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Dismissing chronic illness: A qualitative analysis of negative health care experiences

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Abstract

In the US, medical training is inadequate regarding the symptomatology, prognosis, and treatment for myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS). As a result, many physicians lack the appropriate level of knowledge about effective methods for ME and CFS symptom reduction and often suggest inappropriate treatments, such as increased exercise or psychiatric services. The authors' purpose in this study was to analyze negative patient experiences with health care professionals. Patients with ME and CFS who reported experiencing a dismissive physician attitude were asked to detail the encounter via open-ended response on an international, online survey. Participant responses were thematically coded and analyzed using processes outlined by Patton. Emergent themes related to perceived physician attitudes and how they impact patient wellbeing are described and their implications discussed. Additionally, we highlight suggestions for how the health care system can effectively approach this often marginalized patient group.

Myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS) are characterized by dysfunctional sleep, neurocognitive deficits, and post-exertional malaise (Fukuda et al., 1994; Ramsay, 1988). Despite severe symptom levels that leave approximately 25% of patients housebound (Pendegrast et al., 2016), many patients report a lack of support from their health care providers. Anderson and Ferrans (1997) determined that 77% of patients reported experiencing a negative interaction with a health care professional, while David, Wessely, and Pelosi (1991) found that 57% reported being treated poorly by their doctors. Twemlow, Coyne, Bradshaw, and Lerma (1997) found that 66% of patients with ME and CFS believed that seeking care from a doctor actually worsened their condition. While the details of these negative interactions vary among patient samples, it remains evident that a fracture exists in the majority of doctor-patient relationships.

There are several factors that may contribute to the perception that health care professionals (HCPs) have negative attitudes towards patients with ME and CFS. In some cases, patients may view a physician's focus on nonphysical factors impacting their experiences as evidence that the HCP believes the illness is primarily psychological. Åsbring and Närvänen (2004) and Horton-Salway (2002) found that physicians were likely to utilize a

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psychodynamic or psychosomatic illness model when symptoms could not be objectively measured. Several researchers have demonstrated that patients, unlike their physicians, strongly believe that their illness is not a psychosomatic disorder (Clements, Sharpe, Simkin, Borrill, & Hawton, 1997; Horton-Salway, 2001; Lovell, 1999). Romei, Green, and Heinzen (1996) found that some patients described negative experiences involving providers minimizing the severity of their illness or attributing it completely to a psychiatric or psychosocial factor.

Ascribing illness attributions to a psychological etiology and recommending a course of treatment based on these assumptions could have negative effects on the doctor-patient relationship. In particular, graded exercise therapy (GET) has been recommended, along with cognitive behavioral therapy (CBT), for the treatment of ME and CFS in the UK (Baker & Shaw, 2007). This recommendation was evaluated by the Randomized Evaluation of Pacing, Graded Activity, and Cognitive Behavior Therapy study (i.e. PACE trial), where researchers claimed that patients recovered from CFS following courses of CBT and GET (White et al., 2011). However, the methods of the PACE trial have been widely criticized. One major flaw was that the criteria set for determining recovery were more lenient and specified lower symptom levels than thresholds set for inclusion in the patient group. Independent reanalysis of the data has shown the claims of recovery were not supported (Wilshire, Kindlon, Matthees, & McGrath, 2017). Patients have reported that GET and CBT, rather than helping, caused a deterioration in health (Kindlon, 2011; ME Association, 2015). Patient groups have emphasized the effectiveness of approaches that focus on relapse prevention and the mitigation of symptoms. This involves listening to the warning signs their bodies send during exertion, avoiding situations that might cause symptom exacerbation, and pacing themselves (Clements et al., 1997; Denz-Penhey & Murdoch, 1993)—a sharp contrast from the increasing activity prescribed in GET. Pacing and staying within the individual’s energy envelope is one such method that patients have found helpful (Jason et al., 2013).

