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## Patient perspectives on mental health therapy for myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS)

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*Smith College*

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Brooke Denmark  
Patient Perspectives on Mental  
Health Therapy for Myalgic  
Encephalomyelitis (ME) and  
Chronic Fatigue Syndrome (CFS)

### **ABSTRACT**

This study explored perspectives on mental health therapy of individuals with Myalgic Encephalomyelitis (ME) and/or Chronic Fatigue Syndrome (CFS). ME/CFS can lead to major reduction in quality of life; however, due to limited knowledge about etiologies or effective medical treatments, symptoms may be deemed psychosomatic and patients are referred to mental health treatment. This mixed methods study gathered responses from 169 individuals who identified as having ME, CFS, and/or ME/CFS from ten reported countries. Some of the common themes for what participants found most helpful from therapy were validation, help adjusting to the changes in their lives, and processing grief and loss related to the disease. Many respondents found it unhelpful to be encouraged to increase activity or to change their thinking so as to believe that they are healthy. The data showed the need for client-centered therapeutic approaches and accommodations to make therapy more accessible to this population.

**PATIENT PERSPECTIVES ON MENTAL HEALTH THERAPY FOR MYALGIC  
ENCEPHALOMYELITIS (ME) AND CHRONIC FATIGUE SYNDROME (CFS)**

A project based upon an independent investigation  
submitted in partial fulfillment of the requirements  
for the degree of Master of Social Work.

Brooke Denmark  
Smith College School for Social Work

2017

## ACKNOWLEDGEMENTS

*“Every day is a marathon to just do the bare necessities to care for myself.”*

*“I have no life and feel as though I'm a walking corpse.”*

*“It's hell living with M.E.”*

- Study participants

I would like to first and foremost acknowledge the time and effort that the participants dedicated to responding to the survey. I included the quotes above to capture some of the challenges that living with ME, CFS, and/or ME/CFS can feel like on a daily basis. The energy participants put in to this study is greatly appreciated, especially in light of the struggles of living with the symptoms of this condition. I would also like to thank Dr. Gael McCarthy and Marjorie Postal for their guidance and support throughout this project. In addition, I would like to acknowledge the Bateman Horne Center for their assistance in recruiting participants. Last but not least, I would like to acknowledge Karen Denmark, my mother and my inspiration for this project.

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## CHAPTER I

### Introduction

*Talking with my therapist had helped keep me from losing my mind, but it hadn't kept me from losing my health. Furthermore, the researchers weren't recommending ordinary psychotherapy — they were recommending a form of cognitive behavior therapy that challenges patients' beliefs that they have a physiological illness limiting their ability to exercise...In other words, while the illness might have been triggered by a virus or other physiological stressor, the problem was pretty much all in our heads. -Julie Rehmeyer (2016)*

Mental health practitioners aim to provide emotional support and healing, but sometimes can intentionally or inadvertently cause greater harm through treatment. As the quote above illustrates, psychotherapy for people living with Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS) can be a double-edged sword. On the one hand some feel that mental health treatment has invalidated their physical illness or encouraged over-exertion, while others have found therapy to be a valuable source of support during a very difficult time. Some people living with ME, CFS or ME/CFS have symptoms so severe that they remain bedridden for years and their worlds shrink to the walls of their bedrooms (Lian & Lorem, 2016). Since emotional and cognitive exertion can be as exhausting as physical activity, many limit their social interactions (Larun & Malterud, 2007; Smith et al., 2016). Furthermore, the disease makes it difficult for many to work, which creates personal financial difficulties (Anderson, Jason, Hlavaty, Porter, & Cudia, 2012). The emotional costs of being chronically ill, potentially financially unstable and socially isolated can be devastating. In addition to the impacts of the disease, people with ME, CFS or ME/CFS report feeling ignored and blamed for their condition.

Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) potentially affects up to 2.5 million people in the United States alone (IOM, 2015), yet the medical community remains deeply divided over the case definitions, causes and treatment options. The name itself is a source of much debate. ME appeared in medical literature in 1956 and is considered a neuroimmunological condition (Twisk, 2016). In 1988, researchers studying an outbreak of an illness with an unknown cause in Nevada coined the name Chronic Fatigue Syndrome because among other symptoms, the disease is characterized by “chronic or recurrent debilitating fatigue” (Holmes et al., 1988). Some argue that ME and CFS are two distinct conditions with important differences in diagnostic criteria, while others believe that they should be considered together. With at least 20 case definitions for ME/CFS, there have been some efforts to reach consensus about diagnostic criteria (Brurberg, Fønhus, Larun, Flottorp, & Malterud, 2014). The Institute of Medicine (IOM) published a report in 2015 that argues the two conditions have similarities and recommends a new name for ME/CFS: Systemic Exertion Intolerance Disorder or SEID (IOM, 2015). So far this name has not been popularized. Other names include Chronic Fatigue Immune Dysfunction (CFIDS), Post Viral Fatigue Syndrome (PVFS), and Florence Nightingale Disease. For the purposes of this study, I chose to use invite individuals who identified as having ME, CFS or ME/CFS to participate; however, in some areas of this paper I may use ME/CFS for brevity or when referring to other studies I may use the authors’ terminology.

One of the many reasons why there is so much debate about the name of the condition and linking ME and CFS is that studies have found that the name Chronic Fatigue Syndrome “can trivialize the seriousness of the condition and promote misunderstanding of the illness” (IOM, 2015). Since there is still much that is unknown about the disease and its causes, often medical professionals believe that the symptoms are psychological or psychosomatic. These



perceptions have greatly affected the treatment recommendations and research on the disease. There has been extensive research, particularly in the United Kingdom, about the benefits of Cognitive Behavioral Therapy (CBT) for ME/CFS patients that has had a major impact on international health policy (White et al., 2011); however, other researchers and the patient advocacy community have critiqued the validity of some of these studies and feel that they are detrimental to the condition's being taken seriously as an organic disease (Tuller, 2015; Geraghty, 2016). The basis of CBT for ME/CFS is that patients are limiting their physical activity based on distorted thoughts that they are physically ill (White et al., 2011). A meta-analysis of studies on the diagnosis and treatment of ME/CFS found "low strength evidence that CBT improved function" (Smith et al., 2016).

Throughout history there have been diseases deemed psychosomatic before their physiological causes were discovered. For example, physicians often diagnosed multiple sclerosis as hysteria, particularly in female patients, before neurologists gained a greater understanding of the disease (Talley, 2005). Similarly, there are much higher rates of women diagnosed with ME/CFS (IOM, 2015; Jason, Plioplys, Torres-Harding & Corradi, 2003) and women with ME/CFS are more likely than men to be referred to psychiatrists (Anderson, Jason, Hlavaty, Porter, & Cudia, 2010). Scientists are seeking to better understand the causes of ME/CFS including searching for potential viruses, toxins, or traumas that may trigger the disease, but so far there is no definitive cause (IOM, 2015).

While ME, CFS, and ME/CFS is often perceived by providers as psychologically based, in my literature review I found there has been relatively less research on how people with ME/CFS perceive their mental health providers than there has been on their interactions with physicians. Additionally, much of the research on psychotherapy for people living with ME, CFS

or ME/CFS has focused on reducing physical symptoms, but there have been fewer studies on psychotherapy with the purpose of providing emotional support for living with a chronic illness or increasing patient satisfaction. Norwegian researchers Lian & Lorem (2016) wrote in a study of ME/CFS:

If we overlook the limits of medical knowledge and technology and confuse “not medically verified” with “nonexistent,” stigma is enforced. If we accept the limits of medical knowledge and technology and let the voice of the patients be heard, understood, and acknowledged, stigma is removed. (p.11)

The purpose of my study is to capture some patients’ voices in regards to their experiences, opinions, and recommendations for psychotherapists working with people living with ME, CFS or ME/CFS. Some of the questions that I explored are perceptions of their therapists’ knowledge of ME, CFS, and ME/CFS; their satisfaction with their treatment; what interventions and approaches they found most and least helpful; and what barriers they faced in accessing mental health services. Exploring how patients feel about their experiences with psychotherapy may help mental health practitioners better understand how to serve and validate people with ME, CFS or ME/CFS without reinforcing stigma and blame.

## **CHAPTER II**

### **Literature Review**

The following literature review discusses several areas of research relevant to the perceptions of people living with ME, CFS, and ME/CFS regarding their mental health treatment, although there are few studies that directly address this question. The first part will review studies that explore how individuals suffering from ME/CFS feel about medical professionals' attitudes towards them and the disease, as well as studies of medical professionals themselves. The second part looks at debates in the medical and patient communities about recommendations of Cognitive Behavioral Therapy (CBT) or other psychological treatment to relieve ME/CFS symptoms. The third examines studies about client perceptions of mental health treatment for ME/CFS and the final section address issues of race and racism in diagnosis and research of ME/CFS.

#### **Lack of Validation from the Medical Community**

ME, CFS, and ME/CFS can be life-altering and the lack of recognition from the medical community of these physical effects causes additional stress and even existential crises for patients. One meta-analysis of qualitative studies on ME/CFS found that the illness impacts patients' senses of identity and that seeking a diagnosis and knowledge of their disease is a way of coping as well as reclaiming power. Other major themes were that patients felt dismissed or blamed by doctors who maintained that their symptoms were psychosomatic and that when legitimacy of the illness is challenged, it challenges patients' sense of self (Larun, & Malterud,

2007). Another more recent meta-analysis of qualitative studies of ME/CFS confirmed these themes found by Larun and Malterud and also found that in comparison with other conditions such as fibromyalgia, there is more stigmatization (Anderson, Jason, Hlavaty, Porter, & Cudia, 2012). Patients often have to go to multiple physicians in order to get a diagnosis due to a lack of knowledge or “unwillingness” to make a diagnosis of ME/CFS and an estimated 84% of people in the U.S. with the condition go undiagnosed (IOM, 2015).

Research has documented biases against ME, CFS and ME/CFS within the medical field. For example, one qualitative study of 21 medical students in the UK found they had little to no education in medical schools about the disease and that students had impressions that ME/CFS patients are “lazy” or “making it up” (Stenhoff et al., 2015). Other studies support the finding that medical students receive little training about the disease on a wider scale. The IOM found in its review: “Less than one-third of medical schools include ME/CFS-specific information in their curriculum (Peterson et al., 2013); and only 40 percent of medical textbooks include information on the condition (Jason et al., 2010)” (IOM, 2015, pp.15-16). In addition, qualitative studies have found trends of skepticism and minimization in physicians’ attitudes towards ME/CFS including beliefs that patients exaggerate their symptoms (Anderson, Jason, Hlavaty, Porter, & Cudia, 2012).

