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## A Qualitative Natural History Study of ME/CFS in the Community

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### Abstract

In previous qualitative research on Myalgic Encephalomyelitis/chronic fatigue syndrome (ME/CFS), researchers have focused on the experiences of patients with ME/CFS in tertiary care samples, which limit the representativeness of the findings to those with access to health care. This qualitative study examined the natural history of a community-based sample of people with ME/CFS. Participants (n=19) were categorized into persisting, incidence, or remitting groups based on their reported illness status across a ten year period. Findings highlighted multilayered themes involving the illness experience embedded in multiple systems and the physical construction of ME/CFS. In addition, this study further illuminated unique subthemes regarding community response and treatment, which have implications for understanding the progression of ME/CFS as well as experiences of those within patient networks. There is a need for more longitudinal qualitative research on epidemiological samples of patients with ME/CFS.

### Keywords

illness and disease; chronic fatigue syndrome; qualitative; epidemiology; community and public health; longitudinal

### Introduction

Myalgic Encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a complex medical condition that impacts multiple systems within the body. Previously, researchers have recruited participants for qualitative studies through tertiary care settings. The sample of participants in this study was recruited through a larger epidemiological study of ME/CFS. To date, this is study to utilize a community-based sample in a qualitative investigation of ME/CFS. In this study we analyzed in-depth interviews of 19 people with ME/CFS. Findings exposed the physical construction of the illness as well as the community and health care systems response to people coping with this illness.

Myalgic Encephalomyelitis/chronic fatigue syndrome (ME/CFS) is an extremely debilitating illness, with patients being more functionally impaired than those suffering from type II

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diabetes mellitus, congestive heart failure, multiple sclerosis, and end-stage renal disease (Anderson & Ferrans, 1997; Buchwald, Pearlman, Umali, Schmaling, & Katon, 1996). In spite of this, many studies indicate that patients with this illness have experienced disrespectful treatment by the health care system. For example, Anderson and Ferrans (1997) found that 77 percent of individuals with ME/CFS reported negative experiences with health care providers. Green, Romei, and Natelson (1999) reported that 95 percent of individuals seeking medical treatment for ME/CFS reported feelings of estrangement. It is clear that some medical professionals do not consider ME/CFS to be a legitimate illness (Barsky & Borus, 1999). Dumit (2006) explored the ways in which historically contested illnesses (e.g., ME/CFS, Fibromyalgia, Multiple Chemical Sensitivity) are dismissed or denied at an institutional level when facts, definitions, and illness categories are uncertain. Qualitative studies provide a lens to better understand these high levels of dissatisfaction that people with ME/CFS feel towards the traditional health care system.

Anderson, Jason, Hlavaty, Porter, & Cudia (2011) reviewed thirty-five (35) qualitative studies on ME/CFS and they found three substantive thematic areas concerning: (1) experiences of people with ME/CFS, (2) experiences of physicians, and (3) themes that intersect both of these groups. Findings from this review addressed the different ways in which individuals with ME/CFS as well as those involved in their lives experience and understand the illness. In particular, in previous qualitative studies on ME/CFS, researchers have often focused on the identity and coping experiences of people with ME/CFS and the ideologies of physicians (Hart & Grace, 2000; Larun & Malterud, 2007; Whitehead, 2006b).

Previous studies identified that many patients with ME/CFS feel that their illness is often not acknowledged as legitimate within social and medical settings (Gilje, Soderlund, & Malterud, 2008), and many patients with ME/CFS experience marginalization from family, friends, and healthcare professionals (Donalek, 2009; Whitehead, 2006b). Qualitative research has found transformation in identity among people with ME/CFS often as a result of the illness (Donalek, 2009; Tuck & Wallace, 2000; Whitehead, 2006a). The stigmatization as well as social and physical reductions associated with ME/CFS influence how patients perceive and reaction to this illness. In turn, this overall lack of support and acceptance of ME/CFS as a physical illness has created barriers for treatment (Raine, Carter, Sensky, & Black, 2004).

Almost exclusively, participants with ME/CFS were recruited from medical or tertiary care settings in previous qualitative studies. To date, there are no published qualitative studies that examined the experiences of people with ME/CFS recruited through an epidemiological sample. Thus, there is a need for more community-based studies of patients with ME/CFS, which can provide us with the experiences of more representative samples of patients. As well, there is a need to understand the experiences of patients over longer periods of time. Natural history studies, or longitudinal cohort studies, are one way in which researchers can understand the illness with more socioeconomically and ethnically diverse samples (Jason et al., 2009). In the present natural history study, qualitative methods were used to explore a community-based sample of participants who either had ME/CFS over a 10 year period of time (“persisting”), participants who developed ME/CFS (“incidence”), and participants with a previous ME/CFS diagnosis (“remitting”).

## Method

### Participants

Participants (n=19) in this sample were derived from a larger community-based epidemiology study that monitored participants for a ten-year span (Jason et al., 1999). We attempted to re-contact 213 adults who were medically and psychiatrically evaluated from 1995 to 1997 (referred to as Wave 1). These adults were previously evaluated in our original Wave 1 ME/CFS community-based epidemiology project (Jason et al., 1999). Individuals successfully contacted at the ten-year follow-up, referred to as Wave 2, were provided a structured psychiatric assessment and a complete physical examination and a structured medical history (see Jason et al., 2011 for details on the quantitative portion of this study). Patients were classified with the Fukuda et al. (1994) case definition criteria.

