME of all severities be offered Cognitive Behavioural Therapy (CBT), although these guidelines are currently under review. There is considerable variation in physical and psychological outcomes following CBT for CFS/ME, both across studies and individuals. Yet there has been considerable publicity on how effective CBT is for CFS. It has been suggested that this may underpin the considerable backlash against CBT from patients, much of which has been on social media. One issue is that the fundamental treatment goals for CBT for CFS/ME vary across studies. Some studies have suggested that participants can experience reduced distress and perfectionism, and increased acceptance of their condition. Yet other studies suggest that service users can often feel more distressed following CBT for CFS/ME. Further research is needed to understand the changes, if any, experienced by service users when engaging in CBT for CFS/ME. This study therefore aimed to address this issue, focusing particularly on factors perceived by participants as facilitating such changes.

Methodology

Semi-structured interviews were conducted with 13 service users who had engaged in CBT aimed at supporting them to manage their condition. Interviews were analysed using a grounded theory methodology, in order to build a theory of participants' experiences. Quality guidelines were used to increase the credibility of the research. A research diary was maintained, a bracketing interview was conducted and a positioning statement created. This increased awareness of researcher preconceptions, for example around attitudes to CBT. Two line-by-line coded transcripts, memos around emerging categories and integrative maps were shared with the researcher's supervisor, who has extensive experience in qualitative research. The supervisor offered comments, challenges, and elaborations, which were discussed and incorporated into the analysis. Finally, respondent validation was undertaken to ascertain the credibility of the analysis to participants. The five participants who have responded to date, have all broadly endorsed the results of the study.

Results

Fatigue outcomes

In line with patient surveys participants in this study described either experiencing no change in their symptoms over CBT or some reduction in relapses but ongoing regular symptoms. This was not unexpected given that the CBT model adopted by the service aimed to improve management of life with CFS/ME, rather than eliminate symptoms via reconditioning.

Psychological outcomes

Turning to psychological outcomes, overall the results highlighted two key reported changes after CBT. Firstly, intervention components from the therapy room, alongside subsequent changes made in daily life, seemed to result in participants feeling more able to cope with life with CFS/ME. Participants described feeling more in control and developing greater belief that it was possible to live alongside their condition. This echoes previous studies. Results suggested that it was helpful for the therapist to take a holistic approach allowing understanding and validation of participants' unique difficulties. This allowed participants to process and resolve broader issues such as traumas, relationships, roles and identity, increasing their capacity to manage their condition. Secondly, in line with studies of other psychosocial interventions for CFS/ME, including CBT, several participants reported greater 'acceptance' post intervention, which meant acknowledgement that there was no immediate way of curing or controlling their symptoms. This contributed to making adjustments in daily life, which in turn further increased participants' belief that they could cope, which in turn increased further acceptance of the condition. This suggested a 'cycle' of accepting and coping.

What are the clinical implications?

Firstly, it is important to note that all participants in this study found it appropriate that the goal of therapy was positioned as better management of CFS/ME rather than recovery. This model of CBT may not be suitable for service users who view the goal as recovery.

Results suggest that it may be useful for services to offer interventions incorporating problem solving, a recommended component of CBT in the NICE guidelines (2007), as well as cognitive tools to manage distress, which is a hallmark of CBT more generally. Results suggest that including pacing in interventions is also valuable. Results also suggest that it can be highly

beneficial for interventions to incorporate exploration around the meaning of CFS/ME, identity, roles and self-standards. Clinicians should be aware of the value of addressing holistic issues in service users' lives, in removing barriers to them managing their CFS/ME.

Results also suggest that interventions should include components to facilitate acceptance and values, for example, drawing on principles of ACT. However it should be noted that in this study participants suggested that re-connecting with valued activities was largely facilitated by them feeling more able to manage, which as described above is a focus of traditional CBT.

Conclusion

The study produced several novel findings. Firstly, CBT aimed at improved management of CFS/ME, rather than increased activity, was viewed as acceptable by participants and led to reduced distress about living with the condition. Secondly, this was not dependent on improvements in fatigue. This was facilitated by exploring and resolving issues around CFS/ME and identity, problem solving and learning tools, which together facilitated taking a more adaptive approach to daily life and becoming able to do more of what they valued. It also suggested that this model of CBT can facilitate increased acceptance, again independently of improvement in fatigue, leading to more adaptive coping and in turn reduced distress about the condition. Results suggest the need for interventions addressing the above factors. However, it is unclear to what extent these apparent improvements in daily living may be maintained in the long term, and whether they may lead to less experience of fatigue and activity-restriction. Further research is needed to test out the model suggested in this study.

Appendix T: Author guidelines for the Journal of Health Psychology

Preparing your manuscript for submission

Please ensure that your manuscript is suitable for publication and completely free of errors before you submit. Please pay particular attention to SAGE guidelines on [Authorship](#) and the [SAGE Correction Policy](#).

4.1 Formatting

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the [Manuscript Submission Guidelines](#) page of our Author Gateway.

4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#)

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our [guidelines on submitting supplementary files](#)

4.4 Reference style

Journal of Health Psychology adheres to the SAGE Harvard reference style. View the [SAGE Harvard](#) guidelines to ensure your manuscript conforms to this reference style.

If you use [EndNote](#) to manage references, you can download the [SAGE Harvard EndNote output file](#).

4.5 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit [SAGE Language Services](#) on our Journal Author Gateway for further information.

[Back to top](#)

5. Submitting your manuscript

Journal of Health Psychology is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts.

Visit <http://mc.manuscriptcentral.com/jhealthpsychology> to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

5.1 ORCID

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of [ORCID, the Open Researcher and Contributor ID](#). ORCID provides a unique and persistent digital identifier that distinguishes researchers from every other researcher, even those who share the same name, and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities, ensuring that their work is recognized.

The collection of ORCID iDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID iD you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors to link their ORCID ID to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID iD will become part of your accepted publication's metadata, making your work attributable to you and only you. Your ORCID iD is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.

If you do not already have an ORCID iD please follow this [link](#) to create one or visit our [ORCID homepage](#) to learn more.

5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

5.3 Permissions

Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the [SAGE Author Gateway](#)

[Back to top](#)

6. On acceptance and publication

6.1 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be sent by PDF to the corresponding author and should be returned promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorising the change.

6.2 Online First publication

Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the [SAGE Journals help page](#) for more details, including how to cite Online First articles.