There seems to be less research on mental health providers’ perceptions of the disease; however, one study explored ways in which mental health professionals may be influenced by how the medical field framed the case. It found that mental health practitioners were less likely to view clients as disabled if the physician’s recommended treatment was CBT versus an experimental drug treatment (Taylor, Jason, Kennedy, & Friedberg, 2001). This research was based on providing 93 clinicians who had the same level of knowledge of ME/CFS with the

same case study; the only differences were in the physicians' recommendations for treatment. This study points to possible lack of knowledge among mental health practitioners about ME/CFS clients and how stigma in the medical profession may spill over into therapy. Furthermore, this study helps support the need for more research about how patients feel about their mental health practitioners' attitudes towards the disease in the therapeutic setting because if physicians do not recommend a medically based treatment, biases about whether or not the patients are truly disabled may impact the therapeutic relationship and approach.

### **Issues of Racism in Diagnosis of ME/CFS**

Most studies on ME, CFS, and ME/CFS involve samples that pool from tertiary care centers and are overwhelmingly White and female; however, studies from diverse community-based samples reveal that Latinos and African-Americans actually have higher prevalence of CFS (Jason, Plioplys, Torres-Harding & Corradi, 2003; Reyes et al., 2003). There are several possible explanations for this phenomenon including structural racism and differential access to medical care. In addition, a qualitative study from the UK about ME/CFS patients explores the lower levels of diagnoses in people of color and finds themes of interpersonal racism in the clinical encounter. This study interviewed Black and South Asian patients in England, as well as some medical providers and community leaders. One important theme captured by both patients and providers was the role of racism in the medical field. For example, one general practitioner stated:

A lot of Asian women say they are depressed and miserable because they can't do anything, they're in pain all the time and lots of [GPs] just say oh they're just grumpy, moaning, Asian women (Bayliss et al., 2014, p. 150).

In addition to stereotypes and racism, the study found language barriers for immigrant populations and care that is not culturally appropriate to be other factors that may inhibit a diagnosis of ME. This study points to additional stigma and barriers that people of color with ME/CFS may experience and how further research could seek to be more inclusive through community-based sampling.

### **Controversy Surrounding Mental Health Research for ME/CFS Patients**

There are many approaches to psychotherapy or “talk therapy.” Cognitive Behavioral Therapy (CBT) is a psychotherapy model that focuses on how our thoughts and behaviors affect our emotions. It is typically time-limited therapy and involves goal-setting and homework assignments for individuals to practice skills at home (Calkins, Park, Wilhem, & Sprich, 2016). CBT interventions involve raising awareness of dysfunctional thoughts or behaviors, challenging them and working to replace them with more helpful thoughts or actions. The basis for CBT as a treatment for ME/CFS is the idea that patients’ faulty thinking about their lack of abilities prevents them from carrying out regular activities and that by reducing this fear and avoidant behavior, patients will recover physical functioning (White et al., 2011).

The PACE trials, a major study from the UK that has been the source of a great deal of controversy, reported CBT and Graded Exercise Therapy (GET) to be more effective compared to specialized medical care alone or Adaptive Physical Therapy (APT) (White et al., 2011). GET, which involves gradual increases in physical activity, is based on a similar premise of CBT with ME/CFS patients—that due to avoidance, patients have become deconditioned and muscles have atrophied. APT differs from CBT and GET in its approach because it is based on the premise that the patients are suffering from a physical illness and the therapy attempts to adapt their physical activity to find the optimum level that matches their ability to reduce fatigue (White et al, 2011).

This was a randomized trial with 641 patients in the UK and measured changes in physical functioning and fatigue over the course of 52 weeks. This study was significant because of the amount of resources it received and its health policy implications, as well as the response of patients who disagreed with its findings. It claimed that 59 % of the participants in the CBT treatment group improved in fatigue and physical functioning and 61% of those in the GET group did so (White et al., 2011). While a randomized trial is seen as a gold standard in research, after the study's publication, critics have raised serious questions.

One of the main critiques is that the PACE trials' criteria for participants may have confounded the results. A public health and journalism professor from University of California, Berkeley, David Tuller, wrote:

The study included a bizarre paradox: participants' baseline scores for the two primary outcomes of physical function and fatigue could qualify them simultaneously as disabled enough to get into the trial but already "recovered" on those indicators—even before any treatment. (Tuller, 2015).

The question over the measurement and definition of "recovery" challenges the study's internal validity. Another threat to the study's internal validity is that it used the Oxford case definition, which is one of "the least specific of the definitions" of ME/CFS, and therefore may have captured individuals with fatigue from other conditions who do not have other symptoms characteristic of ME/CFS (Smith et al., 2016). The Agency for Healthcare Research and Quality in the US Department of Health and Human Services found in a meta-analysis of six studies on CBT for ME/CFS that including the studies that used the Oxford criteria there was "low strength evidence that CBT improved function" and when these studies were removed there was

“insufficient evidence to determine the effectiveness of CBT on the outcome of function due to study limitations, inconsistency and imprecision of results” (Smith et al., 2016, p. 3).

After much public scrutiny, the researchers of the PACE trials were required to release their original data due to a freedom of information request. Secondary analyses of the data found that the claims of a 59% and 61% improvement using CBT and GET respectively, dropped to 20% and 21%. This is only 10% more improvement than in the control group (Geraghty, 2016). The researchers have been criticized for not revealing conflicts of interests with ties to disability companies (Tuller, 2015). Apart from the multiple issues with research on CBT as a treatment to improve functioning for people with ME/CFS, a new study with a sample of 990 individuals found that people living with ME and CFS reduce their activity levels due to “impairment and fatigue” rather than “illness beliefs” (Sunnquist, 2016). This finding challenges the foundation of the CBT model for ME/CFS that individuals are limiting themselves due to faulty thinking that activity will worsen their symptoms. This study replicated an earlier study with similar findings (Song & Jason, 2005).

### **Patients’ Perceptions of Mental Health Care**

There are relatively few studies that look specifically at how people with ME, CFS or ME/CFS feel about their interactions with psychotherapists; however, there have been some qualitative studies focusing on patient experiences with mental health services. Qualitative research may capture the perceptions of the patients about their mental health care in greater depth through their subjective experiences, but involve smaller sample sizes that may not be generalizable. Two qualitative studies on this subject that I found in my literature review were both conducted in the United Kingdom; one involved adults with ME/CFS and the other focused on young people and their parents. The first involved a sample of 25 adults who had received



diagnoses of ME by a medical practitioner. The study found that participants had experienced a variety of therapeutic approaches, but that CBT was most common (Ward, Hogan, Stuart, & Singleton, 2008). Patients interviewed had negative reactions to suggestions from the counselor that their condition was psychosomatic and several noted physical difficulties in participating in therapy related to traveling to their appointments and the length of the sessions. Positive benefits that patients described included having an empathetic listener who they felt understood them and their circumstances, as well as “coping with stress, having realistic goals, and learning to pace” (Ward, Hogan, Stuart, & Singleton, 2008, p. 77). The researchers recommended, based on their findings, that counselors working with people who have ME should be knowledgeable about the condition and should use interventions that help with coping using a client-centered approach rather than attempting to cure ME.

The qualitative study investigating the perspectives of young patients and their families on CBT and psychoeducation as a treatment for CFS had a sample size of 16 young people and 16 parents. Overall, participants reported that the therapy was helpful but was not a cure and some similar themes emerged as in the Ward, Hogan, Stuart, & Singleton study. For example, participants found validation and emotional support as positive aspects of therapy; feeling wrongly labeled as having mental rather than physical issues and feeling drained from therapy were among the negative perceptions (Dennison, Stanbrook, Moss-Morris, Yardley, & Chadler, 2010). In their discussion, the authors state:

Although several studies of perception of general medical encounters have been conducted...there is a paucity of qualitative research on psychological interventions. This is a particularly interesting area of investigation given the controversial and contested nature of CFS. CFS patients and CFS support groups often reject psychosocial

explanations of their illness in favor of biological ones...and thus may have skepticism or opposition towards psychological approaches to treatment. (Dennison, Stanbrook, Moss-Morris, Yardley, & Chadler, 2010, p. 169).

Since there is a small body of research focused on the experiences and perceptions of people with ME, CFS, or ME/CFS related to psychotherapy, more exploration could help mental health providers better understand the needs of ME/CFS patients and their feelings about treatment in order to better support and empathize with clients. For example, in the studies described above, therapy was physically taxing for clients -- and if this phenomenon were repeated in another study, perhaps it would point to a need for clinicians to explore other options for therapy for this population using phone or internet communication. Furthermore, studying of experiences of people living with ME, CFS, and ME/CFS in other parts of the world may provide more perspectives and perhaps experiences with different therapeutic approaches.

## **CHAPTER III**

### **Methodology**

This was a mixed-methods study intended to explore experiences of people living with ME, CFS and ME/CFS related to psychotherapy and their opinions about their treatment in order to help providers better understand how to treat this population while ensuring ethical standards. The data were collected through an online, anonymous survey that included space in qualitative comment boxes for participants to write about their lived experiences. Since some people with ME, CFS or ME/CFS have limited mobility, the online survey was intended to make participation more accessible and possibly capture a segment of the population that has been underrepresented in some studies that require participants to leave their homes. The mixed methods approach was intended to capture some qualitative data that provide subjective responses in a way that may be less taxing than an interview for individuals who struggle with fatigue due to cognitive activity. The survey involved one-time participation that required an estimated 20-30 minutes to complete, depending upon how much detail participants chose to include in the comment boxes. The online survey allowed participants to answer some questions, take a break and then return to the survey, which was a feature that aimed to make it more accessible to individuals unable to maintain conversations required by a qualitative interview. However, one of the disadvantages of the online approach is that it may have excluded individuals who do not have regular access to the internet.

## Sample

Any person over the age of 18 who self-identified as having ME, CFS or ME/CFS was allowed to participate in the study. Before beginning the survey, participants were given the following prompts: 1) I am over the age of 18. (Yes/No); 2) I have Myalgic Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), or ME/CFS (Yes/Maybe/No). If participants responded “No” to either of these statements, they were directed to the end of the survey. One of the disadvantages to this self-reporting is that individuals who may not fit criteria for ME, CFS, or ME/CFS may have been included. Some of the distinguishing characteristics of ME/CFS are “post-exertional malaise,” meaning “exacerbation of some or all of an individual’s ME/CFS symptoms after physical or cognitive exertion,” and that fatigue that does not improve significantly with rest (IOM, 2015, p.6). Without knowledge of this distinction and other diagnostic criteria of ME, CFS or ME/CFS, individuals with fatigue from other conditions might have believed that they were eligible to participate in the survey, which could have confounded the results. However, since it can be challenging and often costly to get tested by a specialist who could confirm a diagnosis of ME, CFS, or ME/CFS, allowing people who self-identified as having the condition allowed for a more inclusive study. The benefit was that individuals who feel as though they have been unfairly dismissed by medical professionals or who do not have the financial resources to seek specialized care may be able to participate.