The original Wave 1 sample was a stratified random sample of several neighborhoods in Chicago specifically selected to contain individuals from different ethnic and socioeconomic profiles. As a whole, Chicago, Illinois is an ethnically and socioeconomically diverse city (Jason et al., 1999 for more details). In the original Wave 1 study, procedures developed by Kish (1965) were used to select one adult from each household for subsequent screening for ME/CFS-like illness. The *CFS Screening Questionnaire* was administered to all participants. The questionnaire assessed participants' sociodemographic characteristics and fatigue characteristics to determine whether any changes occurred since Wave 1 of data collection. Structured psychiatric interviews, full medical examinations, a range of self-report surveys, as well as in-depth interviews with participants either in person or over the phone were obtained at the 10 year follow-up. Participants were reimbursed \$100.00 for the time and effort involved in participation and provided informed consent. All portions of this study were approved by the authors' IRB. Refer to Jason et al. (1999) and Jason et al. (2011) for more details about the parent epidemiological studies in which participants were recruited.

### Diagnosing ME/CFS

At the end of Wave 1 and Wave 2, a team of physicians was responsible for making final diagnoses. Two physicians independently rated each file according to the current U.S. definition of ME/CFS, Idiopathic Chronic Fatigue (ICF), Exclusionary for ME/CFS due to medically/psychiatrically explained chronic fatigue (Fukuda et al., 1994), or Control (participants with no exclusionary illness and less than 6 months of fatigue). Reviewing physicians had access to all information gathered on each participant during each of the phases of the study. The review panel was also provided with all results from the physical exam. If a disagreement occurred regarding whether a participant should receive a diagnosis of ME/CFS, Idiopathic Chronic Fatigue, Exclusionary due to medically/psychiatrically explained chronic fatigue, or controls during the physician review process, the participant's file was rated by a third physician reviewer, and the diagnosis was determined by majority rule. We used refinements of the Fukuda et al. (1994) criteria as recommended by an International Research group and the CDC (Reeves et al., 2003). For example, morbid obesity is exclusionary as it could cause severe fatigue, but the Body Mass Index cut off has been changed to 40 or higher. In addition, a lifetime history of major depressive disorder

with melancholic, anorexia nervosa, or bulimia is now not exclusionary if these conditions resolved more than 5 years before the onset of the current chronically fatiguing illness.

We did not collect qualitative data for all 105 Wave 2 participants, and we needed to be somewhat selective in how many participants to bring into this qualitative study, which tends to more intensively study fewer participants than quantitative studies. Participants for this qualitative study were classified into three groups, persisting (n=12), incidence (n=6) and remitting (n=1), depending on their illness status across the ten year study. Those that were labeled as persisting across the studies were found to have ME/CFS at both Wave 1 and Wave 2, signifying that they had ME/CFS across the 10 years of the study. Of the incidence cases, at Wave 1, five were classified as ICF, one Exclusion, and one Control, whereas in Wave 2 all of the cases were diagnosed with ME/CFS. Each of the incidence cases identified a slowly progressing onset via self-report. Conversely, the one remit case was classified as ME/CFS at Wave 1 and then ICF at Wave 2, showing significant improvement but not full recovery across the ten year span. Table 1 outlines the health status of each participant.

Of the 19 participants in the present qualitative study, 84.2 percent were female (n=16) and 15.8 percent were male (n=3) and the average age of participants was 51 (SD=11). The ethnicity of the sample varied, such that there were 42.1 percent White, 31.6 percent Hispanic or Latino, 15.8 percent African American, and 10.5 percent Asian or Pacific Islander participants. All of the names presented throughout the manuscript are pseudonyms in order to protect participant confidentiality.

## Procedure

The qualitative interviews were conducted at Wave 2, which occurred following the medical examination, were conducted by members of the research team who were trained in basics of qualitative methods and effective interviewing techniques. Participants had the option of being interviewed in Spanish or English and also had the option of conducting the interview in person or via telephone. In the interviews, participants provided retrospective insight to their experiences with ME/CFS over the last 10 years with questions concerning major life changes, stressful periods of time, daily life hassles, relaxation strategies, social support, physical health and changes in physical health, employment, and treatment.

## Data Analysis

All of the interviews were transcribed verbatim, and the two interviews that were conducted in Spanish were transcribed and translated into English by a bilingual member of the research team. Next, the coding system was developed through a grounded theory framework in order to focus on the context-dependent and structural processes within the data (Glaser & Strauss, 1967; Strauss & Corbin, 1990). For grounded theory to be applied, multiple readings of the transcripts were conducted to identify and compare emerging themes throughout the interviews (Glaser & Strauss, 1967; Strauss & Corbin, 1990). A mixture of emergent themes as well as themes directly related to the research questions was identified. Given that many of the findings were closely mapped onto the some of the interview questions, a constant comparison method was utilized for a secondary analysis of the transcripts and original codes. Constant comparison theory involves identifying

commonalities among perspectives and themes followed by a cross-analysis of findings (Patton, 1990). NVivo 8 was also utilized in the preliminary data analysis stages for organizing transcripts and analyses. Based on the final coding system, two independent coders checked the reliability of the coding scheme with randomly selected portions of the transcripts and came to a 95 percent agreement.