6.3 Access to your published article

SAGE provides authors with online access to their final article.

6.4 Promoting your article

Publication is not the end of the process! You can help disseminate your paper and ensure it is as widely read and cited as possible. The SAGE Author Gateway has numerous resources to help you promote your work. Visit the [Promote Your Article](#) page on the Gateway for tips and advice. In addition, SAGE is partnered with Kudos, a free service that allows authors to explain, enrich, share, and measure the impact of their article. Find out how to [maximise your article's impact with Kudos](#).

Appendix U:

Table 3. Part B additional quotes

Theme	Subtheme	Quotes
Dealing with ongoing symptoms	Lack of improvement from prior interventions	<p>“With ME, rest just makes you worse. The more you rest, the more your muscles give up, the more your stomach becomes painful and sick, the more your head hurts, the more you rest. And actually it’s movement and getting things going and getting the body going again that actually starts your recovery” (Jean)</p>
	Minimal changes over CBT	<p>“I still have no energy. My energy is, even when I have rested, is low.” (John)</p> <p>“everything else stayed the same. The exercise levels, tiredness levels, nothing else changed” (Charlie)</p> <p>“perhaps I was sleeping better. Just because as I said, I took that night-time worry out of my head.” (Charlie)</p> <p>“It hasn’t helped the symptoms, but it is just your approach to them and dealing with them.” (Susan)</p> <p>“I saw it as a very positive tool. You know, I don’t want to say that CBT is no good for people with ME, because it helped me. But it didn’t help me get more active.” (Judith)</p> <p>“I think the whole journey of this illness is very up and down. So if someone asks you for a trajectory of it, I mean, it’s different for different people, and some people like, it’s more obvious. But for me it’s been so up and down that I couldn’t say like, “I came out of it and I was feeling better,” or “I was feeling significantly better”.” (Eva)</p> <p>the trouble is you do still get the extremities of the symptoms, but maybe there’s a slightly better management overall so they’re not so exacerbated. (Susan)</p> <p>I think if I’d been left to my own devices, sitting at home, I’d still be much further back. And could possibly be deteriorating still. I think I’ve actually stopped deteriorating this year. (Susan)</p>

		<p>“they made me feel like I could manage it, but I don’t think they actually got rid of my symptoms really. Although because I think it is so heavily linked to mental stuff, they probably did alleviate symptoms at the time, but I think I just had so much to get through that probably, you know, perhaps if I’d have had more sessions I might have even got better” (Fiona)</p> <p>“I felt that it was always there. I felt I hadn’t been cured. I felt that I was just containing it. It’s always there. I’ll always see myself as, I’m a chronic fatigue person.” (Sebastian, CBT 2)</p> <p>“I don’t think anything in that period helped me reduce the impact of the fatigue.” (Will)</p> <p>I’ll be in pain but then I can rest and be fine. But if I have stress on top of it, I can’t lift my arms up. (Layla)</p>
<p>Feeling safe and understood</p>		<p>“She was really good, because even when I was sort of like [crying] that she was just very calm and very sort of unruffled.” (Fiona)</p> <p>“It was always nice never to be questioned. Whether that’s in their remit or not, but I didn’t have to prove myself.” (Charlie CBT 2)</p> <p>“I got a very good vibe from her. I think my gut instinct was that she was kind of an affirming person and a person that was kind of believing of the condition and not trying to tell you that you’re just thinking about it in the wrong way” (Eva)</p> <p>“I know I just felt very safe and I felt I could say anything to her. It was very gentle, it was friendly, it was approached with a sense of humour, I could just say anything I wanted, so that was good.” (Susan)</p> <p>“I think it was probably the most I was going to get out of the sessions in the sense that I didn’t think she was ever going to get into my head in the same way as the other lady did.” (Sarah CBT 3)</p>

		<p>I was very lucky that I got a therapist who seemed to get into my head very well and completely understand where I was coming from (Sarah, CBT 1)</p> <p>“I really liked [name of therapist] to be honest, so I think, she kind of got me and where I was coming from and everything” (John)</p> <p>“that was when I really got interested in what she was doing and could understand. Because I could see how it was used in my day-to-day affairs dealing with work.” (Charlie CBT 2)</p> <p>“I felt that it was a little bit more, “these are the questions that I should ask someone who has got ME” it was almost a bit more, it wasn’t a script, but it felt like, it didn’t feel like such a natural conversation” (Sarah CBT 3)</p> <p>“I think it was helpful because she was letting me lead what I was saying was like, the important examples to me.” (Eva)</p> <p>“So I think to me it was better that it was a whole rounded look at the things that are causing me stress or anxiety. I think if it had just been like, “what are your thoughts about your illness”, or I think if it had been forcefully confined to that I would have felt, it would have felt a bit manufactured and not actually addressing what was actually happening in your life.” (Eva)</p> <p>“I just thought, “this is great, I’m addressing issues that are vital and affecting my life massively”, and that hopefully that would just help me. And it wasn’t that it was going to help the ME, it was just going to help me overall.” (Susan)</p> <p>“I had thought like, a constant thing in my head about this trauma, and I feel very strongly that without being able to shift that thing in my head, it was not, you know, it had been a contributory factor, and once I could shift that, it would help me on my progress towards feeling better.” (Judith)</p> <p>“I was hoping that it would help with chronic fatigue, but then it turned out to be a bit more than that. Like it</p>
--	--	---

		<p>helped with family stuff, it helped with friends stuff.” (Layla)</p> <p>“it [CFS] just is in everything, every decision, work, social, like partner, friends, it’s literally in everything” (Rachel)</p> <p>And it’s just so scary, and it’s just such an odd thing to actually have people like [name of therapist] who not only understand it but they’re quite unimpassioned about it, and I mean it in a really good way (Fiona)</p> <p>“she opened up slowly a lot of things, so you started getting that trust.” (Sebastian, CBT 2)</p> <p>“I remember like, the first day we were talking, and she said something, just something really sweet like “you just seem like a really nice person” and der der der, and I started like welling up and I thought “really”.” (Will)</p>
<p>Seeing myself and CFS/ME differently</p>	<p>CFS/ME is real and not my fault</p>	<p>“And the fact that she drew out that way and she showed me different ways and she showed me the way that she thought I got it, which is the psychological way, made me realise that you know, there are different ways you can get it, but the way I’ve got it was part of my past, sort of thing. And that’s sort of made me who I am, so in a way, it’s not my fault, kind of thing? I think a lot of the time I was self-blaming myself, but I don’t think I am anymore.” (Layla)</p> <p>“I suppose it just gave me a bit of resolution really.” (John)</p> <p>“there’s always going to be the person inside that goes, “oh you’re just a bloody hypochondriac, get up and sort yourself out”.” (Fiona)</p> <p>“to kind of think “well okay they are ignorant and they are wrong”” (George)</p> <p>“And kind of validating it, because I think a lot of the times, talking about the chronic fatigue, I’d say, you know, you have a decent day and I look fine, so I call it chronic fatigue in that, you know, I mean I look fine day-to-day and then I get embarrassed kind of telling people or expecting special treatment because of it, or anything</p>