The survey was only available in English, so it was limited to English-speakers. The study was open to individuals from different countries and asked participants to identify their country of residence. There are significant national and regional differences regarding access to mental health services and treatment modalities. Including participants from different countries was intended to capture a diversity of experiences and opinions. Some major ME, CFS and

ME/CFS studies on mental health treatment have focused solely on the UK where the dominant mental health treatment model has been CBT.

## **Recruitment**

I received approval from Smith College School for Social Work's Human Subjects Review Board before beginning recruitment in order to ensure the study's compliance with ethical standards in research (see Appendix A). I made minor changes to questions in the survey before beginning recruitment, which were then approved by the HSRB. In order to recruit participants I contacted prominent physicians who specialize in ME/CFS in order to request that they share information about the survey with their patients. I made the research proposal available upon request. I also contacted patient-led groups for people with ME, CFS, and ME/CFS in the United States, United Kingdom and Australia. I did not receive a response from many groups. One of the possible challenges to recruitment is that some ME/CFS research has left patients feeling invalidated and therefore they may have been hesitant to participate in this study due to mistrust of researchers. In addition, many patient groups are volunteer-run by patients, who may have limited time and resources to assist with this project. After a well-known specialist on ME/CFS shared the study through social media, some other researchers and patient groups from the US and Australia reposted the link to the survey. One of the disadvantages of this approach to recruitment is that it follows the pattern of many studies that focus on tertiary care centers, which leads to a less diverse pool of participants than a community-based sample. This choice was made for convenience due to the time limits for this study and is a limitation to generalizability of the study's findings.

## **Confidentiality**

Responses were gathered through an anonymous online survey. The online survey platform encrypts the data so that the researcher cannot trace IP addresses. This ensured anonymity and helped protect the privacy of the participants. Participants were asked to volunteer demographic information but if participants included their names or contact information in their qualitative responses, I removed such information before including quotations in the thesis report.

## **Risks and Benefits**

All participants were required to provide informed consent before entering the survey. Participants did not receive any compensation for their participation in the study. The potential benefits for participants include helping educate mental health professionals about the experiences of ME/CFS patients in therapy, which could lead to better treatment and understanding of the disease. Participants might not have seen a direct benefit but it may have helped them feel as though they have contributed to other patients' wellbeing, and perhaps their own in future. Some participants may have experienced relief in writing about their experiences in the comment boxes, and knowing that these experiences are to be viewed by multiple readers who may care about them.

There were no expected risks, though some participants may have experienced distress if describing experiences that were not helpful or emotional difficulties related to their chronic illness. In the event some might wish to have referrals to resources for coping with such reactions, a list of support groups and counseling service resources was offered at the end of the survey. Based on some of the comments from participants, another potential risk that some may

have experienced was feeling distressed by the survey questions and perceived lack of understanding by the researcher.

### **Data Analysis**

The qualitative data from the written responses to survey questions were analyzed for themes and subthemes by the author. Dr. Gael McCarthy, my thesis advisor, reviewed them as a second reader for validity. For clarity in citations, minor corrections to spelling or punctuation of the comments were made when necessary without changing any of the meaning or content of the responses. The quantitative data were analyzed for frequencies and Pearson correlations were run by the Smith College School for Social Work data analyst Marjorie Postal using SPSS. There were 222 responses to the survey; however, only 169 responses were used in analysis and the rest were excluded because they were either blank, did not provide informed consent, or reported they were under 18 years old.

## **CHAPTER IV**

### **Findings**

This was an exploratory/descriptive study about the experiences of individuals with ME, CFS, or ME/CFS with mental health therapy. This chapter will first examine the demographic make-up of the participants and some of the quantitative trends in the data; then I will highlight some of the major themes and subthemes from the responses. Many participants opted to write in comments to the open-ended questions in the survey and provided a wealth of qualitative responses. These responses included a wide variety of experiences with mental health professionals. Some participants reported they had seen multiple therapists and had very different experiences with each. While there were varied experiences and opinions, several common themes and subthemes emerged.

One major theme was the supportive role of mental health therapy for individuals struggling with feelings of grief, loss and social isolation due to the chronic nature of the disease. On the other hand, another prevalent theme was how patients feel invalidated when mental health providers deny the biological nature of the condition, make suggestions that lead to over-exertion, or do not make therapy accessible to the needs of people with ME, CFS, or ME/CFS. Another common theme was the therapists' knowledge or lack of knowledge about the disease and how this either benefited or inhibited mental health care. Although there was no question that specifically asked participants to identify resources to educate mental health providers about ME, CFS, or ME/CFS, respondents provided suggestions throughout the survey that I have



compiled (see Appendix D). This chapter also includes reported issues about accessibility to mental health treatment. Finally, it discusses some findings related to respondents' participation in support groups.

## Demographics

Table 1

### Participant Demographics

<b>Country of residence (n=169)</b>	
United States	n= 74 (43%)
Not Reported	n= 44 (26%)
Australia	n= 19 (11.2%)
United Kingdom	n= 12 (7.1%)
Italy	n= 7 (4.1%)
Canada	n= 4 (2.4%)
Spain	n= 3 (1.8%)
Ireland	n= 2 (1.2%)
Netherlands	n= 1 (0.6%)
Belgium	n= 1 (0.6%)
Netherlands	n= 1 (0.6%)
<b>Gender identity (n=169)</b>	
Female	n= 114 (67.5%)
Not reported	n= 39 (23.1%)
Male	n= 14 (8.3%)
Genderqueer or gender non-conforming	n= 1 (0.6%)
Transgender male	n= 0 (0.0%)
Transgender female	n= 0 (0.0%)
Trans	n= 0 (0.0%)
Other	n= 1 (0.6%)
<b>Age Range n= 169</b>	
18-25	n= 7 (4.1%)
26-33	n= 9 (5.3%)
34-41	n= 11 (6.5%)
42-49	n= 19 (11.2%)
50-58	n= 37 (21.9%)
59-66	n= 29 (17.2%)
67-74	n= 12 (7.1%)
75-82	n= 2 (1.2%)
83-90	n= 1 (0.6%)
Not reported	n= 42 (24.9%)

The question about race/ethnicity provided space for participants to write in responses rather than providing pre-determined categories. It was designed this way since the survey was open to all nationalities and standardized racial/ethnic categories vary amongst countries; it also allowed participants to self-identify in their own words. Of the 169 participants, 28.4% (n= 48) did not respond to this question. The majority (57.4%) wrote in variations of White (n=51) or Caucasian (n=46); 0.6% (n=1) identified as Black; 0.6% (n=1) identified as White/Hispanic. Some wrote in their nationalities or geographic region including: 1.8% (n=3) Australian, 0.6% (n=1) British, 0.6% (n=1) Irish, and 3.6% (n=6) European. Other identified as Anglo-Saxon (1.2%; n=2) or Anglo-Celtic (1.2%; n=2); 0.6% (n=1) identified as Jewish and 1.8% (n=3) identified as White Jewish. The remaining three participants wrote in other responses.

### **ME/CFS Diagnosis**

Table 2

<b>Number of years with ME/CFS</b>		
1-3 years	n= 22	13.0%
4-6 years	n= 21	12.4%
7-10 years	n= 19	11.2%
11-15 years	n= 27	16.0%
Over 15 years	n= 80	47.3%

Table 3

### **Source of ME, CFS or ME/CFS Diagnosis**

\*Total adds up to more than 100% because participants were allowed to select all that apply.

Primary care physician/general practitioner	n=50 (29.6%)
Medical Specialist	n=96 (56.8%)
Self-diagnosis e.g.: through research I did on my own	n=26 (15.4%)
Other	n=15 (8.9%)

Of the 15 participants who selected “Other,” four wrote in they were diagnosed by a ME or CFS specialist, six wrote in multiple medical professionals, and the remaining five comments described challenges receiving a diagnosis. In addition, of the 26 who selected “self-diagnosis,” 12 also selected they were diagnosed by a primary care physician/general practitioner and 11 also selected medical specialist.

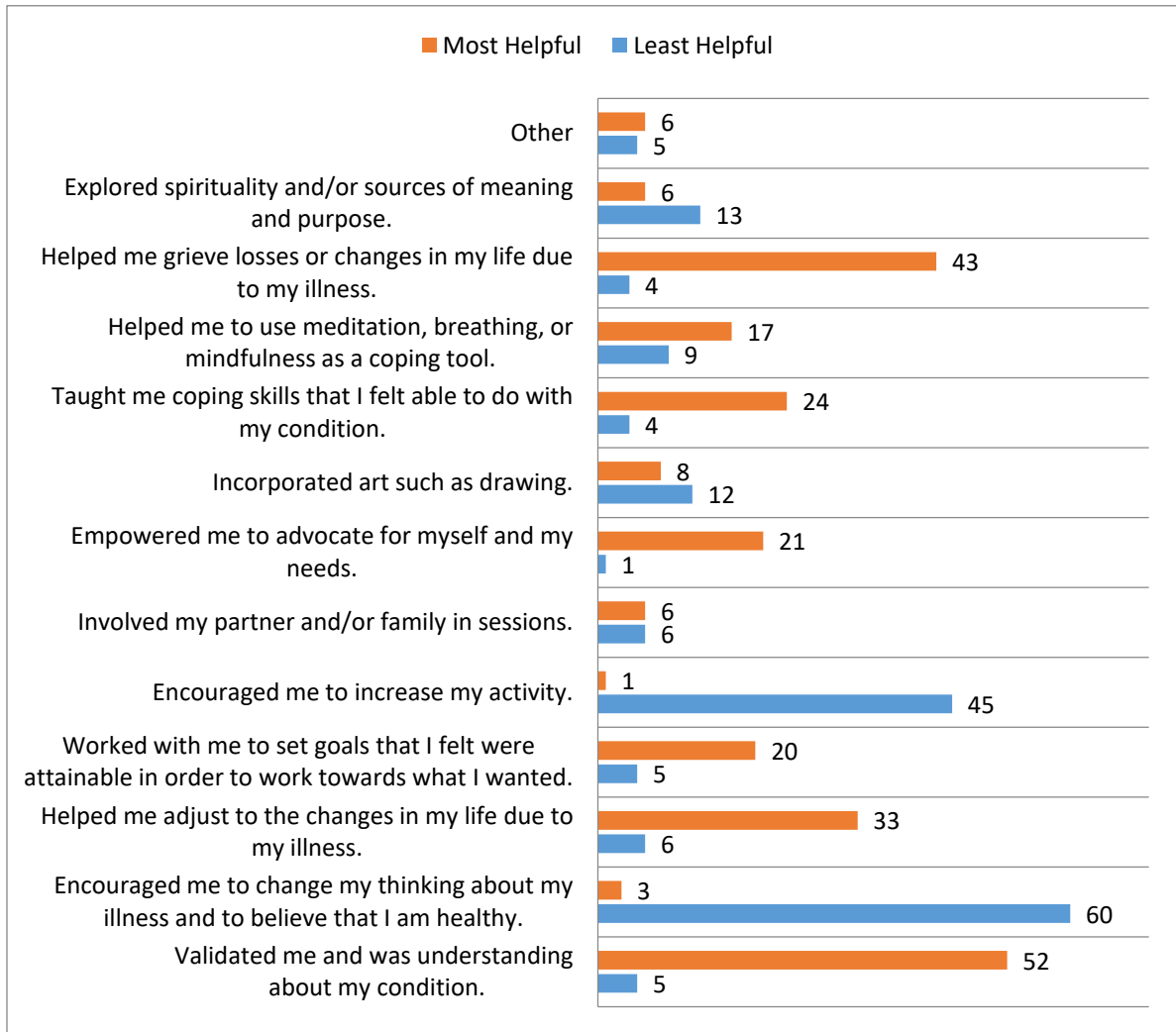
The overwhelming majority of the survey participants, 79.3% (n=134), reported that they had spoken to a mental health therapist since they developed ME, CFS, or ME/CFS. The survey directed the remaining 20.7% (n= 35) of participants to skip over the questions that asked about satisfaction with therapy, therapists’ knowledge of ME/CFS, interventions used and what was most/least helpful from their sessions. All participants -- regardless of whether they reported having spoken to a mental health therapist since they developed ME, CFS, or ME/CFS or not -- were invited to comment on recommendations for improving mental health therapy for people with ME/CFS, support groups, barriers to accessing therapy, and improving accessibility.