Another factor that may lead patients to view their HCPs as dismissive is the discrepancy between the HCP’s ideal patient-physician roles and the reality of treating a patient with ME or CFS. Åsbring and Närvänen (2003) showed that physicians are uncomfortable when biomedical ideals do not fit with the clinical reality and they often express feelings of frustration, helplessness, and failure as a consequence. Physicians also expressed skepticism about illnesses such as ME and CFS that cannot be characterized by objective measures, and they reported thinking that patients were exaggerating their symptoms. Some physicians expressed doubt regarding whether patients who identified with CFS were truly sick, and reported wondering if they were malingering for some other purpose. Additionally, physicians may perceive patients to be demanding and overly insistent about being helped, while also appearing to doubt the physician’s capacity to do so (Åsbring & Närvänen, 2003). Furthermore, researchers like Horton-Salway (2002) and Raine, Carter, Sensky, and Black (2004) have found that physicians perpetuate harmful stereotypes of CFS by claiming that the diagnostic category is dubious and by characterizing patients as “lacking fortitude” and having pejoratively described personality traits such as “low symptom threshold.” In turn, the patients viewed these kinds of reports as dismissive of the credibility of their illness (Åsbring & Närvänen, 2002; Denz-Penhey & Murdoch, 1993). Finally, lack of training or knowledge concerning ME and CFS among HCPs may also be influencing the patient's perception of dismissive interactions. Several studies have suggested there is a lack of knowledge about ME and CFS in health care settings. Peterson et al. (2013) found only 28.2% of medical schools included CFS in their curricula and only 29.6% included information about clinical treatment for CFS. Jason, Paavola, Porter, and Morello (2010) found that 40.3% of medical textbooks included sections on ME and CFS, but only 0.09% of the pages in those textbooks contained material on ME and CFS—far fewer pages than were devoted to less prevalent diseases such as Lyme disease or multiple sclerosis. Bowen, Pheby, Charlett, and McNulty (2005) found that 48% of general practitioners were not confident in their ability to properly diagnose ME and CFS and only 72% were able to recognize it clinically. These findings are concerning as they indicate that HCPs are not being adequately trained in the proper diagnosis and symptom management of ME and CFS, which could have a deleterious effect on the patients and their relationships with the HCPs. Moreover, access to health care specialists is limited. Sunnquist, Nicholson, Jason, and Friedman (2017) found that of 898 participants, less than half had ever seen an ME or CFS specialist, though 99% of participants were interested in specialist care. Participants cited geographic and financial barriers as most frequently precluding access to specialists. Furthermore, satisfaction with specialist care greatly exceeded satisfaction with non-specialist care. These researchers suggested that individuals with ME and CFS represent a medically underserved population, due to lack of available care.

Many of the prior researchers in this domain have focused on the physician perspective of what leads to the fracture in their relationship with patients with ME and CFS. Our purpose in this study was to analyze the patient perspective and further elucidate this underserved population and any issues in the doctor-patient relationship that may be leading patients to perceive HCPs as dismissive.

Method

Participants

An international convenience sample of individuals self-reporting a diagnosis of ME or CFS was recruited as part of a larger study. To be eligible, participants had to be at least 18 years of age and be able to read and write in English. The questionnaire was completed using Research Electronic Data Capture (REDCap), an online survey tool (Harris et al., 2009). Participants were recruited through a variety of methods including postings on social media websites, patient advocacy newsletters, and internet forums.

Measure

Participants ($N = 541$) were asked, "Have you ever experienced a dismissive attitude from a health care professional?" Those who answered "Yes" (89.4%) were then prompted with the following open-ended question: "Please describe this experience." Participant responses ($N = 464$) were thematically coded and analyzed using NVivo software, following the processes outlined by Patton (2015). The analysis sought to identify specific types of interactions with HCPs that patients interpreted as dismissive.