		<p>like that. And you end up, you kind of doubt yourself and you think, “well am I just a hypochondriac? Am I just really lazy and unfit?”, and this and this. And then it just kind of very quickly spirals into “oh well I’m not worth duh duh duh duh, and I can’t do this anyway”.” (Will)</p>
	<p>CFS/ME is manageable</p>	<p>“It made me feel sort of more relaxed about it in a way because I was reassured that this is something that happens to other people.” (George)</p> <p>“Because she didn’t make it seem like such a massive deal, it became more okay” (Layla)</p> <p>“It was more like, “oh you go out and have your fun, because you deserve it, and then whenever a blip comes, deal with it then”, sort of thing.” (Layla)</p> <p>“I think with CBT it made me realise that, you know, yeah, you’ve taken that step back but once you’ve took that step back, you can move two steps forward.” (Layla)</p> <p>“coming here made me realise if other people can do it, why can’t I?” (Layla)</p> <p>“she’s an expert, she’s spending her time and energy on me, she’s telling me this might help”. (Eva)</p>
	<p>Lowering expectations of myself</p>	<p>“I think I was always looking...to fix things as well, that I needed to make things right. And actually it wasn’t always up to me, it’s up to other people as well.” (Susan)</p> <p>“It’s given me a better attitude, by putting less pressure on myself , that I don’t need to make everything perfect” (Susan)</p> <p>“The core beliefs about yourself was actually quite illuminating because it was about beliefs about your worth and what makes you valuable or worthy.” (Eva)</p> <p>“I think it was a way of training myself to be like, less over-vigilant about things” (Eva)</p> <p>It’s not just my husband that’s made sacrifices, I’ve already made loads of sacrifices myself. And that can be enough. I don’t always need to be pushing to do more. (Susan)</p>

		<p>“It’s just being not as hard on myself” (Susan)</p> <p>“basically it was, not everything is a priority. You must knock that out of your head.” (Sebastian, CBT 1)</p> <p>“Don’t be a perfectionist. But as long as you can work, love people the best you can, you’ve got your self-respect, you’ve got your health. You know, you’ve got one life, why are you killing yourself to please others? (Sebastian, CBT 2)</p> <p>“Just accept who I am. And before I didn’t accept who I was, I was always trying to be something better than what I am. And that’s what it was, I was always striving to be better.” (Sebastian)</p> <p>“She would say like, if I was coming here from work, “don’t walk it, get the train, take things easy”. It was that sort of, being easy on your body” (Sebastian, CBT 2)</p> <p>“So it was sort of learning to do less and accepting that you can do less” (Susan)</p> <p>“when I’d say “I am worthless” or whatever it was, she’d just say “well no you’re not, because you’ve just told me that you did this this morning and you did this and you did this”. (Fiona)</p> <p>“[She] advised me to take like two weeks off. Which took me a while to get to that decision, but I did actually do it, and I’m really glad that I did.” (Rachel)</p>
	<p>It’s ok to put myself first</p>	<p>I’ve become a lot more self-centred, if you like. A lot more selfish. (Susan)</p> <p>“The therapy, it was more making me realise that it’s okay to put myself first. Because sometimes I’m like, “oh, is that being selfish or not?” (Layla)</p> <p>“And just turning it into a much more of a positive than me seeing it as “oh my god, my poor kids, I am having to make them do, they are having to do more and that is not fair on them.” (Sarah)</p>

		<p>I certainly think she was talking to me a bit about sort of general sort of empowerment (Jean)</p> <p>And it was that sort of reflection of getting control and being, I hate the word selfish, just getting more time for yourself.” (Sebastian, CBT 1)</p> <p>“it made me think more about family life and the work-life balance” (Sebastian)</p> <p>“if you want something to change in your health or with anything, you have to put yourself first” (Layla)</p> <p>“she talked to me about, you know, setting boundaries, and saying, “look I’m focusing on me, so I’m going to start standing up for myself”.” (Jean)</p>
<p>Finding ways to move forwards</p>	<p>Understanding what was happening</p>	<p>“She was trying to get me to break things down so not just even mentally, right down to what I was doing. So you know, making a timetable.” (Fiona)</p> <p>“Doing those hourly slots on those reports, and thinking, “god, I worked for what? I did six hours for that project?”, or this or that. And it was just seeing it in black and white, really.” (Sebastian, CBT 1)</p> <p>“Also [learning] that your emotions also take up as much energy as physical things, and mentally.” (Susan)</p> <p>“Unpacking what my assumptions were about other people’s intentions and judgements was helpful” (Eva)</p> <p>“[name of therapist] talked about catastrophising, which is what I was doing massively, and I didn’t know I was doing that. So just learning to sort of understand how you’re thinking.” (Eva)</p> <p>“She would also explain about your brain and about survival instincts. You know, fight or flight. And the thought processes. Things that directly affect the ways you react now.” (Sebastian, CBT 2)</p> <p>“Actually just knowing, just being able to visualise what’s happening and think, “okay you’re stuck in loading mode, if you either just get on with what you want to do, you’ll</p>