The authors took on an explicit constructivist, feminist approach to data analysis by paying close attention to both the gendered responses and the social construction of the illness. This is particularly important for this population, given the historical context of the treatment of women with ME/CFS (Richman & Jason, 2001). Themes were also coded across categories and are not necessarily mutually exclusive. For example, one participant describing how her memory and concentration problems affected her work status which may subsequently effect the relocation of the family, causing a disruption in the family system which then may exacerbate other symptoms. Thus, one code may also contribute to other codes and corresponding themes.

## Results

The purpose of this study was to examine the natural history of people with ME/CFS and the events occurring over time that may contribute to the course and progression of the illness. The results are categorized into three major thematic groups. These groups include (1) understanding the contextual factors and systems in which the illness is experienced, (2) the physical construction of the illness, and (3) coping mechanisms and illness management techniques. Table 2 illustrates the percentage of cases exemplifying themes across the different illness status groups. In addition, these domains and themes are not mutually exclusive; rather, there is interplay among these thematic groups. For example, a participant may describe how the death of a family member affected him or her on both levels of a loss of support system and subsequent health changes from the stress of the death. Therefore these categories should not be thought of as independent or dichotomous, but rather as multilevel, mutually reinforcing categories. Table 2 includes summaries of each theme as well as frequency of themes across participant groups.

### Illness Experience Embedded in Multiple Systems

A pattern within the participants' responses indicated that the ME/CFS illness experience cannot be teased apart into simple groups, rather these themes work in tandem. This categorization includes changes with family systems, identity, occupational shifts, reductions across various domains, and the larger community response to ME/CFS. Finally, it should be noted that stress, in general, has been implicated in the course of many health conditions and, in particular, chronic health conditions, including ME/CFS (Clements, Sharpe, Simkin, Borrill, & Hawton, 1997; Donalek, 2009; Lovell, 1999). Stress is interwoven in many of these categories and themes as it has been either implicitly or explicitly implicated in the participants' responses.

**Family System Changes**—Themes that fall under the code of family system changes comprise the discussion of changes including additions to the family, death and bereavement, shifting into the role of a caretaker, and general family stressors that have

affected the health of the participant. Almost all participants mentioned a theme within this category. Death within the family was a common theme among the participants. Leslie described becoming widowed a year after getting married and the stress during that period of time worsened her health condition:

Getting married, it's a stress. [His death] added depression, sadness. You want to stay inside, you don't want to go out, don't want to be social. Just weakness, tiredness, you know. My health was ignored. I didn't pay attention to it [for] about six months after the death. It just increased [my fatigue]; I was more tired, weaker, and just real fatigued.

Similarly, a participant in the incidence group, Mitchell, shared that the murder of his nephew affected him and the family system:

[A gang] killed my nephew. But I don't have his information. [It happened] like four years ago. It was very emotional, it affected all of the family, because he was 16 years and it was his birthday.

Another common theme in this category among many participants was having the responsibility of being a caretaker for someone. For example, Brittany discussed the toll of taking care of her brother with schizophrenia and how his death provided relief and a shift to focus on self-care:

My brother died which was actually, eliminated a lot of stress for me. [...] I think the chronic fatigue got really bad from the stress of him hospitalized because basically my husband and I were in charge. My mother was like, now she's 87 so, you know, there was no one to take care of him. Constantly hospitalizing him, finding him an apartment and I'm what's called the secretary of the family. I'm the one that makes everything happen. I'm the doer, not the talker. So that was really tough, but it's been a lot easier, it's just much more at ease and relaxed [...] it was another alleviation of stress, yeah, but other than that I've got enough energy now that I started doing my own artwork; I had two shows last year of my work, that I can work at my own pace. So I worked maybe three, maybe four hours a day and rested in the afternoon, maybe do something in the evening, maybe not. It's kinda nice.

As well, Jennifer discussed the experience of being sick while taking care of her ex-husband in addition to working:

A big change came again when I had to move in 1998 in the end of the year from Chicago to the suburbs to take care of my ex-husband who was ill, who had heart problems, had open heart surgery [...] I was working full-time, so the stress of work and caring for him at night because during the day I hire some people who come in and give him his breakfast and his medication [...] at night if he needed anything I had to be up, so it was very stressful. Those were big changes [...] He will call, I will wake up. I'm a very light sleeper, so I can wake up with anything. But that was stressful, very stressful, yes, and then of course I had a lot of stress at work.

These types of family system could serve as a contributor to the onset of the condition or the exacerbation of symptoms by adding to the physical turmoil their body is already experiencing.

**Identity**—As a psychological construct, identity is defined as a person’s self-image and self-esteem and how an individual views himself or herself in relation to others (Gray & Fossey, 2003). This theme includes references to disruption in lifestyle and adjustment to ME/CFS in the context of making meaning of their personal experiences. Issues with identity and the reconstruction of identity because of ME/CFS were brought up less frequently than in previous studies (Anderson & Ferrans, 1997; Tuck & Wallace, 2000; Whitehead, 2006a; Woodward, Broom, & Legge, 1995); however, this theme was slightly more common among the participants in the persisting subgroup, with three out of 12 mentioning this theme. Only one person in the incidence group referenced changes within or reconstruction of identity based upon the development of ME/CFS. For example, Jennifer explained the shift in identity as it connected to her work and family life:

A full year did not feel like, I could not realize the fact that I had no place to go. Nothing to do. You don’t have an identity. I’m no longer the mother that was needed a long time ago, I’m no longer any wife, which I never like anyway, but still, I had a title. I had a title at the office, I had things to do at the office. I had things to do with people, with work, and I was busy. I was doing something. Suddenly, I’m doing nothing and I am nothing because you feel like your identity is gone.