### **Most and Least Helpful Therapeutic Approaches or Interventions**

Participants were asked to select up to three therapeutic approaches or interventions from a list provided that they considered the most helpful, as well as up to three that were the least helpful. As this list was not exhaustive of all possible kinds of interventions, there was also an option to write in other responses. The three most frequently chosen as “most helpful” were: “Validated me and was understanding about my condition” (n=52); “Helped me grieve losses or changes in my life due to my illness” (n=43); and “Helped me adjust to the changes in my life due to my illness” (n=33). The three selected most frequently as least helpful were: “Encouraged me to change my thinking about my illness and to believe that I am healthy”

(n=60); “Encouraged me to increase my activity” (n=45) and “Explored spirituality and/or sources of meaning” (n=13). Below is a table that illustrates the results.

Table 4: Most and Least Helpful Therapeutic Approaches or Interventions



The therapeutic interventions or approaches that respondents wrote in for “other” that they labeled as “most helpful” included three responses that indicated the participants did not find mental health therapy helpful; two respondents indicated they practiced in self-help; and one wrote the most helpful was practical advice rather than discussing emotions. The “least helpful” written in interventions included: delving into childhood trauma, being encouraged to find

another diagnosis, dismissing ME as a psychiatric disorder, “discussing how people can bring on physical illness by the way they think” and not addressing grief/loss related to the disease.

The following section focuses on common themes and subthemes that emerged from the qualitative data. The first part highlights what participants found most helpful from mental health therapy followed by the least helpful. Much of these findings mirror the trends in the qualitative data.

## **Most Helpful Approaches**

### **Listening and Emotional Support**

A number of participants commented that what they found most helpful from mental health therapy was that their therapists listened to them and provided emotional support and empathy. While this is a benefit that most individuals seek from mental health therapy, respondents with ME/CFS commented on the importance of having a non-judgmental listener due to the social isolation that the disease can cause and the way that participants feel they have been ignored, judged, or disbelieved by family, friends, or medical professionals. Below are some quotes that illustrate this theme:

It's nice to have someplace to vent about my disease without stressing the listener. When I tell my family members how I feel, they are troubled - it affects them, too, and they worry about me. The counselor's office is a place where I can be honest about my symptoms - where I need not be optimistic in order to reassure others.

I became ill with ME/CFS more than 38 years ago. It took more than 37 years to be correctly diagnosed with ME/CFS. During those 37+ years I experienced more harmful medical errors and moments of condescension, open hostility and even gross malpractice from most physicians by whom I was examined and treated. I suffered three near-death experiences because of physician mis-education and malpractice. The disease of ME/CFS has long been stigmatized and ultimately people with ME/CFS ourselves become stigmatized and lack credibility in the eyes of physicians. In this context it was helpful to talk with a "neutral" third party while going through the long and horrific process of seeking an accurate diagnosis of ME/CFS. 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.

I knew this therapist and it is just good having someone non-judgmental to talk to. Many friends and relatives eventually just get tired of it no matter how much they care about you. Therapist was a very non-judgmental listener.

The ability to talk about my symptoms without feeling like I was burdening a friend. I was fortunate enough to have a therapist who had knowledge about ME/CFS, and she did not attribute every physical symptom to psychological causes, i.e. depression or anxiety.

Having someone to talk to, as I used to have a lot of friends, and since getting sick, I've become increasingly isolated (not by choice - just too sick), and learning coping skills for dealing with being sick.

A place to vent, process medical decision-making, process interactions with doctors, process emotions about not being able to work/giving up career, process how family & friend relationships change with chronic illness. Not feeling alone in the battle.

### **Grief and Loss**

Another common theme was grief and loss of identity, relationships and roles that the participants had before they became sick with ME, CFS or ME/CFS. Addressing these issues appeared several times in responses about what was most helpful from psychotherapy and what participants recommend for therapists working with people who have ME, CFS, or ME/CFS.

I felt I needed a bereavement therapist who could comfort me and talk about my losses, grief, loneliness, anger.

They need to learn about how severely this illness affects our life. Understand how we feel like we have lost the life we once had and the person I once was. The grief is so deep. Also for many of us it is the first time in our lives that we are alone with our thoughts, feeling and emotions and all of our distractions have been taken away, many times one moment we were able to live a full life and then the next minute our life changed. I lost 90% of my life and many of the things that gave me purpose in life. I became dependent on others for all of my needs. I felt like a burden to others. And at times I lost the will to live. I could no longer look to the future and be excited. When I would look to the future, I felt like I cannot continue this. They need to help us live today and to find small joys in our day. And helping our family to understand is very important. Not only are we struggling to live, but many times we are not believed by doctors, friends and even family. That causes another level of our suffering.

In my case, I believe what I most needed was help with the GRIEF of losing the life I had, and the plans I had made for retirement (I was almost ready to retire!!)

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.

Even though my therapist did not have much knowledge of ME/CFS, she did understand that I was suffering loss. Loss of career I enjoyed; loss of being able to cope because I used to increase my physical activity [in] times of stress, which in turn helped to decrease stress, so I guess the loss of a favorite coping mechanism.

Understanding that it is basically a living death if you are unable to do anything or go anywhere, you are watching everyone else live their normal lives through videos and podcasts, knowing that you can no longer participate and are completely cut off from society. There is a massive amount of grief to process, you lose everything, people abandon you which is very hurtful, your dreams and goals are destroyed and everything that you enjoyed doing. You endure abuse from 'professionals' and benefit agencies, media and society.

### **Acceptance**

A subtheme related to the theme of grief and loss was acceptance. Some participants commented that one of the most helpful aspects of therapy was their mental health providers helped them accept that they were seriously ill.

I needed help to go through the stages of grieving and come to a place of 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 (I had just had a baby, emergency C-section, and then an infection). In fact, I created an exercise group, and promptly drove myself into a horrific crash of exhaustion and pain.

She was able to guide me through accepting [that] not all people would understand and many fear what they don't understand.

She helped me accept that I was severely ill and was the first person that I spoke to whom I could be honest with.

On the other hand, some participants commented that they found the concept of acceptance to be unhelpful.

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? There is no such thing as accepting or coping; it's like accepting and coping with your own death.

I was so angry and filled with grief about being sick. My therapist wanted me to accept it. I remember one day making up an analogy to help her understand why doing therapy felt so shitty. Imagine, I said to her, that you were hungry. Really, really hungry-- starving in fact. You come to therapy and tell your therapist that you're starving. She asks how it feels to be starving, she asks about how your parents dealt with your feelings about being starving, she asks what being starving reminds you of. You can talk about all these things, about how miserable starving is, about how you feel powerless to change it -- but really, what you really, really need is FOOD. And your therapist doesn't have any. That's how therapy felt. The whole time I was just felt so sick and no matter how much I talked about it or developed insight, I was just desperately and miserably sick, and nothing besides feeling better could help.

### **Finding Meaning and Identifying Strengths**

Another subtheme was finding a new meaning and/or identity and building on strengths as part of the grief process. Several participants suggested that therapists incorporate this exploration into their work with individuals with ME, CFS, or ME/CFS in response to the question about what participants would recommend to mental health therapists to improve their treatment and support of people with the condition.

Learn about the illness. Treat patients with respect, always, and don't imagine that you know better than they do what they're going through. Simultaneously support them in dealing with the loss and recognize the strengths they continue to have.

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!).

Be willing to become more knowledgeable about ME/CFS ...the abysmal treatment of patients by governmental agencies, especially the CDC and NIH. Also the effect of having your life ripped out from under you, the lack of support and ridicule from everyone including doctors, family, friends and co-workers. The loss of losing the you that you have always known and the need to find meaning and purpose in the life you now have.

I still hope to feel better, but in the meantime I want as full a life as I can find, with purpose, hope and meaning. That's what I needed her help to achieve.

Take this illness very seriously. Believe what the patient tells you and follow them and where their mind goes. At the same time be encouraging and supportive and help them focus on the positive, as well as allowing them to grieve loss.



I found the loss of my profession which I loved to be very difficult. I however learned that I have value in who I am, not what I do. My strong Christian faith has really helped me - seeing myself how God sees me (not needing to achieve to be loved) versus how the world sees me (a bit useless!)

### **Validation**

In addition to support in the process of grief, acceptance, and finding strengths, another common theme related to what participants found most helpful from therapy was validation and being believed by their therapists that their illness was organic.