Qualitative analysis

Qualitative responses were coded using an inductive and iterative approach (Patton, 2015). First, authors familiarized themselves with the data through repeated readings. The first 100 responses were read individually and authors noted recurring ideas and possible themes. Initial major themes and subthemes were generated after the authors met and organized their notes into meaningful categories, creating a preliminary codebook. Using the codebook, DM and JS each coded 25% of responses, for a coverage of 50%. SM coded the same responses and updated the codebook as authors clarified themes. SM then met with DM and JS to discuss differences in coding and the codebook was updated as necessary. To establish inter-rater reliability, the authors aimed for good reliability on each code ($K \geq 0.80$). For themes where agreement was moderate or below, the authors clarified the definition of the code. Each time the codebook was updated, the authors went back through previously coded responses and recoded based on the updated guidelines until good reliability was attained. The final inter-rater reliability ranged from $K = 0.97$ for the Psychological Treatment code to $K = 0.82$ for the Insensitive to Physical Needs code. After solidifying a coding scheme, SM coded the remaining 50% of the responses.

Cross-group comparison

A series of Chi-Square tests were conducted to compare gender-based response differences across each theme and subtheme. The observed frequencies of male and female coded responses for each theme was compared to the expected pattern of response distribution if gender was unrelated to experiences of dismissive physician interactions.

Results

Responses were coded into five main themes: Disbelief, Inappropriate Causes, Inappropriate Treatments, Insensitivity, and Lack of Knowledge. These main themes were further categorized into subthemes as described below. Table 1 provides the percentages of patients that described experiences related to each theme and subtheme. Table 2 provides a summary for each theme.

Theme 1: Inappropriate Causes (53.45%)

More than half of the participants ($n = 248$) reported dismissive interactions in which a HCP attributed their illness to causes they viewed as inaccurate or inappropriate.

Depression

Many participants ($n = 68$) in this group had their CFS symptoms attributed to primary depression. Some participants mentioned a history of depression that was unrelated to their ME or CFS while others stated their illness caused their depression. However, the HCPs often attributed all of a patient’s symptoms to depression and were not willing to diagnose the participant with ME or CFS.

> [The HCP said] that my illness was imagined, and I was depressed because my husband worked away from home
>
> (Record 18).

Anxiety

A smaller portion of participants *(n* = 24) had their symptomatology attributed to an anxiety disorder. Again, when laboratory tests were inconclusive and a HCP was unable to pinpoint an exact anatomical location as the cause for symptoms, they pointed to a psychological diagnosis to explain patient symptom experiences:

> When my tests came back negative from my primary care physician, he referred me to a neurologist who suggested that I just had anxiety, suggesting that that was the core issue
>
> (Record 369).

Often depression and anxiety were offered together as explanations for patient symptoms.

General psychological

Other psychological explanations for participant symptoms *(n* = 131) included substance use disorders, stress, Munchausen syndrome, repressed traumatic experiences, or more vague statements attributing the illness to a psychological etiology such as "*it's all in your head"* (Record 6). Participants often described multiple and repeated misplaced illness attributions from HCPs during their journey to receiving a confirmed ME or CFS diagnosis. These types of interactions were viewed as harmful because the participant believed the physician was dismissing their physical symptoms in favor of a stigmatizing psychological etiology:

> One prominent OB/GYN in [city] told me that my symptoms were caused by repressing memories of a past sexual assault. No such thing ever happened to me
>
> (Record 350).

> Another doctor told me the illness was all in my mind when I came to him to find out what was causing widespread diffuse pain, burning feeling in hands and feet, chest pain
>
> (Record 45).

Lying or faking illness

Some participants (*n* = 46) were accused by the HCP of lying or faking their illness. Participants in this group reported being told that they were simply seeking attention or trying to get out attending school or work. These experiences can be particularly harmful to the doctor-patient relationship as they leave the patient feeling as though the HCP does not trust or believe them.

> [The HCP told me:] "Stop reading stuff on the internet, you are a full blown hypochondriac"
>
> (Record 270).

> I was treated like I was mental and that I was stupid. My diagnosis was dismissed. I was made to feel like I was making it all up. It was disgusting
>
> (Record 107).