One of the persisting participants, Noah, described the difficulty of teasing apart his experience of coming out, coping with chronic illness, and the integration of, and changes to, his individual, familial, and professional identity:

Just coming to terms with who I am and I guess kind of bringing together two halves of my life so to speak, you know, the personal sexual side and the professional, family. Not having that wall between the two that I have to maintain between the two and stay in the closet. Although it was also coming more. It was also coming more to riffs cause it was a period of time when I wasn’t sure if I was gay or not and what was going on [...] I don’t know if there’s a relation. I really don’t, I don’t know if there’s a relation necessarily between the whole. Emotionally, [I am] great, phenomenal [...] I’ve flowered, but yeah it’s just like a ton of bricks have come off me, but as far as the physical health aspects, I don’t know.

**Occupational Shifts**—Every participant mentioned occupational shifts, which include reductions in work or change in work status because of health. This theme also includes changes in community, obtaining disability income, and references to financial stress due to ME/CFS. Natalie, a persisting case, discussed a period of time in which she was unable to work because of her health:

It was actually pretty nice. It was nice because, I had a live-in, I had a babysitter at the same time so, but it, during that time was when we were getting ready to move

so I was packing and doing stuff but I was able to do it at kind of my own pace. So it was nice, as far as dealing with the chronic fatigue, it helped. I had it good back then.

While one participant described how cutting down on work hours helped cope with intense physical symptoms:

Less hours helped me a little to recuperate, a little to have left the job right because I work but yes I have felt, I told you, I'm not good but it helps me a little to leave the job because when I was working it was a thing that I was painful in my arms and everything. It has calmed a little [of] the pain.

Another consistent pattern among participants was the discussion on the difficulty of obtaining disability due to the contested nature of ME/CFS. Participants in the persisting group discussed disability more frequently than those in the incidence group. Shannon described applying for disability multiple times and the negative treatment she received:

It took a couple years to get it. I was denied on paper so I had to go before a judge and then I got it [...] all they would do is send a letter saying we are denying, you are not receiving disability at this time. Then they would list jobs that you may be able to perform, like taking tickets at a movie theater.

Shannon's experiences highlight how key stakeholders in the community minimized the seriousness of the illness. In addition to Shannon's experience, Brittany started receiving disability about five years prior to her interview and described how her life is not as consumed by her ME/CFS and that disability income helped her cope with limiting her work activity:

I'm on disability, SSI. I'm physically unable [to work], just too, too tired. [Not working] makes it easier. I mean I just can't handle. Before I had no life and now I feel like I have a life. I have a social life and I have a sort of physical in terms of I can exercise where before when I was working I could barely make it to work from home, just go to sleep. There was nothing else I could do.

Many participants described the financial burden that ME/CFS causes them and their families. For example, Brittany described that her health status directly impacted her finances:

It's an economic stress too because I'm still responsible for supporting my husband and I. So I do all the bill paying, all the finances, all the investing of money. [ME/CFS] diminished income completely.

Finally, many of the participants continued to work because of difficulty obtaining disability income and wanting to maintain their pre-illness occupational identity. Other reasons included keeping their health insurance as well as the mental and physical impact of continuing to work. Tim described having a physically labor-intensive job and the chronic stress it put on his system:

I was a manager for a uniform company so it was very demanding running around, a lot of driving long hours and that was more mentally tiring than it was physically, to where now [it's more] physically [than] mentally tired.



**Reductions**—In addition the occupational shift theme, other types of reductions were referenced by approximately one third of the participants. This theme includes social and personal domains that reference lifestyle changes and adjustments made because of ME/CFS as well as changes in residence as it was related to the illness. Again, these themes are not mutually exclusive. Brittany discussed the personal stress and health impact involved in the co-occurrence of an occupation change and moving:

I've sold my business, I've moved to Colorado for health reasons, the pace is much slower there; it's a town with about 100,000 so the workaholic tendencies are pretty much decreased. I can't do as much because there's not as much to do then I feel less deprived. [I sold my business] because I couldn't work.

Changing residence was a common theme among participants in the study. Over the 10 year period, Laura described her move from California, where she attributes her ME/CFS improving because of the warmer weather, back to her original home in a big Midwestern city:

I didn't really consider the weather and chronic fatigue when I moved back here, but I think that it did affect, the weather did affect me a little, to some degree. I was more fatigued again, but not to the degree I had been in '95. No, not to that, because in '95 I was totally debilitated. What I have noticed is that I always have a sore throat and my glands are swollen a lot and I'm still able to, you know, kind of push myself.

In addition to moving, participants described making lifestyle adjustments after developing ME/CFS. For example, Mitchell described current difficulties with daily life activities:

Before I walked without a cane and I was able to clean the backyard and do other little things that I can't now. I put myself [...] I put myself to do something and I have to go to lie down.