Also I found one session with a psychiatrist who listened and understood my situation with my health, the poor understanding of Specialists who I was dealing with who belittled or made hurtful comments to me. Back when I became very ill and debilitated in 1988 not much was known about ME/CFS , and many doctors ... including specialists knew very little to nothing about it and I certainly [felt] they were judging me very unfairly; they really had no idea how overnight my entire life changed, and changed forever. I was totally honest in answering all his questions and he told me I was not crazy and wrote a letter for me to carry with me to show doctors I was sane so they could get on with helping me instead of thinking I was depressed. I carried that letter with me a long time, although I never showed it to the doctors, it did give me strength and remind me I really was not crazy but certainly very ill.

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. We also had sessions with my husband to enable him to understand and allow him to verbalize his feelings.

They were focused on helping me - discerning my issues, my needs, and helping to develop positive strategies - instead of questioning whether I was actually ill, or making stuff up, or whether my illness was real or not.

The opposite of this theme came up frequently in the responses about what was least helpful.

This will be further explored in that section.

### **Practical Advice and Referrals**

Several participants commented that what they found most helpful was not emotional support but rather practical tools, assistance with navigating social service and health systems and referrals.

Offered practical help toward getting effective treatment instead of wasting time exploring feelings.

Providing information on rheumatologists who specialise in chronic fatigue syndrome and Arthritis Foundations which offer sound advice on managing it. Referring me to an affordable exercise physiology clinic at the university was also helpful. Developing assertiveness, learning to prioritize and identifying self-sacrificing traits which stifle good management of chronic fatigue syndrome. Advice to begin things without over-thinking them. Encouraging me to maintain healthy eating habits and to objectively research my condition. Writing letters in collaboration with doctors to educational institutions to legitimize and confirm the impact of the condition.

Two of my therapists were very helpful, but not because they counseled me on emotional problems. Both had ME/CFS and offered me some practical advice. One suggested hyperbaric oxygen for pain. The other recommended a technique for increasing oxygen to the brain. A hypnotherapist was also helpful: again, he did not counsel me. Overall I found therapy to be most helpful when it wasn't therapy.

To be honest, the main benefit of therapy was having someone to talk with. But this is the tiniest band-aid that is really inconsequential. What I really need is biomedical research and safe, effective treatments for ME. Another potential benefit I could imagine a therapist providing are resources: Knowledge of good social security attorneys who specialize in and have successful track records winning SSI and SSDI benefits for people with ME. Knowledge of outstanding ERISA attorneys who specialize in and have successful track records winning appeals and/or lawsuits for people specifically with ME/CFS - after private disability insurance companies deny their claim. Names and contact information for expert ME/CFS clinicians, although there are fewer than a dozen in all of the US. Names, contact information for ME/CFS advocacy organizations including meaction.net and the Solve ME/CFS initiative.

She's very practical and gives me skills/advice on self-talk. She was also one of the professionals who suggested I write a letter when I told her that the Mayo Clinic had classified me as a psychiatric patient.

### **Issues Not Related to ME, CFS, or ME/CFS**

Several participants noted that that they sought therapy for support with issues in their lives not directly related to their medical condition such as loss of a spouse or family dynamics. Others commented that they had seen mental health providers before developing ME, CFS or ME/CFS for other reasons.

I started seeing my therapist several years before my illness. Using EMDR she helped me overcome some really crippling childhood abuse issues. I'm grateful to her - her therapy was on point and extremely useful. I was winding up my sessions when I grew ill, and I kept seeing her as I adjusted and dealt with my illness. Here she hasn't been as much help. She seems a little lost as to how to treat me. I'm actually doing fine emotionally (most of the time), but I see her every three months to clear the air and make sure I'm doing all right.

I mostly go to see her because of outside anxiety problems, and not directly because of the ME. She's very helpful about dealing with anxiety.

Actually I've been to a handful of therapists and not primarily for ME/CFS. I started going for treatment for bipolar but found that without addressing the ME/CFS part of my life, treatment wasn't going so well.

### **No Benefit**

In response to questions focused on what participants who had attended therapy found most helpful, several participants commented that they found nothing helpful.

The only helpful outcome was my realization that the illness was completely unknown except possibly as "yuppie flu." I had, after 18 months, received SSDI and moved into public housing in a town where I knew no one. In the nine years before diagnosis, I had used up every resource, retrained three times, each precipitating a crash and greater disability which left me unable to perform whatever I'd retrained for. I went to one session, explained that I did not know how to live within the limits the disability sets were imposing, and requested help in coping strategies with the myriad demands of the illness, including hopeless poverty financially, socially, professionally. I was told to get a book on time management and coping with chronic pain. I told the therapist she was in great error and left.

Nothing really. My psychiatrist helped by prescribing palliative medications but that's about it. Nothing psychological has ever helped any physical or mental symptom of mine.

I have been quite disgusted with the lack of knowledge and support by therapists and other healthcare providers in general. TO ANSWER THIS QUESTION: I have not had any benefit from seeing a therapist since developing ME 2 1/2 years ago.

I didn't find anything helpful about my sessions because the therapists were not educated in ME/CFS.

These themes in the comments reflect a number of trends in the quantitative data. Below is a table showing correlations between the frequency that participants reported their therapists used

the following therapeutic interventions or approaches and their reported satisfaction with therapy. These options do not represent an exhaustive list of therapeutic interventions and the comments mentioned other approaches not included in the multiple-choice survey question. There were no significant correlations with “Involved my partner and/or family in sessions” or “Incorporated art such as drawing.” The two interventions with the highest rates of positive correlation were “Validated me and was understanding about my condition” and “Helped me adjust to the changes in my life due to my illness.” Notably, “Encouraged me to increase my activity” was the only intervention to have a significant negative correlation between frequency and participant satisfaction with mental health therapy. This will be discussed further in the next section with themes related to what participants found least helpful in therapy.

**Table 5 Correlations between Frequency of Approach and Satisfaction with Therapy**

<b>Approach/Intervention</b>		
Validated me and was understanding about my condition.	$r=.598^{**}$	$p=.000$
Encouraged me to change my thinking about my illness and to believe that I am healthy.	$r=.352^{**}$	$p=.000$
Helped me adjust to the changes in my life due to my illness.	$r=.580^{**}$	$p=.000$
Worked with me to set goals that I felt were attainable in order to work towards what I wanted.	$r=.447^{**}$	$p=.000$
<b>Encouraged me to increase my activity.</b>	<b><math>r= -.240^{**}</math></b>	<b><math>p=.011</math></b>
Empowered me to advocate for myself and my needs.	$r=.469^{**}$	$p=.000$
Taught me coping skills that I felt able to do with my condition.	$r=.460^{**}$	$p=.000$
Helped me to use meditation, breathing, or mindfulness as a coping tool.	$r=.269^{**}$	$p=.005$
Helped me grieve losses or changes in my life due to my illness.	$r=.463^{**}$	$p=.000$
Explored spirituality and/or sources of meaning and purpose.	$r=.259^{**}$	$p=.007$

\*\* . Correlation is significant at the 0.01 level (2-tailed).

## **Least Helpful**

Among the responses about what participants found least helpful from mental health therapy were several themes related to feeling as though their providers either did not have any knowledge about the illness or that they did not believe that their disease was biological and could be cured solely by psychological interventions. Some subthemes related to this were feeling pushed to over-exert themselves and feeling as though providers misunderstood, dismissed, or judged them about their condition. Cognitive behavioral therapy (CBT) was mentioned several times in comments related to these themes. Other common themes about what was least helpful were the cost and issues of accessibility.

### **Psychosomatic versus Biological**

An important theme in response to the questions about what was least helpful and in space for additional comments was providers' disbelief or minimization of the organic nature of the disease. Participants wrote about being diagnosed with depression (not secondary to their physical illness), malingering, or having their condition attributed primarily to childhood traumas.

I had one session with a psych resident who questioned me for an hour on my health. His supervisor also sat in on the visit. The resident left after compiling his info on me, and she -- a psychiatrist -- very quickly told me I was depressed, got a book out on depression and read me the symptoms, all of which were symptoms of ME/CFS. I told her I felt I was not medically depressed, that there was so much I wanted to do but my body and brain failed me over and over again for almost 29 years. Thus I probably was not as happy as my peers who were living a healthy, productive life, most of whom had long given up on me. She asked why I was sent and I explained I was just discharged from a Health clinic dealing with ME/CFS because there was nothing more they could do for me and the nurse practitioner thought I might want to talk with a psychologist. I agreed. Well, apparently the psychiatrist said they did not do that at their clinic; I apologized for wasting their time and left. As I walked out of the department I read the sign Mental Health Clinic and promised myself I would never put myself through that again.

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. It is likely that these factors would weaken the immune system, but the claims that ME/CFS may have a psychological basis are unfounded and harmful to patients.

### **Perceived Negative Provider Attitudes**

There were a number of comments that reflected participants' feeling that their mental health providers were judgmental, dismissive or disrespectful. In some cases this was part of comments related to practitioners who believed that the symptoms were psychosomatic, while other comments were more general about their providers' attitudes or bedside manner. Some of the language to describe their experiences with mental health clinicians that came up in these responses was: arrogant, condescension, bullying, judgmental, disrespectful, forced, dismissive, prejudice, blamed, aggressive, offensive, animosity, and derogatory.

My own difficulties were ignored completely, and indeed, were blatantly disrespected.

The trainee therapist was absolutely brilliant. The other therapists were stuck in their own entrenched ideas and assumptions, and egotistical beliefs about the client/therapist dynamic, i.e.; they know what's going on in my body and mind better than I do. They need to stay humble with an attitude of discovery, and remember that they are there to ASSIST the client in their own process and to check whether a person's health issues are being addressed not ignored...

### **Over-exertion**

Another common theme was feeling as though mental health practitioners encouraged participants to engage in more physical, cognitive, or emotional activity than they felt able to do and some mentioned experiencing a "crash." This was attributed to either clinicians' ignorance about the symptom of post-exertional malaise, their beliefs that the symptoms were psychologically based, or lack of accommodations for people with ME, CFS, or ME/CFS. In reference to the latter, participants noted the challenges of having to drive to appointments or sit

for long periods of time, as well as the “brain fog” and cognitive exhaustion from talking to their providers or the coping tools recommended.

My doctor insisted that I go to counseling when I got sick 17 years ago. I went weekly for 5 years. Spent lots of money. Was told to take a bath, read a book or go on a vacation to help with stress. She never knew anything about ME CFS and I don't think she read the materials I gave her. I finally lost it and cried and told her I was not going to take a bath because I had no energy to clean the bathtub and it wasn't worth the energy of getting my kids to do it for me. And I couldn't afford a vacation so I quit going there.