		<p>get through this, or maybe just go and take a break or have a walk or something". So I found that very helpful." (Will)</p> <p>"I think it kind of helped me to think "oh this isn't just part of depression that I could deal with before", and "why am I not dealing with it now". To kind of define that there are two strands to this." (Will)</p> <p>"seeing like the diagram of how the brain works and being like "that's me! That's what happens to me!"." (Will)</p>
	<p>Separating what we can and cannot control</p>	<p>"And don't worry about what you can't worry about, just let it go and let someone else, let my man that's assisting me, let him do the worrying." (Charlie, CBT 2)</p> <p>"Another thing that she taught me about anxiety: "How can this help?"" (Judith)</p> <p>"And kind of, make it clear in your mind what those are and what you're going to focus on. Or how you can take more control of the things that you want to and how you're going to leave the things that you kind of can't ever change." (Eva)</p> <p>"like, "stop worrying about what's going to happen, whether I will even be able to go to uni or get a job or have kids, just deal with stuff now" (Layla)</p> <p>"You can't change how someone thinks about your illness." (Eva)</p>
	<p>Learning tools and problem solving</p>	<p>"My son was very young at the time, he was four and it was a case of right well you know, you can give him different things actually snuggling down on the sofa with him and watching a movie that he wants to watch." (Sarah, CBT 1)</p> <p>"I wanted someone who, when I said, "this was my issue, this frustration over my brain wanting to be active, wanting my body to be active all the time.".. Use your knowledge, use your knowledge as a psychologist to tell me what I need to do with my brain to sort that out. That's what I didn't get (Sarah, CBT 3)</p>

		<p>“It made me look at everything that I had going on around me, and so I gave jobs out to my rep, he dealt with it. So I did have someone to lean on, I wasn’t doing it on my own.” (Charlie)</p> <p>“I’m quite happy to put the plan b into place. Because I’ve got my parachute on, and I just jump when I know, and jump. So, all of a sudden, you don’t worry.” (Charlie, CBT 2)</p> <p>“The sessions were much more about practical things, so one of the sessions I remember coming out thinking “ok I need to employ a cleaner” (Sarah, CBT 3)</p> <p>“I felt like I was going home with something new” (George)</p> <p>“Stepping back from singing. So the first time was kind of as a suggestion from [name of therapist], because then it’s that kind of like, that she’s able to like look at your life and what you’re doing and feeling and how you’re coping” (Rachel)</p> <p>she broke it down into three different sections and it was like a red green and blue, and it was, red is a warning sign, you know, working late, being tired, eating not healthy. So what do you do when you get into that red? You need to get into, so the blue is the normal, your cool blue shall we say, is where you need to be to get back into your green. (Sebastian)</p> <p>“it’s got to be something that’s going to help you in the long term, so it’s got to be like a healthy comforter” (Will)</p> <p>“she talked to me about, you know, setting boundaries, and saying, “look I’m focusing on me, so I’m going to start standing up for myself”. (Jean)</p>
	<p>Finding opportunities for enjoyment</p>	<p>“We kind of discussed well okay you can’t do that but you could have a nice afternoon out somewhere , so how would you prepare and you know manage that and so on and do it in such a way that you enjoyed it and wouldn’t risk further relapses” (George)</p>

		<p>“I would be able to look at what she’d written and go, written down, and go “oh my god, actually my life could be really good”. Because I’d had to give up work, but I’d managed to, you know, I’ve got private clients and things like that. So I’ve been really lucky in that way, that she managed to make me see that. Whereas before I was in such a fog I couldn’t even see that there was anything positive” (Fiona)</p>
<p>Lightening the load</p>	<p>Getting things off my chest</p>	<p>“Just having an opportunity to go and I suppose let off steam.” (George)</p> <p>“I liked the opportunity to talk about myself for all of that time” (George)</p> <p>“I find it really boring talking about it to my spouse and my family and stuff, and you don’t want it to be a constant conversation because that’s not helpful either. But then sometimes you do just need to talk about it with someone that gets it.” (Rachel)</p> <p>“there’s kind of like a duty of care to not be always talking about being tired and therefore kind of moving into a negative space. When you’re with the people that you love and want to spend quality time with, being tired isn’t fun.” (Rachel)</p> <p>“you kind of stop talking about it. But then that’s bad as well, because you don’t have an outlet. So part of me wishes I could do CBT or something equivalent like once every few months just to check in with someone and have a space.” (Rachel)</p> <p>“I think it’s just having quiet time to think about stuff.” (Will)</p> <p>“I found it quite cathartic, all the sessions, you know particularly when we kind of went quite deep and talked about my childhood and things like that.” (Will)</p> <p>“But actually having someone say “actually yeah that sounds really hard, going through all of that stuff as a teenager and not having anyone to talk to”” (Will)</p>

		<p>“Clear off my chest and then cut it off, move on, start a new chapter sort of thing.” (Layla)</p> <p>“I think she made me realise that even though I always say to my mum, “oh I don’t care about it”, blah blah blah, I think she made me realise it was suppressed in me because I always felt like, “oh, why does everyone else get a dad and I don’t”, sort of thing.” (Layla)</p> <p>I feel like there were still bits that I needed to get out in the open. (Layla)</p> <p>“It did give me the chance to, this stuff was going on in my head, it did give me that chance to get it out” (Sarah)</p> <p>When I came out, I felt like a weight had been lifted off my shoulders (Judith)</p> <p>“there was a weight off your shoulders just because of the acceptance of “there is something”, and that was, I found that probably the biggest helpful part” (Charlie)</p> <p>“I felt better because I actually heard it come out of my mouth and not just in my mind.” (Sebastian)</p> <p>“it was just releasing and it was like another layer that’s come off.” (Sebastian)</p>
	Resolving broader issues	<p>“I don’t want to talk to them [family] about it because it makes it worse. So, it’s a way of containing it. Having been able to talk to someone else about it.” (Judith)</p> <p>“It was just stepping back from it [family relationships] and trying not to get so involved and trying to change things” (Susan)</p> <p>“Having a wider perspective on it [personal trauma].and being able to keep it to.. with myself.” (Judith)</p> <p>“It helps perhaps towards forgiveness. Forgiveness of the person, people.” (Judith)</p> <p>“it was definitely through the CBT and so on that I yeah, just got rid of a bit more of the guilt” (Susan)</p>

		<p>“I was sort of relapsing and getting emotional about things like to do with my dad. So actually coming to terms with some of those emotions. Stepping back from them and letting go was then helping.” (Susan)</p> <p>“I used to take that really to heart but now, if that happens, that happens. I’ll just go to another pub. Or I don’t want to shake your hand because you’re a racist.” (Sebastian, CBT 2)</p> <p>“If I’m not good with my mental state, I wouldn’t be good physically to do anything anyway. So by trying to iron those things out and putting those things to bed, it then allowed me to move to the next stage, or to the next page of rehabilitation.” (Sebastian)</p> <p>“It was having to be twice as good as the white person to get a job. And it was a combination of opening all these things up which was screwed down.” (Sebastian)</p> <p>“we touched on a lot of personal stuff, from, you know, my mum’s death to my son’s death, because I had a son that passed away. To growing up as a young black person in west London” (Sebastian)</p>
<p>A life I can cope with</p>	<p>Having ways to take control</p>	<p>“it was giving me some autonomy and choice over the actions I would take and some feeling that I had some control over what happened” (Eva)</p> <p>So to say, “here’s another way of thinking about X scenario”, gives you a bit of freedom. (Eva)</p> <p>“Things don’t need to go to extremes anymore because you’ve got those tools whether it’s with the pacing, but also controlling the emotions.” (Susan)</p> <p>“I think the small successes of using those techniques to get out of the funk once, twice, and it just starts to build the confidence” (Will)</p> <p>“it kind of made me feel that I was starting to get a bit of a sort of handle on it” (George)</p>