As well, Mitchell described other reductions in the social and personal domains. Mitchell describes how he and his wife counteracts his problems with others that are worse off and his wife's support:

[She] tells me not to worry, that there are others more badly off than me, because sometimes we can't see that well, I can't walk, but there are others that don't have legs nor arms and that helps.

The construct of reductions has particular salience among researchers and clinicians in light of the ME/CFS diagnostic system. To receive a diagnosis of ME/CFS, people have to experience substantial reductions across domains such as personal, occupational, social, or educational (Fukuda et al., 1994).

**Community Response**—The community response to ME/CFS includes themes centered around how members from the medical community as well as other related networks, such as support groups, understand and respond to the illness. The thematic group is further broken two into two main areas: (1) the availability or lack of resources within the community for people with ME/CFS, and (2) attitudes towards people ME/CFS.

First, negative attitudes as a community response towards people with ME/CFS, such as physician minimization, were frequently discussed by participants. Andrea went to her physician in pain and described how her condition was dismissed:

[My doctor] just put me on calcium, for my bones, cause of all the aches and pains that I get and there's this one pain I get on my hips all the time and she says it's just stress. She's not [convincing] because it seems like she doesn't take me, if she would take some tests or something then maybe I can believe her, but she won't. I have [physical symptoms] and it's like [my doctor] says it's just stress. I don't believe its stress, I really don't. I believe it's some of it, but not all of it.

Laura also described how general physicians are not well trained in terms of understanding the various components and controversies of ME/CFS:

It's something that allopathic doctors are kind of worthless about. I think they're worthless period, but they certainly don't understand chronic fatigue.

After dealing with the stress of moving to a small city, Shannon experienced that her illness was not taken as seriously or legitimized in her new community:

It was stress related to not really finding out that ME/CFS is not really even recognized here. I think the only thing that would make someone up here believe me is if I had a terrible relapse, which I don't want to have.

Another level of the community response to the illness includes the availability of resources for people with ME/CFS. One such resource that was commonly mentioned among participants was different types of community support groups. This includes ME/CFS-related groups, or other support groups that the individual defined as helpful. For example, Brittany described the lack of a personal support system after her move:

I mean I go out and I have friends but it's not a support in terms of CFIDS, you know, and for me that's a really big issue. We have tons and tons of friends but it's not the same. When we come back, my friends are all here and there are more people who understand what CFIDS is so I mean we have a heavy social schedule. My husband is just out doing a lot of stuff and when I feel well I go with and if not then I just stay home. But I don't feel like it's a support system.

Finally, there may be a use for individuals to seek out groups that they identify as inclusive and potentially helpful for issues outside of ME/CFS, but still may have an impact on their health. These issues involving stigmatization and the allocation of resources within a community are important sociocultural factors that influence not only people with this illness on an individual level, but also at other levels such as how researchers and clinicians define the illness which subsequently affects how they conduct their work and treat their patients.

### **The Physical Construction of ME/CFS**

This category includes themes focusing on the symptomatology of ME/CFS, the mode of illness onset, as well as other important health changes occurring over the 10 year period. Many previous qualitative studies have found that people with ME/CFS provide rich

accounts describing the physical symptoms they experience as well as precursors to the development of ME/CFS (Anderson & Ferrans, 1997; Lovell, 1999; Soderlund, Skoge, & Malerud, 2000).

**Symptomatology**—Symptomatology codes include the discussion of key physical ME/CFS symptoms. About two-thirds of participants made direct and indirect references to experiences related to fatigue, cognitive problems, post-exertional malaise, sleep disturbances, and pain. Lisa discussed the development of her fatigue:

I had so much energy in me [before getting sick] it was ridiculous. I really, really start getting a bad fatigue I wanna say in the last five years. The last five years I have really been tired.

Additionally, many participants described symptoms involving memory and concentration problems, another key ME/CFS symptom. For example, Emma described the cognitive problems she developed with her ME/CFS:

I would say that the concentration level has lapsed. I mean I'm having trouble focusing. I can make myself do it, you know, but it takes tremendous effort to do that.

Finally, symptoms such as post-exertional malaise were described by participants. Shannon described how exertion and the experience of stress, either positive or negative, can be detrimental to her health:

I went for a walk one day on a lake front and I got really cold and within about three or four days I was really sick again.

In addition to post-exertional malaise, Shannon's description also taps into the relapsing nature of ME/CFS and if people with the illness are not careful about activity their symptoms may increase. She further described in her interview that exertion and the experience of stress, either positive or negative, can be detrimental to her health. Another key feature of ME/CFS described by the participants includes sleep disturbances. Andrea detailed her unrefreshing sleep:

I think I put too much on my plate, I do more since I've [been sick] and forget about what my fatigue is and so the only thing I just don't sleep that good at night, um, I'm up almost every two hours.

Finally, another common symptom includes experiencing pain. Sarah experienced incapacitating pain with her ME/CFS:

The only time that I get to a point where I can't work are my cycles. And they, uh, it's usually the one day of extreme pain and I can't, I just can't take it. And it's like I can't stand, I don't wanna talk.

These themes are critical in furthering our understanding of how ME/CFS operates as an organic, physical condition. There was no major theoretical difference (e.g., psychological explanations) among how the participants in different groups described their condition.