The 'therapists' didn't really seem to know much about ME or Fibromyalgia which was also covered by the course, only the somewhat inaccurate view that the NHS has on both conditions. It felt like we were being encouraged to push ourselves further than our bodies were telling us we were capable of doing with regard to exercises. Overall it felt like the course was being run as a cure for false illness beliefs...I know from past experience that this is a very bad way to manage ME as it has caused me to suffer a massive ME crash and several smaller ones when I get the required balance wrong.

Sometimes I would leave the sessions so mentally exhausted that I would completely forget about what was even discussed.

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. Between the brain fog and the lack of energy, trying to perform mental coping mechanisms is often not even an option.

### **Cognitive behavioral therapy (CBT)**

The practice of CBT was mentioned in relation to the subthemes described above.

Several participants remarked that CBT was unhelpful because it led to over-exertion; feeling invalidated; or did not address individual needs.

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.

In the Netherlands we have only a few physicians that are specialised in ME/CFS. The policy in case of ME/CFS is to send patients to CBT/GET. The therapists that provide CBT do strongly believe that ME/CFS is not a biomedical disease but is due to psychological causes. So the main barrier that I faced was the perception, belief, and attitude of the caregivers.

Overall, I found that the use of very prescriptive protocols, without adaptability to the individual or any real listening to patients' concerns was a clear signature that something was not going to work for me.

I even still get nausea thinking about the group I had to participate in (CBT with GET). So please, stop putting ME/CSF patients in such groups!!!!!! In my opinion it is not useful at all.

While the views expressed towards CBT were generally negative and appeared in responses related to what was least helpful from therapy or what participants would recommend to mental health providers, there were some mixed comments about the use of CBT with people who have ME/CFS in response to other questions. For example, one respondent who identified as a participant from the PACE trial wrote:

I think there's a lot of value in CBT but not in the way that has been put forward by the PACE trial.

In addition, as a response to the question about what was most helpful, one participant commented:

CBT-- I was referring to myself semi-jocularly as weak and feeble. They turned that around to make me proud of the control I was taking of my illness. I also developed rules based on logging so I would stay within my energy limits.

### **Knowledge of ME/CFS**

A Pearson correlation found a significant positive moderate correlation between satisfaction with mental health therapy and therapists' perceived knowledge of ME/CFS ( $r=0.522$ ,  $p=0.000$ ; correlation is significant at the 0.01 level (2-tailed)). Since the survey design did not allow participants who worked with multiple clinicians to individually rate their satisfaction or therapist's perceived knowledge of the condition, there may be some issues with



internal validity. However; this trend was also reflected in the written comments. One of the subthemes was that perceived lack of knowledge of the disease was what some participants found least helpful from mental health therapy, even if they perceived therapists had good intentions. The following comments are in response to the question about what was least helpful from mental health therapy:

I felt like my therapist was not familiar with chronic fatigue and that I had to do a lot of explaining (that chronic fatigue encompasses a whole lot more than just fatigue.) She did her best, however, to counsel me. Even after a handful of sessions, I still did not feel equipped to deal with my chronic condition. I still felt hopeless and ill prepared to deal with the daily stress.

She doesn't know anything about ME/CFS personally. She's heard of it and believes it's a real disease and sympathizes that not much is known about it; however, this lack of knowledge has resulted in some rather hurtful comments and suggestions.

Whether a therapist was perceived to take initiative in learning about the condition was another subtheme. Some noted in their comments on what was most helpful that their mental health therapists educated themselves on the illness; others commented in what was least helpful that their providers relied on the respondents to educate them or did not seem to seek information outside of the sessions. Learning more about the disease was a common theme in response to what participants recommend that mental health providers do to improve their services for people with ME, CFS, or ME/CFS.

Educate yourself about the disease. Be aware that people can have depression and anxiety along with the disease, and as a result of all the physical and financial challenges of the disease, and to be careful not to minimize how difficult it is to live with invisible illness.

Mental health therapists appear to not keep up to date about current research and remain fixated on outdated and inaccurate paradigms that flow in the direction opposite to the reality of living with ME/CFS. If therapists do not have an accurate working knowledge of the consequences and phenomenology of ME/CFS, then their assistance is superficial and fails to target deeper, more relevant issues in coping with ME/CFS. Indeed, advice given could be detrimental to patients and their families, without the therapist even realizing it.

A list of educational materials that participants mentioned in their comments can be found in Appendix D.

### **Accessibility**

Several participants cited the expense of mental health treatment as the least helpful aspect of therapy and as a barrier. One participant noted that using mental health services can pose a risk of being denied long-term disability from private insurers so that in addition to the cost of services, there is a potential to lose benefits. In addition to prohibitive costs, another theme that emerged from the comments about the least helpful aspects of mental health therapy was lack of accommodations for ME/CFS symptoms. This also came up in response to the question about what participants recommend to improve services for people with ME/CFS. A number of participants commented that it was physically taxing to get to their appointments or that they would have to cancel, which led to treatment being suspended or additional fees. Others noted that when they went to sessions there was difficulty finding parking for people with disabilities; it was challenging to remain upright in a sitting position for long periods, and that the offices had too many lights or chemicals.

Access to the clinic: it was up stairs and in a new building full of chemicals and people wearing perfume. After a few sessions, I SKYPED which was much better.

...just getting to an appointment is often a major task in itself for an ME patient. Sitting for hours under bright artificial lights on hard uncomfortable chairs is tantamount to torture for us.

A common suggestion to providers was to offer alternatives to in-person therapy at the providers' office including home visits, phone sessions or video-conferencing. In response to a multiple-choice question about barriers to accessing therapy also reflected these themes, which are included in the table below along with write-in responses.

Table 6

<b>Barriers to Accessing Therapy</b>		
Exhaustion	n=104	61.5%
Therapist's lack of understanding about condition	n=79	46.7%
Cost	n=67	39.6%
Transportation	n=63	37.3%
Chemical, noise or light sensitivities	n=3	1.8%
Schedule/time of appointments	n=2	1.2%
Child-care	n=2	1.2%
No desired treatment options in area	n=2	1.2%
Risk of losing private disability benefits	n=1	0.6%
Symptoms make it difficult to leave home	n=1	0.6%
No interest in psychotherapy	n=1	0.6%
Finding someone who takes insurance	n=1	0.6%
Parking costs	n=1	0.6%

### **Support Groups**

The survey included some questions focused on the respondents' participation in support groups.

Table 7

<b>Participation in Support Group</b>	
Patient-Led Online Support Group	n= 66 (39%)
Therapist-led Online Support Group	n= 5 (3%)
Patient-led in-person support group	n= 37 (21.9%)
Therapist-led in-person support group	n= 12 (7.1%)
None	n=47 (27.8%)

### **Understanding, Validation and Emotional Support**

Some of the common themes from the comments about support groups were understanding, validation and emotional support that members felt from sharing with people who had similar experiences. Participants commented on both online and in-person support groups that provided these benefits.

The patient support groups have validated symptoms and associated problems. Since I have not met in person someone with my illness, this has been important for my mental health.

Like-minded people, who can relate to symptoms and illness. Some offer ideas and interests for medical therapies which might be relevant. Some need my support which gives me a sense of achievement. Overall, it's a sense of community that I no longer can find elsewhere.

It has been imperative to have the support of other patients with ME/CFS. I know that they understand the emotional and physical pain that is this illness.

I am a board member of our local ME Society and regularly attend the support group. Finding the support group has been a godsend! It is so comforting to know others are going through the same things. The topics covered and coping strategy suggestions from other members have been invaluable. I would be totally lost without it!

### **Practical Advice, Information and Referrals**

Another set of themes from the comments about support groups were practical advice, information and referrals. Several respondents commented on the benefit they received from exchanging knowledge and resources with other members.

I am in an online disease specific support group. IT IS AMAZING. People get it. They understand. They listen and can offer advice or just a shoulder to lean on. I found my ME/CFS specialist through a Facebook group. I asked if there were any and got a list of names. I've learned about ongoing research and advocacy efforts from the online groups. I do not have the ability to go to an in person group. I am homebound for 3 years now [and] 14 years 11 months ill.

I have found a patient group who discuss a range of topics (not just illness) in a positive and humorous way. Having a group of people who really understand the long term effects of chronic illness and who always try to be positive and supportive to each other helps counteract the isolation that results from living in such a different way to other people. This group also reviews treatments they have tried which can be useful if you wish to know more about a particular therapy or medicine.

I participate in a great support group: first is an 8-week class online, then ongoing support group. [It covers] ways to manage your illness from physical, social, emotional and spiritual aspects of life,[and offers] a book and online articles to support, [as well as] weekly discussion with 4 programmed sessions per year, interspersed with group member open discussion periods. This is the CFIDS group.

As most support groups are populated by patients, they at least have a lot more knowledge and understanding of the condition than anyone we are likely to come across in the NHS. You can often gain helpful little tips from other patients about

simple techniques to manage the condition or ways to approach talking about it with others.

## **Negativity**

One common theme from the comments related to what was not helpful about the support groups was perceptions of negativity within the groups; however, some had a more favorable view and seemed to find it cathartic to have a space to vent. Related to this theme, some commented on the value of moderators or facilitators to help manage conflicts and foster more balanced participation.

It is very helpful to connect with other patients and feel like there are others who understand what you are going through and to find out how they are coping and what treatments they are using. It can be not helpful if people with very negative attitudes (angry, hopeless) show up at a support group. Also in person support groups tend to be limited to those few who are well enough to come to the group but not so well that they are off doing other things.

Patient support groups can be a place of understanding and friendship, but can also be a place full of negativity. Most people with ME/CFS are understandably frustrated, lonely and depressed. This can cause an environment of negativity which can in turn make one feel helpless. Groups that are more positive, but also share struggles can be very inspiring and helpful.

It's okay to have a pity party once in awhile but not okay to live there. Don't expect other group members to be able to solve your problems. Let people vent and cry but don't let them monopolize the entire meeting.

I often find that there is a very negative view on negativity. Sometimes people do just need a place to let out negativity and grief and avoiding it isn't helpful. Not that groups should be fully focused on that, but I don't see the harm in occasionally giving it attention because dealing with these complex emotions alone can often make one feel worse.

In the DISCUSSION chapter following, I will discuss the findings and draw some recommendations for mental health practitioners based on themes from the respondents' comments, as well as possible improvements to this study and future research that could be done to expand on this issue.