		<p>“it does control your life but it doesn’t have to. So it’s whether you let it control your life” (Layla)</p> <p>“it wouldn’t be like I was mentally conquered with all the CFS stuff” (Layla)</p> <p>“So then feeling like I have more emotional energy to try to pursue things that would make me feel better.” (Eva)</p> <p>it made me feel much more able to cope with what was going on. (Fiona)</p> <p>I feel I’m more in control of it. And in control of it as in, even if I’m feeling tired or chipped, I can now say, “I’m going back to my room” (Sebastian)</p> <p>“it was like empowering to say no. It was a big, you know, not enjoy saying it, but it was taking control of your life now.” (Sebastian, CBT 1)</p> <p>“I’m in a very painfully slow process of hopefully making things better, you know, and what can’t get better I can kind of manage” (Will)</p> <p>“I certainly think some of the after-effects of it, I definitely feel much more in control now, and that’s brilliant, and that’s amazing. I think in the period of the CBT, I was still very much trial and error and it still felt like one step forward one step back, and you know, so obviously by the time I got to the end it was like, “okay, I am more in control”, but I think it’s quite a volatile period in those ten weeks” (Will)</p> <p>“I felt less emotionally kind of up and down, I felt more able to take on things” (Rachel)</p> <p>I was mentally feeling more prepared and more resilient (Eva)</p> <p>“makes you feel like you’re not sort of going to be here on your own” (Fiona)</p> <p>But with her compassion and understanding and the structure that she started me off with, I was able to</p>
--	--	---

		follow through, do something else, which has helped me. (Judith)
	Getting my confidence back	<p>“So probably I come across as better at my job because I’ve stopped caring about, as much what people think.” (Eva)</p> <p>“I became very very sociable. I started to go to football matches more” (Sebastian)</p> <p>“You don’t have to beat yourself up for it when you have a blip, you know why it’s happened.” (Layla)</p> <p>“I think her sort of encouraging me to do that sort of made me feel like I can actually do it” (Layla)</p> <p>“it’s kind of having more confidence in myself” (Will)</p> <p>“That [CBT] was a big factor in making me more, less ashamed of it and more kind of like, “well this is just something that is happening to me”(Will)</p> <p>“More easier on myself about it. More like I believed myself” (Will)</p> <p>“it helped me feel a bit more relaxed about other people’s judgements or lack of judgements or whatever” (Eva)</p> <p>“I just feel more confident in who I am and what I bring” (Sebastian)</p> <p>“and not beat myself up about not doing the things I can’t do.” (Will)</p>
	Living beside CFS/ME	<p>“It’s there and you can’t forget about it, but I live with it rather than it, you know, it lives through me.” (Susan)</p> <p>I just feel a more whole person, that I can look at things in a different way (Susan)</p> <p>“This year I haven’t actually really read up much on ME at all. I can just give things a break now.” (Susan)</p>

		<p>“So me and her were always discussing, for me it’s a battle of what I can do and what I want to do. So she made me realise that maybe it doesn’t have to be that, maybe I can do a balance, sort of thing.” (Layla)</p> <p>“it was more like “I am more than just CFS”” (Layla)</p> <p>“it was more like yeah, it’s another thing I’ve got, but then that’s not going to stop me from getting where I want to get.” (Layla)</p> <p>“I think it’s the whole thing of putting it in my back pocket. Because then it doesn’t have to become your whole future or your whole now, it’s sort of like, stop trying to predict and get on with it and see what happens for yourself.” (Layla)</p> <p>“And then it was sort of like, CFS isn’t my whole life, kind of thing, you know, I can actually enjoy life a little” (Layla)</p> <p>“I realised okay, I’m not at uni yet, but I will get there, and then I’ll get my degree and a job, blah blah blah. So although it might take longer, I’ll still get there” (Layla)</p> <p>“thinking of it as a separate thing and thinking, you know, this isn’t like you’re tired and therefore you’re depressed, and therefore give up on everything. Well it’s just kind of like, “you’re tired and that’s unfortunate”.” (Will)</p> <p>“I think having that motivation, and those skills to kind of overcome the dread and the negative feelings that come with it, have really kind of helped me kind of think “it’s just a physical thing that I can manage”” (Will)</p> <p>“I feel as though there’s a lot, I still have a lot to offer.” (Sebastian)</p> <p>“okay, I’m a chronic fatigue sufferer, I just have to make, I just carry on with life but I just have to pick up, to make sure that I recognise any triggers” (Sebastian)</p> <p>“I wouldn’t say at the end of eight weeks, “right, I’m dealing with all of this now”. No. It helped me start that process.” (Judith)</p>
--	--	--

<p>Making peace with CFS/ME</p>		<p>“More positive towards my life and my situation with a chronic illness.” (Eva)</p> <p>“I was happier with my life. I wasn’t as depressed.” (Sebastian, CBT 1)</p> <p>“it really helped me dust myself off, pick myself, don’t feel sorry for yourself” (Sebastian, CBT 1)</p> <p>“I was becoming very depressed to the point where I think you may see from the files when you’re allowed to see them, my score was different, was very high, compared to when I finished CBT when it was very low” (Sebastian, CBT 1)</p> <p>“I was a bit gutted [realising CFS/ME was chronic] But then I started, once it sunk in and I accepted it, I kind of, “okay, that’s it”. It was just a new dawn.” (Sebastian)</p> <p>“I was gutted, to be honest. Because I thought I’d get the old [Emmanuel] back. Happy go lucky, always a bit of banter, you know. Practical joker sort of thing. So that took a while to accept.” (Sebastian)</p> <p>“I’ve had cycles of acceptance where you get to a point and you think, “okay, for the last two years I’ve been deteriorating”, you know, and you get upset about it and get sad about it. I can see myself occasionally going through a cycle and realising, “okay, this is now...””(Susan)</p> <p>“there’s so much I want to do, and even with massively lowered expectations compared to what other people can do, I still feel like I’m not even scratching the surface. And I do feel incredibly frustrated” (Will)</p> <p>“But I can’t fulfil that part of me anymore. Which is frustrating.” (Susan)</p>
<p>Accepting the reality of CFS/ME</p>		<p>“even at the beginning of the CBT, I still wanted to think, “oh it’s got to be something that I can just take something for”.” (Fiona)</p>