**Onset**—The onset subtheme, mentioned by approximately half of the participants, included how the participants describe the development of their illness, the participants' illness attribution beliefs, and the progressive nature of the condition. Shannon described her sudden onset after contracting a virus:

I got a virus called CMV, cytomegalovirus. I got it in November, well the last day I worked was November 15<sup>th</sup> or October 15<sup>th</sup> I think I remember that like very, very well, because I was too sick. I was—I am—a nurse and I worked in psychiatry and I was too sick to do the floor and I was in charge so I assigned myself the desk because I knew I was sick and then I ended up, we had a person come in that had to be put in restraint and I had to help with it and then that night I went to bed, I was sick and the next day I couldn't get up and I never went back to work again and I couldn't even get up and became violently sick.

In addition to descriptions of onset, participants described the progressive nature of the condition over the 10 year period. Willa, a participant in the persisting group described the progression of her fatigue:

It's gradually gotten worse. It kind of leveled off, it wasn't, I could live with it, in other words, but now, within the last three months it's gotten much worse.

It should also be noted that four of the six incidence cases were classified as ICF at Wave 1. In terms of these cases, there was no clear, direct onset related to their condition because they were already symptomatic prior to meeting ME/CFS case definition at Wave 2. This further implies evidence of the progressive nature of ME/CFS.

**Health Changes**—Most of the participants in the study described other health changes over the past 10 years. The health changes included references to the development of other conditions, health conditions that have co-occurred during the length of time the person had ME/CFS, surgeries, weight gain, and gender-specific health changes. Willa described developing other illnesses and the overall worsening of her health condition:

I just recently have been diagnosed with this anemia, but this has been within the last few weeks. Health problems, before that it was just run of the mill getting older type stuff. [My overall health] has worsened.

It is interesting to note that four other participants in the study described having co-occurring fibromyalgia with their ME/CFS. Finally, all but three of the participants were female and there were many accounts for and descriptions of gender-specific health conditions. Sarah discussed her myomectomy surgery and ectopic pregnancy as the most physically and psychologically stressful period while being sick:

[I had a myomectomy] to remove the fibroids so the baby could and, um, the first one I got pregnant right after the first one. That's when I had the ectopic. Then the second one I had I really should have been given a hysterectomy. So they went in what should have been a one-hour surgery to four hour.

Gaining weight was another common theme among the participants in the study. For example, Jennifer described her weight gain to which she partially attributed to her illness:

I did gain a lot of weight. Right now I am, I just weighed myself here. A hundred pounds overweight! It's like 10 pounds every year. Sounds like so little for a year, but put it all together, never losing any, it's already 100! I was shocked.

These findings indicate that ME/CFS may work in conjunction with other illnesses and viruses, and ME/CFS-specific symptoms can worsen when living with multiple conditions. This also indicates a reason why this illness gives researchers trouble because it manifests differently in individuals and different populations and there may be multiple etiologies (Clements et al., 1997; Donalek, 2009; Horton-Salway, 2001; Whitehead, 2006b).

### Coping Mechanisms and Chronic Illness Management

Concurrent with previous studies, these themes reflect the use of alternative treatments (Lovell, 1999; Whitehead, 2006b) and balancing activities (Clarke & James, 2003; Clements et al., 1997; Travers & Lawler, 2008) to cope with ME/CFS. Previous findings have shown similar variations in coping response in people with ME/CFS that were based on symptom presentation and severity (Travers & Lawler, 2008). As well, balancing activities supports the envelope theory proposed by Jason et al. (2010), which suggests patients with ME/CFS can increase strength and lower fatigue levels by balancing perceived and expended energy levels.

**Alternative Treatments**—Alternative treatment thematic group includes explicit references to the use of treatments outside of traditional medicine such as relaxation strategies and other complementary and alternative medicines (CAM). According to the National Center for Complementary and Alternative Medicine (NCCAM, 2007), CAM encompasses a diverse collection of health care systems, practices, and products outside of traditional, conventional medicine. The majority of participants discussed trying alternative medicine, given that there are currently no conventional medications that specifically treat ME/CFS. First, participants described relaxation strategies that helped with their fatigue and related symptoms. Lisa explained:

The only thing I really use is to sit and relax that if I'm not at home go, maybe, out to eat because that's more of a relaxing thing for me than maybe anything else. Because for some reason even if I'm laying in bed at home by myself the telephone ringing is just like it set everything backwards.

Additionally, Anne described that going to church is the most effect method of relaxation and support for her condition:

I go to church, I like that a lot, I mean it relaxes, it helps me a lot to go find God at church, that lifts my energy and everything more than anything. I go to church, well look I go every Sunday, I should be going during the week but I go every Sunday [...] when I don't go to church, well, I feel that something is missing.

In addition to general relaxation strategies, participants discussed alternative medicines used to cope with their ME/CFS. Some of which include taking nutritional supplements or vitamins, going to spas, receiving massages, light or very controlled exercise, chiropractors, among others types of treatment. Laura described that acupuncture, massage, and herbal medicine were helpful treatments:

I took the medicine, some kind of herbs that I had to cook into a tea. I went to a Chinese doctor and I really, that really helped me, whatever he gave me. It took about two years... I felt a lot better, after I started taking the tea.

Anne also found that acupuncture helped her ME/CFS symptoms:

I was going to acupuncture, I was going, uh, I went with a lady that would give me massages, [with] the acupuncture I was feeling better. I was feeling, the thing is that since I did not have money to go, I went only one time and I felt that it was helping me. when she would put the acupuncture where it hurt, [the pain] would stop.