## **CHAPTER V**

### **Discussion**

#### **Implications for Practice**

The results of this study show how important it is for mental health providers to understand more about ME, CFS, or ME/CFS as some of the symptoms can be easily confused with other conditions. Since many individuals may go undiagnosed, knowledge about this condition is not only relevant for practitioners who are working with someone already diagnosed with the disease. During the psychosocial assessment, it is important to ask about when was the last time the patient visited a doctor and if they have any medical conditions. When making differential diagnoses, mental health providers should be aware of ME/CFS symptoms such as, fatigue, decreased energy, generalized pain, loss of concentration or memory, which could be easily confused with depression or other psychological diagnoses. As the results show, overly attributing ME, CFS or ME/CFS symptoms to psychological factors can lead to patients feeling invalidated, dismissed, or pushed to over-exert themselves. Having diagnostic clarity and understanding the symptoms of ME/CFS is very important in treatment plans. While mental health professionals may have good intentions with recommendations, they could unintentionally be harmful. For example, to recommend increased exercise to individuals may be beneficial to those struggling with depression or stress, but this is counter-indicated for people with ME, CFS, or ME/CFS due to the post-exertional malaise and the potential to exacerbate other symptoms. It

is important to make sure to avoid inadvertent harm by being educated about the condition and following the lead of the patients.

The findings also show the need for more accommodations in mental health therapy for this population such as finding alternatives to in-person sessions at the clinicians' office, such as using phone or video-conferencing or making home visits. This may also require some systemic changes as some health care systems or insurers do not offer these options or provide reimbursement for phone or video sessions. For people with ME, CFS, and ME/CFS who are mobile enough to leave their homes, mental health professions can make accommodations to improve accessibility at their offices. For example, some recommendations that the participants mentioned are reducing chemicals and fragrances, dimming lights, having chairs or couches that patients can lay down on, and sufficient parking for people with disabilities near the office.

Furthermore, the findings show that patients have differing views on what they would or would not like from individual and group therapy and that it is important for mental health providers to assess the individual needs of their client. For example, while grief, acceptance, and creating new purpose were common themes that emerged from what was most helpful, others seemed to feel that this approach would be resigning themselves to the condition and it turned them off to therapy. Some expressed a desire for less focus on adjusting to the disease or the psychological issues related to ME, CFS, or ME/CFS and a greater focus on finding treatments for the organic disease. Another example of meeting clients where they are in the process relates to group therapy. While some may wish for a cathartic space to express feelings of anger, sadness or frustration, some respondents commented they found this unproductive. Group facilitators may wish to explore ways to find a balance between expressing difficult emotions

and other issues that participants reported as helpful from groups, such as practical advice, coping skills and relationship building.

Mental health clinicians could also be engaged in macro work to not only treat their individual clients struggling with a chronic illness with no known cure, but also support advocacy efforts to increase funding for treatment research. Research on the causes and potential cures for the disease is crucial and has been historically underfunded. In addition, mental health providers could play an advocate role with their patients in health care systems. Some respondents commented on how their mental health providers helped them advocate for their own needs or provided documentation to help clarify that their condition was not psychosomatic in order to help patients access treatment or disability benefits.

### **Study Limitations**

There were several limitations to this study and some threats to validity that could be improved upon in future research. One of the limitations of this study was the homogeneity of the gender and race of the participants. Of those who reported their demographic information, the overwhelming majority identified as female and White or Caucasian. This reflects a trend in research on ME, CFS, or ME/CFS that draws from tertiary health care or self-identification rather than community-based samples. A broader community-based sample could provide a more representative sample of the population living with ME, CFS, or ME/CFS-- particularly as other research has shown that the disease may actually be more common among Black or Latino populations in the U.S. (Jason, Plioplys, Torres-Harding & Corradi, 2003; Reyes et al., 2003). It is possible that the themes that emerged from this study may be similar in a more diverse sample, but it may be other issues, barriers or preferences are important among other individuals that were not captured in the current study.



Another limitation of the study was that participants self-identified as having ME, CFS, or ME/CFS. Self-reporting can pose a threat to validity because it is possible that the responses may have included individuals who do not meet diagnostic criteria for ME, CFS or ME/CFS. While there has been progress in reaching consensus about diagnostic criteria in the medical community, a challenge in research on ME, CFS, and ME/CFS has been that researchers may be using different definitions of the disease as well as instruments based on different criteria. The IOM (2015) has recommended:

The development of clinical questionnaire or history tools that are valid across populations of patients and readily usable in the clinical environment should be an urgent priority (p.9).

As tools increasingly become more standardized, this will help improve research such as this study.

An additional threat to validity for the data from the quantitative questions about mental health providers is that the design did not allow participants to rate different clinicians separately. This was an oversight and perhaps an assumption on my part when creating the study that most participants would not have been to more than one provider since developing ME, CFS, or ME/CFS due to high rates of attrition from therapy among the general population along with the additional challenges for people living with this condition.

### **Future Research**

While much of the research on mental health treatment for people with ME, CFS, or ME/CFS has focused on CBT or GET interventions to change beliefs about illness and increase activity, findings from this study reflect that patients find other interventions to be more helpful that address dealing with the emotional difficulties of living with a debilitating chronic illness. In fact, being encouraged to increase activity had a negative correlation with level of satisfaction with therapy and the negative impact of over-exertion appeared as a theme in the

written responses. It may be beneficial for future research on therapeutic approaches or models with people who have ME, CFS, or ME/CFS that focus more on grief related to chronic illness, adjusting to life changes, and finding manageable coping skills.

## **Conclusion**

Overall the findings show that mental health providers working with people living with ME, CFS, or ME/CFS need to take a client-centered approach that looks at the individual goals, preferences, and physical condition of the patient. Seeking to understand the disease and how it personally impacts the patient and their support networks is essential for treatment planning, building rapport, and making necessary accommodations. As more research has emerged about the flaws in research claiming significant reduction of symptoms through manualized behavioral health treatment, as well as research on the biological nature of the disease, the way that mental health providers approach ME, CFS, and ME/CFS needs to be updated. While patients hope that someday researchers will find biomarkers and effective medical treatments for the disease, this should not be a prerequisite for mental health practitioners to recognize that people with ME/CFS are living with a poorly understood organic illness.

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## Appendix A: Human Subjects Review Board Approval Letters



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**School for Social Work**  
Smith College  
Northampton, Massachusetts 01063

November 16, 2016

Brooke Denmark

Dear Brooke,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

*Please note the following requirements:*

**Consent Forms:** All subjects should be given a copy of the consent form.

**Maintaining Data:** You must retain all data and other documents for at least three (3) years past completion of the research activity.

*In addition, these requirements may also be applicable:*

**Amendments:** If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

**Renewal:** You are required to apply for renewal of approval every year for as long as the study is active.

**Completion:** You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Congratulations and our best wishes on your interesting study.

Sincerely,

A handwritten signature in black ink, appearing to read 'Elaine Kersten'.

Elaine Kersten, Ed.D.  
Co-Chair, Human Subjects Review Committee

CC: Gael McCarthy, Research Advisor



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School for Social Work  
Smith College  
Northampton, Massachusetts 01063  
T (413) 585-7950 F (413) 585-7994

January 10, 2017

Brooke Denmark

Dear Brooke:

I have reviewed your amendments and they look fine. The amendments to your study are therefore approved. Thank you and best of luck with your project.

Sincerely,

A handwritten signature in cursive script, appearing to read 'Elaine Kersten'.

Elaine Kersten, Ed.D.  
Co-Chair, Human Subjects Review Committee

CC: Gael McCarthy, Research Advisor



## **Appendix B: Informed Consent**

Please read this form and ask any questions that you may have before agreeing to be in the study.

### **Introduction**

You are being asked to be in a research study of how individuals with Myalgic Encephalomyelitis, Chronic Fatigue Syndrome or ME/CFS feel about mental health treatment. Any person over the age of 18 who has ME, CFS or ME/CFS and is able to respond to an English language survey is invited to participate in the study. You have indicated that you meet these criteria. I ask that you read this form and ask any questions that you may have before agreeing to be in the study. If you agree to participate, you will then be directed to the rest of the survey.

### **Purpose of Study**

The purpose of the study is to improve mental health services for people living with ME, CFS, or ME/CFS and to ensure that mental health providers are not causing more harm through treatment.

This study is being conducted as a research requirement for my master's degree in social work thesis project for Smith College School for Social Work.

Ultimately, this research may be published or presented at professional conferences.

### **Description of the Study Procedures**

If you agree to be in this study, you will be asked to do the following things: Fill out an anonymous, online survey that should take between 20-30 minutes in total depending on how much you decide to comment. If needed, you can pause and take a break to return to the questions at a later time. You may exit the survey and your responses will be saved for up to one month for you to complete at your convenience. You can simply return to the survey link from the same computer. Once you have submitted your responses, you will not be able to go back and make any changes.

### **Risks/Discomforts of Being in this Study**

There are no expected risks, though some participants may experience distress if describing experiences that were not helpful. In the event some might wish it, there is a list of support groups and counseling service resources offered at the end of the survey.

### **Benefits of Being in the Study**

The benefits of participation are having an opportunity to share your opinions about mental health treatment for people living with ME, CFS, or ME/CFS.

The benefits to social work/society are: gaining a better understanding about how to best support people with ME/CFS and how to ensure that practitioners are living up to the primary ethical requirement to do no harm.

**Confidentiality**

This study is anonymous. I will not be collecting or retaining any information about your identity.

**Payments/gift**

I am unable to offer any financial payment for your participation.

**Right to Refuse or Withdraw**

The decision to participate in this study is entirely up to you. You may refuse to answer any question or withdraw from the study at any time before submitting your responses to the survey without affecting your relationship with myself as the researcher of this study or Smith College.

Your decision to refuse will not result in any loss of benefits (including access to services) to which you are otherwise entitled. As this is an anonymous survey, simply exit at any point by clicking on 'escape' at the top of the screen if you wish to do so. Answers to questions prior to exiting will remain in the survey up to that point, but I will have no way to know who you are, and the survey will be discarded as I will not use incomplete surveys in my study.

**Right to Ask Questions and Report Concerns**

You have the right to ask questions about this research study and to have those questions answered by me before, during or after the research. If you have any further questions about the study, at any time feel free to contact me, Brooke Denmark at bdenmark@smith.edu. If you would like a summary of the study results, an Abstract will be available online through the Smith College's Neilson Library once the study is completed in summer 2017. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

**Consent**

By clicking "Agree" and entering the survey below you indicate that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above. I encourage you to print and keep a dated copy of this form for your own files to keep.

I have read the information above and I am volunteering to participate.

- Agree
- Disagree

If Disagree Is Selected, Then Skip To End of Survey

## Appendix C: Survey Questions

Q5 How many years have you had ME, CFS, or ME/CFS?

- Less than 1 year
- 1-3 years
- 4-6 years
- 7-10 years
- 11-15 years
- Over 15 years

Q6 Since you have developed ME, CFS, or ME/CFS, have you ever spoken to a mental health therapist?

- Yes
- No

If No Is Selected, Then Skip To What would you recommend to mental he...