		<p>“they didn’t say “well you are not going to go back to normal so forget it” you know it was just, at least for the time being you know, you’re stuck with it” (George)</p> <p>“so kind of an acceptance of... well, I don’t know really what the prognosis is, but acceptance of what the prognosis might be.” (Eva)</p> <p>“I think just having regular weekly sessions to discuss things, I think that helped to kind of, to underline the reality of it.” (Will)</p> <p>“I think it helped acknowledging that I have genuine problems that I can’t ignore away. You know, that there are, that I can’t just think “oh come on, you’re fine, don’t be silly”.” (Will)</p> <p>“It is just more acceptance of, this is how my life is.” (Susan)</p> <p>“the penny dropped that I’ve just got to accept it, that’s just part of me now.” (Sebastian)</p> <p>“I think part of it was like, working through that stage where I was realising that this might never go away. So like kind of an acceptance of that, although still not sure if I could say that’s complete” (Eva)</p> <p>“yeah just kind of accepting that at least for the time being.” (Will)</p> <p>“I still have no energy. My energy is, even when I have rested is low. But it’s about, it’s it’s just about acceptance really.” (John)</p> <p>“I think also the CBT just helped me realise that you know, you can’t fight the ME. I’d also sort of reached a point of exhaustion of trying different things, that I couldn’t fight it, and actually embracing this way of life would be a much better way forward.” (Susan)</p> <p>“I think because I’d known about it, or whatever, had been diagnosed for a few years, I’d kind of, an acceptance level was fairly secure. I think it was more just general frustration and annoyance at not being able to do things that I wanted to do. So acceptance-wise, I</p>
--	--	---

		<p>was pretty, yeah, not okay with it, but yeah, accepted.” (Rachel)</p> <p>“I can’t avoid my feelings and my energy levels just by pumping full of adrenaline” (Will)</p> <p>“you can’t do it, it’s not worth it. You’re doing yourself harm.” (Susan)</p> <p>“It’s a huge thing, the acceptance actually. I just learnt so much through the pacing about activities, and I only try and go out once a week with a friend (Susan)</p> <p>“I think it was partly seeing people who dealt with this all day made it feel relatively kind of normal” (George)</p> <p>“what I think came out of the sessions was that you may not be fully cured. There’s people that suffer chronic fatigue for twenty years” (Sebastian, CBT 2)</p> <p>“they said sometimes there’s no magic wand, there’s no magic cure for it. It’s just how you manage your life and you just need to be that little bit more thoughtful of when you’re doing things” (Sebastian, CBT 2)</p> <p>“it was the ME service overall, the CBT, letting go of standards, that actually then facilitated more acceptance. It was definitely that things like doing the pacing, chatting about my standards, letting go of guilt” (Susan)</p> <p>“it meant that I could try and work on just like, listening to myself for a little bit. Where I think I’d just been ignoring things for so long” (Fiona)</p> <p>“Just try and get into myself a bit mentally and what I really am and what I wanted, and what’s going to make me feel better. Rather than sort of burying my head in the sand all the time.” (Fiona)</p> <p>“You need to accept that that’s what you’ve got, I think, and then, because otherwise you’re just shoving everything to the back of your head again.” (Fiona)</p> <p>“It’s not just an acceptance and a giving up, it’s just an acceptance and a, so that you don’t cause yourself more</p>
--	--	---

		<p>stress by constantly searching for answers or cures or things like that” (Eva)</p> <p>“I thought I was cured. The symptoms were still there, but I just thought it was that I was just a bit tired.” (Sebastian, CBT 1)</p> <p>“You reach a happy medium where, “I kind of need to accept some of this but I need to not give up completely”. (Eva)</p>
Having tools	Taking a different perspective	<p>“So having these in like a cheat sheet, to be like, that might be what you’re doing, and that might not actually be true” (Eva)</p> <p>“in terms of being able to understand things more and have more tools, like I keep saying, but to be able to recognise things, like translate things, and whatever that results in stuff that results in saying no or saying yes or pushing back or taking a step back from something” (Rachel)</p> <p>“understanding the type of emotional... type thing, whatever it’s called, was really helpful for me. Because... yeah, you can kind of like stop things in their tracks before it gets, “oh no, the world’s going to end and everything’s awful”.” (Rachel)</p> <p>“now I’m more able to kind of go back to, well why am I catastrophising about it? Is it because it’s a realistic thing or is it just a fear?” (Rachel)</p> <p>“I’d managed to like, calm down the sort of emotional, extreme emotional response to dealing with symptoms” (Eva)</p> <p>“I’ve had this thought that “I’m incompetent because this person said this to me at work, but let’s look at the evidence”” (Eva)</p> <p>“having tools to think about things in different way, to like recognise thought patterns that are maybe not helpful.” (Eva)</p>

		<p>“I would have some ideas about how to look at it in a less upsetting way” (George)</p> <p>“the CBT gave me structure and introducing thought processes to dampen down the anxiety that I get” (Judith)</p> <p>“learning to step back a little bit and look at actually what’s happening and rather than trying to look at everything that’s not going to happen” (Fiona)</p> <p>“In more of an intelligent way, rather than emotional” (Fiona)</p> <p>“So giving me I suppose the tools for times when I would feel really dreadful about certain things, anticipating that and then having tools to sort of see it differently and cope.” (Fiona)</p> <p>“the CBT helped me manage my emotions better and to look at things in my life and how I am dealing with things and giving different alternative ways.” (Susan)</p> <p>“having some tools in my mental repertoire to be like, you feel like absolute crap but you remember the last time you felt like crap, you would eventually like, you did feel better again so this isn’t going to be forever” (Eva)</p> <p>“It helped me to yeah, not completely stop but to definitely like, not let that run out of control.” (Eva)</p> <p>“it would just be called as a blip, and then I can just deal with the blip there and move on. It’s not that usually when I would get in a blip, then I would be like, “oh am I ever going to get better”” (Layla)</p> <p>“I would now say to myself “how can this help?”, “what’s the worst that can happen?”, and then really pull myself up” (Judith)</p> <p>“things had shifted in terms of how I was thinking and kind of like emotional energy into it [work], I think that had shifted in a way that was making it easier by the end of it.” (Eva)</p> <p>“Trying to reinforce beliefs about being valued for other things, or being, that my work is good enough” (Eva)</p>
--	--	--