However, after years of dealing with a chronic illness, people with ME/CFS may have used up all of their resources whether financial or social or even develop a sense of hopelessness after years of being sick. Resting was described as the most frequent “treatment” among the persisting group and will be discussed in the next section. Participants indicated that alternative treatments are costly and most types of insurance do not cover this kind of care. Mitchell explained his frustration:

The Medicare doesn't pay for that, for nothing. I just rest and when I get pain and the fatigue, well, I lay down and I know that there isn't any doctor.

Many participants commented that it is difficult to find well-trained and empathetic physicians to help treat the various components of ME/CFS.

**Balancing Activity**—Balancing activities theme is defined by participant descriptions of attempts to manage the illness by heavily monitoring or restricting activities, resting, and listening to their bodies. Participants described balancing activities as a coping mechanism. In particular, Noah described that the new flexibility in his work schedule allows for better management of his illness:

In some ways I kind of feel like because of the changes I've made in my life I'm able to manage the fatigue better. I'm able to adjust my sleep patterns more around my lifestyle. I can adjust my schedule more so I can sleep longer or different hours. I can manage it more. But I don't know if the level of fatigue is different.

Noah's lifestyle adjustment did not necessarily change his physical symptoms, but he responded to the illness by developing adaptive coping strategies. As well, Willa described how she adapted her lifestyle to cope with the illness:

I do have to adapt my day towards what's going on in a particular day. If I know it's going to be a long day then I will take a rest period in the afternoon and then, you know, kind of really just forming my day around what's going on. So that I can have enough time to rest or that I'm not, you know, too exhausted.

Shannon also described how she actively listens to her body now and almost automatically monitors herself as to not experience post-exertional malaise:

I feel fatigued after I'm doing something. It is almost like I have trained myself to know the feeling when to stop. So I'll stop and go lay down. I totally self monitor, but see because it has been so long, it has become just a part of me. I don't even need to think about it.

This theme was very common among the persisting group (occurring in 83 percent of this group), but was experienced less by individuals in the incidence group (only 33 percent), who did not have the illness for as long. For example, Emma described how she mentally copes with her condition and pushes through:

I'm probably more determined to not see myself as ill and more determined mentally to just get through, you know, to not make that the focus but make the focus more positive, you know, and what the goal is and what we need to accomplish, than focusing in on, you know, being sick. And that has come to haunt me, but you know it's okay.

In addition the theme of balancing activity, a large portion of the participants in the persisting group also referred to continually pushing themselves. This may be interpreted as a way to cope with the chronicity of the illness and/or as a mechanism that may ultimately exacerbate the illness.

## Discussion

This study aimed to understand the phenomenology of ME/CFS by examining a sample of people with the illness from a larger natural history study using qualitative methods. While qualitative research does not seek external validity, these findings may still have community-level implications given that this sample was derived from a larger epidemiological study. This group of participants is not biased by access to the health care system, which provides us a richer and more diverse representation of people with ME/CFS. The thematic findings bring up a unique set of results that confirms and builds upon previous qualitative work, which describes similar processes in community samples that previous researchers have found in tertiary and more specialized samples (Anderson et al., 2011).

Using qualitative methods to study contested illness provides us with a deep understanding of the interaction of the multiple systems involved in chronic illness. There is a particular salience and applicability of these methods to the ME/CFS patient community as qualitative methods have the ability to give voice to a group of people who have been marginalized, disbelieved, questioned, and historically silenced. It is important to note that ME/CFS is one of many "invisible illnesses" where patients are denied recognition of their illness or, even when the health care system recognizes their illness, patients' experiences are trivialized or minimized by physicians on the basis of a lack of facts about the illness (see Dumit, 2006 for a more detailed discussion). Thus, these patient insights and descriptions of symptoms on onset provide researchers and clinicians with critical information when working with not only patient groups but also policymakers and other community stakeholders who may have different theoretical explanations and attribute different causes to ME/CFS.

It is of interest that balancing activities were more common among the persisting than the incidence group. One explanation of this finding might be that the persisting group has had more time to develop their skills in balancing activities than the incidence group. However, limiting activities in order to accommodate to the illness is related to greater impairment in people with ME/CFS (Ray, Jeffreies, & Weir, 1995). More recent investigations demonstrate that people with ME/CFS who stay within their energy envelope improve their fatigue

severity and physical functioning (Jason et al., 2009). Therefore, carefully monitoring energy, staying near one's perceived energy level, and attempting to not overexert oneself may be ways to manage symptoms and cope with ME/CFS. Similarly, resting techniques and alternative medicines may help alleviate some of the symptoms. Certainly, resources play a role in the treatment of ME/CFS, and this is important for individuals who may not have access to the health care system. As well, given that this is a chronic condition, individuals may have used all of their financial resources on both traditional and alternative treatments. People with ME/CFS experience both occupational reductions as well as the individual and societal level economic impact of living with ME/CFS. For example, other researchers have found that people with ME/CFS suffer from profound losses related to their careers, which in turn negatively impacts their financial stability (Anderson & Ferrans, 1997). Other substantial reductions that people with ME/CFS face include the loss of their social roles and changes in personal relationships (Tuck & Wallace, 2000). These areas of economic and social impact as well as functional status (e.g., physical, emotional functioning) are critical areas in life that are negatively impacted after developing this illness. Furthermore, additional research is needed to address other areas of concern for people with ME/CFS (e.g., suicides within the patient community).