Q7 About how many sessions did you have with your therapist or therapists since you have had ME, CFS, or ME/CFS?

- 0-3
- 4-10
- 11-20
- Over 20

Q8 On a scale of 1-7, how satisfied were you with your therapy in general? 1 being extremely dissatisfied and 7 being extremely satisfied.

- 1
- 2
- 3
- 4
- 5
- 6
- 7

Q9 On a scale of 1-7, how knowledgeable was your therapist about ME, CFS, and/or ME/CFS as a disease? 1 being no knowledge at all and 7 being very knowledgeable.

- 1
- 2
- 3
- 4
- 5
- 6
- 7

Q10 What did you find most helpful about your sessions with your therapist or therapists?

Q11 What did you find the least helpful about your sessions with your therapist?

Q12 How often did your therapist do the following?

	Never	Very Rarely	Rarely	Occasionally	Frequently	Very Frequently
Validated me and was understanding about my condition.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Encouraged me to change my thinking about my illness and to believe that I am healthy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helped me adjust to the changes in my life due to my illness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worked with me to set goals that I felt were attainable in order to work towards what I wanted.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Encouraged me to increase my activity.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Involved my partner and/or family in sessions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Empowered me to advocate for myself and	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

my needs.						
Incorporated art such as drawing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taught me coping skills that I felt able to do with my condition.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helped me to use meditation, breathing, or mindfulness as a coping tool.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helped me grieve losses or changes in my life due to my illness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Explored spirituality and/or sources of meaning and purpose.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q13 Please comment about anything you would like to add about what you did in therapy or your therapist's approach.

Q14 Please click and drag the items to the box that best matches your opinion. Select up to 3 for each box.

- \_\_\_\_\_ Validated me and was understanding about my condition.
- \_\_\_\_\_ Encouraged me to change my thinking about my illness and to believe that I am healthy.
- \_\_\_\_\_ Helped me adjust to the changes in my life due to my illness.
- \_\_\_\_\_ Worked with me to set goals that I felt were attainable in order to work towards what I wanted.
- \_\_\_\_\_ Encouraged me to increase my activity.
- \_\_\_\_\_ Involved my partner and/or family in sessions.
- \_\_\_\_\_ Empowered me to advocate for myself and my needs.
- \_\_\_\_\_ Incorporated art such as drawing.

- \_\_\_\_\_ Taught me coping skills that I felt able to do with my condition.
- \_\_\_\_\_ Helped me to use meditation, breathing, or mindfulness as a coping tool.
- \_\_\_\_\_ Helped me grieve losses or changes in my life due to my illness.
- \_\_\_\_\_ Explored spirituality and/or sources of meaning and purpose.

\_\_\_\_\_ Other (Please specify)

Least Helpful	Most Helpful

Q15 What would you recommend to mental health therapists to improve their treatment and support of people with ME, CFS, or ME/CFS?

Q16 Please select any and all barriers that you experienced in accessing therapy, especially which ones were most difficult to overcome.

- Transportation
- Exhaustion
- Cost of therapy
- Therapist's lack of understanding about my condition
- Other (Please specify) \_\_\_\_\_
- None

Q17 Please comment about any barriers that you faced in accessing therapy.

Q18 If therapy could help you, but there were barriers such as transportation or physical difficulties in accessing the treatment, would having an online/internet method of treatment help you?

- Yes
- Maybe
- No

Q19 Please select all that you have participated in related to ME, CFS, or ME/CFS.

- Patient-led online support group
- Therapist-led online support group
- Patient-led in-person support group
- Therapist-led in-person support group
- None

If None Is Selected, Then Skip To Please describe any suggestions you h...

Q20 Please comment if you wish about what you found helpful or not helpful about any support groups that you have participated in.

Q21 Please describe any suggestions you have for solutions to increase your access to treatment that you find helpful.

Q3 How did you receive your diagnosis of ME, CFS, or ME/CFS? Please select all that apply.

- Primary care physician/general practitioner
- Medical specialist
- Self-diagnosis eg: through research I did on my own
- Other (please specify) \_\_\_\_\_

Q22 Please mark what percentage of the time in the past six months each statement has been true. The total for all combined must equal 100%.

\_\_\_\_\_ I am able to do about half of what I was able to do before I developed ME, CFS, or ME/CFS in terms of work, social, personal or educational activities.

\_\_\_\_\_ I am homebound but able to get out of my bed.

\_\_\_\_\_ I spend most of my days in bed.

\_\_\_\_\_ I spend most of my days bedbound and I need help from others for daily physical functions.

\_\_\_\_\_ Other (please specify)

Q64 Please select the best response that describes how you have felt in the past 6 months.

	Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
I have felt fatigue that is not a result of excessive exertion or another known medical condition. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My fatigue or exhaustion does not improve after rest.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

(2) Activities that I used to do before I started feeling sick now wear me out. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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Q67 Please select the best response that describes how you have felt in the past 6 months.

	Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
My symptoms worsen after physical, emotional or cognitive activity.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel like I crash or collapse after exertion and it can take days, weeks or months to recover.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

66 Please select the best response that describes how you have felt in the past 6 months.

	Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
I have unrefreshing sleep, meaning I wake up feeling tired	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



no matter how long I have slept. I have sleep disturbances such as insomnia, waking up frequently or needing prolonged naps.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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Q65 Please select the best response that describes how you have felt in the past 6 months.

	Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
My symptoms worsen after being upright and improve when lying back down.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel lightheaded or dizzy when I sit or stand for long periods of time.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q68 Please select the best response that describes how you have felt in the past 6 months.

	Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
I have had short-term memory loss.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have difficulty concentrating.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have difficulty processing information.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q70 Please select the best response that describes how you have felt in the past 6 months.

	Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
I have had chronic headaches and/or migraines.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have had significant pain.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q71 Please select the best response that describes how you have felt in the past 6 months.

	Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
I have had flu-like symptoms.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have had gastrointestinal issues such as nausea, irritable bowel syndrome, or bloating.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I have sensitivities to foods, smells, chemicals and/or medications.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have experienced urinary urgency or frequency.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have been susceptible to viruses.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q69 Please select the best response that describes how you have felt in the past 6 months.

	Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
I have been unable to tolerate extreme temperatures.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have had cardiovascular symptoms such as heart palpitations or dizziness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have had difficulty breathing not related to other medical conditions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have felt feverish, had fluctuations in my body temperature, or had cold extremities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q72 Please select the best response that describes how you have felt in the past 6 months.

	Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
I am sensitive to light, noise, or other sensory stimulation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I experience muscle weakness, twitching, poor coordination or feel unsteady on my feet.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q24 Please add any comments that you wish about your symptoms.

Q25 This information is requested only so that I may accurately describe the survey's participants. The information is encrypted it is not possible to connect to your IP address or other identifying information. Please select all that apply. How do you identify your gender?

- Male
- Female
- Genderqueer or gender non-conforming
- Transgender male
- Transgender female
- Trans
- Other (please specify)
- Prefer not to answer

Q26 How do you identify your race/ethnicity?

Q27 Please select the country where you live. (Drop down list of countries and territories)

Q28 What is your age range?

- 18-25
- 26-33
- 34-41
- 42-49
- 50-58
- 59-66
- 67-74
- 75-82
- 83-90
- 91-98
- Over 98
- Prefer not to answer

Q29 Please comment, if you wish, about how you feel that any parts of your identity have impacted your mental health treatment. For example, you may include ways in which you have experienced forms of oppression such as racism or sexism related to your ME, CFS, or ME/CFS treatment.

Q30 Please click the red arrow below in order to submit your responses. Before doing so, you may review your responses by using the back arrow if you wish.

If you wish, please feel free to write anything that you wish I had asked and/or any comments about the survey.

Q31 If you are experiencing emotional distress, you may reach out to one of these resources for assistance.

Crisis services in the United States:

-National Suicide Prevention Lifeline: Call 1.800.273.8255

-Lifeline Crisis Chat: Go online at <http://www.crisischat.org/chat>

-Crisis Text Line: Text 741741 for a crisis counselor to respond to you via text. For more information visit: <http://www.crisistextline.org/faq/>

You may also call the Substance Abuse and Mental Health Administration's help line for referrals to local services: 1-800-662-HELP (4357).

For a list of international crisis resources please

visit: <http://unsuicide.wikispaces.com/Online+Suicide+Help#.V8dc1JgrK00>

## Appendix D: Participant Recommendations for Educational Materials about ME/CFS

This list is a compilation of materials that participants referenced in their responses as educational resources they would recommend to mental health practitioners. Since this was not a specific question in the survey, it does not reflect an exhaustive list.

### Documentaries and Videos

- Prior, R. & Castillo & N. (Directors). (2015). *Forgotten Plague: ME and the future of medicine*. [Documentary film]. United States: Blue Ribbon Foundation.
- Biggs, J. & Boulton, N. (Directors). (2011). *Voices from the Shadows*. [Documentary film] Retrieved from: <http://voicesfromtheshadowsfilm.co.uk/>
- Brea, J. (Director) (2017). *Unrest*. [Documentary film]. United States: Shella Films.
- Brea, J. (2016, June). *Jennifer Brea: What happens when you have a disease doctors can't diagnose*. [Video file]. Retrieved from: [https://www.ted.com/talks/jen\\_brea\\_what\\_happens\\_when\\_you\\_have\\_a\\_disease\\_doctors\\_can\\_t\\_diagnose](https://www.ted.com/talks/jen_brea_what_happens_when_you_have_a_disease_doctors_can_t_diagnose)

### Reports

- IOM (Institute of Medicine). (2015). *Beyond myalgic encephalomyelitis/chronic fatigue syndrome: Redefining an illness*. Washington, DC: The National Academies Press.
- International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis. (2014). *Chronic fatigue syndrome myalgic encephalomyelitis primer for clinical practitioners 2014 edition*. Retrieved from: [http://iacfsme.org/portals/0/pdf/Primer\\_Post\\_2014\\_conference.pdf](http://iacfsme.org/portals/0/pdf/Primer_Post_2014_conference.pdf)
- Carruthers, B., van de Sande, M., De Meirleir, K., Klimas, N., Broderick, G., Mitchell, T...Stevens, S. (2011). Myalgic encephalomyelitis: International consensus criteria. *Journal of Internal Medicine*, 270, 327-338. doi: 10.1111/j.1365-2796.2011.02428.x

### ME/CFS Specialists' Online Resources

- *CFIDS & Fibromyalgia Self-Help*. <http://www.cfidsselfhelp.org>
- *Bateman Horne Center*. <https://batemanhornecenter.org>
- *Hunter-Hopkins Center, P.A.* <http://drlapp.com/>