		<p>“But I think the big thing is if I’ve got the skills and the motivation and to kind of overcome the fatigue, I can kind of work through it, you know, and I can kind of forget about it for a while? And I can take the steps to counteract it. And I can recognise, “oh god I feel awful, I feel so tired”, without that kind of spiralling into “and I’m miserable and everyone hates me and I’m going to kill myself”” (Will)</p> <p>“So what she’s helped me with on that side of the ME is dealing with the anxiety and the panic.” (Judith)</p> <p>“It gave me tools to deal with the trauma that I had had, and all the things that had come from that.” (Judith)</p>
	Control over my responses	<p>“I remember my boss kind of asking me that [additional work demands] and my initial reaction was to just get really upset and stressed. But because of the sessions that I’d had, I was like, “wait a minute, I’ll just leave it, I’m gonna get off the tube, I’m gonna sit down, process it” and then I was able to say to him, “look, it’s too much, I can’t take on any more.” (Rachel)</p> <p>“just being able to take everything bit by bit and break things down, I think.” (Fiona)</p> <p>“I know it sounds really like nothing, but when I’m feeling overwhelmed or when I do something so I’m like too scared to get up and go in the shower, if I just kind of make my decision and then block out other thoughts just by counting, “one, two, three, four, one, two, three, four”, that’s really helped me be able to get up and take the next steps, rather than thinking “I can’t do this now, I’m too tired, I’m too scared, I’m too anxious”.” (Will)</p> <p>“I learnt to keep it, put it out of the way.” (Charlie)</p> <p>“I use it mostly to sleep, but even just taking a step back and thinking about things for a few more seconds and stuff.” (Rachel)</p>
	More helpful communication	<p>“then I could come back into the meetings, the meetings at work, with a clear head. Knowing that you can’t touch me” (Charlie)</p>

		<p>“It was just building up inside of me, or it was just coming out as “bleh”, because I didn’t know how to communicate it.” (Rachel)</p> <p>“it’s really frustrating when you’re trying to say something and people don’t understand. And not from like a “oh they don’t understand me!”, but just in a like, it’s a really difficult thing to explain!” (Rachel)</p> <p>“I was more able to talk about things and explain things. Yeah, just having more of a less emotional lens on stuff.” (Rachel)</p> <p>“When you see people at work, because they’re like, “oh here it comes, still swinging it are you?”, but now rather than sitting down and getting, not cross, but you know, trying to explain.” (Charlie)</p> <p>“where someone was being difficult and sort of saying that they wanted me to do things I didn’t feel like I could do having sort of discussed how I could approach it with them kind of thing. You know left to my own devices I might just you know slam the phone down or something if I was getting stressed out or something, not that I make a habit of that, but I mean how I could sort of approach it and say “well I need you to be flexible or something”” (George)</p> <p>“I knew that if I said to him, “I can’t do this because reasonability-wise, I can’t take on my other thing”, so that’s quite a rational, literal thing to say.” (Rachel)</p> <p>“I could come to the CBT sessions and spend an entire hour being sort of listened to and taken seriously and so on, that would then mean that I wouldn’t feel quite the same need to burden everybody I know with it you know.” (George)</p> <p>“for me being able to break it down to my husband, who is a man. Men are a lot more practical, generically, so for me to just go “blah blah blah”, that’s not very helpful because he’ll just see pain and he won’t know how to fix it. So being able to say, “this is this, because of this, so I</p>
--	--	--

		<p>think I should do this, what do you think?”, that’s a bit more dissectible.” (Rachel)</p> <p>“it was probably getting to a point where it was probably quite frustrating for both of us because I’m saying that I’m really tired and stressed and he doesn’t know what to do. So for me, being able to go, “oh, I’ve learnt some things, and this is what I think”, or “this is what I’ve learnt”” (Rachel)</p> <p>“So I’ve just noticed, maybe from the way that I’m communicating about stuff, it’s more rational, so I’m more able, like my friends know this, I’ve actually recently stopped doing singing again for a bit because I’ve just felt like, I’ve just changed roles at work and I’ve just been really tired. And that’s fine, she just gets it. I don’t have to really overly explain it to her, I don’t have to be really emotional, or I don’t have to run away and not talk about it and pretend it’s not there and make up excuses and not go. I can just, it’s a bit more like, okay, I get it.” (Rachel)</p> <p>“I think just more understanding from yourself and people around you. You’re more able to more naturally get things quicker. I think maybe before, it was, I wasn’t maybe communicating things properly, so therefore it’s harder to know what to do in that scenario.” (Rachel)</p>
<p>Putting less pressure on myself</p>	<p>Cutting back on demands</p>	<p>“I’ve got better at A, not doing a million new things in the first place, and B, saying “look, I was on a bit of a high then, but I have to be honest with myself what I can manage and what I can’t”(Will)</p> <p>“I’ll actually take time out to make sure that I’m resting rather than resting once I’ve had a relapse” (Layla)</p> <p>“something helped me just being like, I can do something maybe every other day at the most, in the evenings, if I’m feeling well. I can’t do anything except on the weekends if I’m not.” (Will)</p> <p>“So, it was training my, no more back to backs, no more quick responses, schedule time for yourself” (Sebastian)</p>