The remit case is of particular significance as this person reported improvement in health status across the 10-year study. While time was invested in balancing activities and alternative treatments, it is important to note the remit case did not experience full improvement across the ten years. In addition, the remit case also continued to describe symptoms of ME/CFS but with less impairment. Other findings show that participants who experience recovery from ME/CFS may in turn be experiencing less stress, which is a factor that can exacerbate the progression of this illness (Lim et al., 2003). Subsequently, those who experience remission of ME/CFS may be learning to manage symptoms and reduce activity levels. The present study was limited to analyzing the occurrence of one remitting case. Future researchers should further examine the experiences of those with ME/CFS who describe improvement in or recovery from their illness.

Overall, these findings have implications that may impact individuals with ME/CFS (e.g., learning about different types of treatment strategies), members within the network of individuals with ME/CFS and how they might better understand the illness, as well as people who work in the medical or health care sector (e.g., disseminating better educational materials and potential interventions to the medical community). Identifying the community response to ME/CFS is a critical part of understanding the systems involved with the people experiencing the illness as well as how people think about or work with this illness. Finally, there is a sociocultural and political salience to these findings, such that how we as a society think about people who develop chronic illnesses has implications for how we respond to and treat people with chronic illness. In particular, there is a need to take a deeper look at the connection of illness to the distribution of power and privilege within the medical community as well as the social response to chronic illness and health care. There is a need for researchers and clinicians to work towards developing consciousness-raising strategies that target and disseminate the reality of the ME/CFS experience to members of the community.



In terms of limitations, the groups that were analyzed potentially comprise theoretically different subsets of people with ME/CFS; that is, those who developed ME/CFS over the course of 10 years, those with persisting ME/CFS for at least 10 years, and those that remit, or their condition improved. As well, issues within longitudinal research such as recall bias is also a limitation. Future qualitative and epidemiological research should continue looking at the larger systemic structures that impede individuals' access to care and eventually ways to ameliorate this dimension of medical and social inequality.

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**Table 1**

## Participant Health Status

Pseudonym	Wave 1	Wave 2	Status
Jennifer	CFS	CFS	Persisting
Natalie	CFS	CFS	Persisting
Samantha	CFS	CFS	Persisting
Andrea	CFS	CFS	Persisting
Leslie	CFS	CFS	Persisting
Tim	CFS	CFS	Persisting
Brittany	CFS	CFS	Persisting
Lisa	CFS	CFS	Persisting
Laura	CFS	CFS	Persisting
Noah	CFS	CFS	Persisting
Shannon	CFS	CFS	Persisting
Anne	CFS	CFS	Persisting
Eleanor	ICF	CFS	Incidence
Heather	ICF	CFS	Incidence
Willa	ICF	CFS	Incidence
Sarah	ICF	CFS	Incidence
Mitchell	Excl.	CFS	Incidence
Emma	Control	CFS	Incidence
Brooke	CFS	ICF	Remitting

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**Table 2**

## Thematic Summaries and Frequency Analysis

Coded Theme	Description of Theme	Persisting Group N (%)	Incidence Group N (%)	Remit Group N (%)
Category 1: Illness Experience Embedded in Multiple Systems				
Family System Changes	Includes changes involving members of or dynamics with the family system and/or close network members including death and bereavement, additions to the family, shifting into a caretaker role, and general family system stressors	11 (91.7)	6 (100.0)	1 (100)
Identity	Includes disruption in lifestyle and adjustment to ME/CFS, making meaning of their experience, and references to autobiographical accounts	3 (25.0)	1 (16.7)	0 (0)
Occupational Shifts	Includes any reduction in work, impact of job or work status based on health, disability income, commuting, and general references to financial stress due to ME/CFS	12 (100.0)	6 (100.0)	1 (100)
Reductions	Includes reduction within personal and social domains, particularly referencing lifestyle changes and adjustment to ME/CFS, changes in residence or moving in connection with the illness experience	4 (33.3)	2 (33.3)	1 (100)
Community Response	Includes responses from members of the medical community, the response of members from other important networks (e.g. support groups), and references to physician minimization	6 (50.0)	1 (16.7)	1 (100)
Category 2: The Physical Construction of ME/CFS				
Symptomatology	Includes direct or indirect references to key physical ME/CFS symptoms including cognitive problems, sleep disturbances, pain, fatigue, and post-exertional malaise	8 (66.7)	4 (66.7)	1 (100)
Onset	Includes descriptions of onset, beliefs of illness attribution, and references to the progressive nature of ME/CFS	7 (58.3)	3 (50.0)	0 (0)
Health Changes	Includes references to new diagnoses, co-occurring chronic health conditions, surgeries, weight gain, and gender-specific health changes	10 (83.3)	6 (100.0)	1 (100)
Category 3: Coping Mechanisms and Chronic Illness Management				
Alternative Treatments	Includes explicit references to types of treatments utilized outside of traditional medicine such as complementary and alternative medicine, and specific relaxation strategies	8 (66.7)	5 (83.3)	1 (100)
Balancing Activity	Includes attempts to manage illness by heavily monitoring or restricting activities, resting, understanding and listening to body	10 (83.3)	2 (33.3)	1 (100)