		<p>“Maybe when I had permission from her to do it the first time, I was therefore more able to do it the second time” (Rachel)</p> <p>“I was still having fun and living life, but I was being also cautious, do you know what I mean? So it’s the balance of doing what you can do and doing what you want to do.” (Layla)</p> <p>“Achievements are now very small. Whether it’s that actually today I did clean the bathroom sink, and actually, if that’s all I do today that’s absolutely fine. So it’s changing the amount and my standards and how I perceive achievements.” (Susan)</p> <p>“Giving myself space and time and being compassionate towards myself.” (Susan)</p> <p>“I still am quite driven, but I was very very driven until I went to the ME service in London. And now I’m just a lot more chilled. I wouldn’t say I’ve given up, because it’s not giving up, but it’s just, “yeah, this is fine, this is where I am”.” (Susan)</p> <p>“You do have to let some of your life go, a bit. And yeah, it is sad!” (Susan)</p> <p>“when I send an email it’s like three paragraphs of everything that you could think about and everything’s like right in a document. And now to three bullet points.” (Sebastian)</p> <p>“Now I’ll give myself twice as long. Do you know? It’s that sort of, not putting pressure on yourself “(Sebastian)</p> <p>“Totally different strategies. Not always putting your hand up and asking questions, not always volunteering” (Sebastian)</p> <p>“I lock my laptop in the office, I don’t bring it home.” (Sebastian)</p> <p>“to the point where I was putting post-it notes up as reminders, as in no. I had a digital clock that would alarm me to take breaks, not work sit at my desk for six hours” (Sebastian)</p>
--	--	--

		<p>“when I first came back [to work] it’s like, “I’m going to come in, I’m going to do three hours, then I’m going to have two hour lunch break and I’m going to have some food, then I’m going to go to the sick room and lay down and listen to a mindfulness breathing thing or whatever, and then I’m going to do three hours, then I’m going to go home”.” (Will)</p> <p>“I can just take myself away and we’ve got a little room in the office, I just lock myself in and lie down and quite often fall asleep or just listen to a radio programme or something. And actually just being like, I don’t care if that looks a bit weird” (Will)</p> <p>“I know I’m an asset to them, and if I need to take these, if this is what I need to do to work then this is what I’m going to do, and people are going to lump it”. (Will)</p> <p>“I subsequently learnt that management is about pacing and not trying to push through.” (Judith)</p>
	<p>Re-prioritising my needs</p>	<p>“Yeah so I think it made me re-focus I suppose on my own priorities” (Sarah)</p> <p>“I haven’t let go of everything, but I rely now on other people to do more of it.” (Susan)</p> <p>“I think it was self-preservation. I had to speak to my wife about it. I said, “you know what, I can’t always be driving around or topping up your oyster card”” (Sebastian)</p> <p>“And letting go of controlling things, as well. That I don’t need to be in control of everything. And letting other people step in and have a go.” (Susan)</p> <p>“in the heat when you have the blip, you make sure that you’re putting yourself first. Because you need to get over it and stuff like that, but you need to make sure that you’re resting and taking the time out for yourself.” (Layla)</p> <p>“I needed to say that I couldn’t do something because it was too much, I was able to have that conversation.</p>

		<p>Whereas before, I was just kind of saying “yes yes yes yes yes”, and getting more and more stressed.” (Rachel)</p> <p>“I actually started booking time in my diary for my own, for self-time.” (Sebastian)</p> <p>“I think it’s even focusing on the friends that will give you the right support and letting other things go.” (Susan)</p> <p>“But now I’m quite comfortable to say “no, I really need to go”, because otherwise I know roughly that if I don’t go now, I could be in trouble here. So I need to go get some rest or get something to eat or whatever, get back into my space.” (Sebastian)</p> <p>“In the old days, a hundred percent I would say yes. And so it was now a, “can I come back to you on that”” (Sebastian)</p> <p>“Go to bed at a good time. Don’t watch TV ‘till late. Have a bath. Relax. Dark room, no TV on.” (Sebastian)</p> <p>“I need to be able to have time at home and be domestic and uh, yeah, and catch up on things and feel more in control of my life.” (Will)</p> <p>“[name of therapist] just saying you know “you need to start needing to be a bit kinder to yourself” (John)</p>
	<p>Being more open about my needs</p>	<p>“I think I was more open about it afterwards, definitely.” (Fiona)</p> <p>“I was a bit more open with my husband after the sessions” (Sarah)</p> <p>“[The therapist] explained what I do as catastrophising, and why I shouldn’t, and how I could overcome that and stuff. So, I would then tell my friends about it. Because I thought, you know, well actually it is interesting, and I suppose that can provoke being able to talk about it a bit. Because it is actually sort of a thing, isn’t it, again?” (Fiona)</p>

		<p>“I was never one for talking, but now I can talk until the cows come home, really.” (Sebastian)</p> <p>“my friend Helen, because she is thinking of me so she is passing on useful information which is helpful as well, and she sort of always asks you know “how are you feeling today” so it has helped.” (John)</p> <p>“definitely during this period I made an effort to try to be more open with my closer friends about it.” (Will)</p> <p>“Whereas before, I would still be quite open and stuff, but it would more just be with my teachers, sort of thing. Because I had a feeling like, obviously if you don’t feel well, to the point where you’re staying at home or something, and you go to someone “oh, I’m tired”, or something, they’ll just be like, “oh you know, you’re tired, man up, let’s go out”” (Layla)</p> <p>“being able to be a bit more detached because someone else has said it rather than you. You know, if you’re talking to other people.” (Fiona)</p> <p>“You have to open it up and let people know what’s going on. And my wife’s appreciated that” (Sebastian)</p>
Doing more of what I value	More courage to do things	<p>“I’m sort of more living life. Whereas before it was more like, just going through life, if that makes sense. Whereas now I’m more living life” (Layla)</p> <p>“So instead of being doomsday and thinking I’m just going to be really tired, maybe I should just go, but have the option to leave if I need to.” (Rachel)</p>
	More capacity	<p>“I’d be probably more interested to engage with other people’s problems I guess you know rather than thinking mine overshadowing everything” (George)</p> <p>“it’s just switching from being a patient to being a normal person who has ideas and thoughts for themselves, rather than someone who’s doing things because other people have suggested them” (Jean)</p> <p>“You know, “oh I’m ill and I’m doing these things”, to suddenly, “oh what’s on the listings this week?”. I think</p>

		<p>there was a shift in going back to my old mindset of you know, I'm an active human being rather than I'm a patient that is going through motions." (Jean)</p> <p>"I think for me it was starting to get my social life back. Going on holiday, you know, went to Turkey, we'd have a great family holiday, going to Florida. You know, there was quite a just, yeah, this is what life is all about, you know? Making sure I was doing nine to five and not seven thirty to nine thirty" (Sebastian)</p> <p>"So yes if I could forget about it and you know have a break and you know just sort of have a nice day out or something I would be good." (George)</p> <p>"I started just doing different things that I never used to do before. It was like, as I said, I kind of used to read a book" (Sebastian)</p>
--	--	--

Appendix V: Example of coded transcript

This has been removed from the electronic copy