Lazy or lack motivation

Furthermore, a subset of participants *(n* = 20) also described interactions in which the HCP attributed their symptoms to laziness or deconditioning. They described being told they were unmotivated and were not putting in the effort that healthy individuals use to complete their normal daily activities. Counterintuitively, some HCPs who were aware of their patient’s previous levels of functioning seemed to chastise the patient as having somehow lost the motivation to function at that level. Thus, pre-illness functioning, such as having successful career or a history of enjoying outdoor activities, can be used against a patient:

> People questioning my motivation and basically trying to say that I don’t want to do things, rather than am no longer able to do those things which I used to do, loved doing, and really miss! Oh, and I have also had doctors trying to say that there is no way that I could possibly have the cognitive issues that I do now, so I must be faking them, esp. since I had a pre-illness IQ of 148
>
> (Record 301).

Theme 2: Inappropriate Treatments (44.61%)

Frequently in conjunction with inappropriate causal attributions, participants (*n* = 207) reported high levels of HCPs suggesting treatments that were ineffective or detrimental to their health.

Psychological treatment

CBT and antidepressants were often prescribed when the HCP held a belief that the illness had a psychological origin. Many participants (*n* = 106) were referred out to psychological or psychiatric treatments. Participants seemed to feel as though the absence of a definitive physical etiology, combined with normal lab work, resulted in the HCP becoming frustrated and resorting to psychosomatic explanations.

> [The HCP suggested that] there’s nothing that can be done, I should focus more on how I feel as they are related
>
> (Record 365).

> I would explain to my doctor (the one that eventually diagnosed me) the symptoms I was having and after we ran all the tests and they kept coming back normal, she started behaving in a more dismissive manner than before and recommended I see my psychiatrist
>
> (Record 378).

Physical activity

Additionally, many participants (*n* = 84) were told to engage in some form of exertion, such as GET. Although pacing has been shown to be beneficial for some patients (Goudsmit, Nijs, Jason, & Wallman, 2012; Jason et al., 2013), the participant descriptions of their interactions with HCPs suggested that some of these professionals misinterpreted findings related to pacing and/or suggested harmful physical activity. Some participants described how their HCP told them to ignore the symptoms they came to interpret as warning signs and push themselves beyond their comfort level because *“it will be the way to recover’* (Record 109). Others described attempting to tell their HCP that GET made them physically worse or that psychological treatment was not helping, but their concerns and viewpoints were often dismissed:

> At first when I queried ME, I was told by a GP it was probably depression, and even if it was ME, the cure was the same—graded exercise, CBT and antidepressants. I diligently followed this program and went from being mildly affected to losing my mobility
>
> (Record 693).

Unable to help

Several participants *(n* = 41) reported feeling as though their physician was not able to provide any help at all. Some HCPs communicated that there was nothing that they could do to treat a patient with ME or CFS. These interactions left the participants feeling hopeless and even suicidal:

> [The HCP said:] “I can’t help you anymore, I did everything I could and we can’t help you”
>
> (Record 109).

> On one occasion she repeatedly stated that doctors could not help me, which briefly made me suicidal, since happy thoughts certainly weren’t going to cure me and I couldn’t bear the thought of staying that sick without even symptom relief
>
> (Record 73).

Resolve on its own

A few participants *(n* = 18) were told to wait out their illness until they recovered without treatment. As with the Unable to Help subtheme, these participants were told there was nothing the HCP could do for them to alleviate their symptoms. However, these participants were told the illness would resolve without any medications or treatments.

> As part of my employment health insurance program I needed to see what is called in the UK an “Occupational Health Doctor.” He point blank said this to me: “I believe in ME but I think it is an illness that affects old codgers. You should be right as rain in a few weeks.” He then wrote letter to my employer indicating I should be well again in a few weeks
>
> (Record 223).

Theme 3: Disbelief (29.74%)

While the above themes centered on misplaced etiological or treatment assumptions related to ME and CFS, some participants described experiencing an outright disbelief from HCPs.

ME or CFS is not real

Over a quarter of participants (*n* = 63) reported experiencing interactions with HCPs that left them feeling as if the HCPs did not believe that ME and CFS was a legitimate diagnosis.

These participants felt that their illness was being dismissed completely due to the HCPs view on the legitimacy of the diagnosis:

> A rheumatologist said “There is no such thing as CFS/Fibromyalgia— those symptoms can be replicated in a lab with sleep deprivation”
>
> (Record 929).

Patient not ill

Additionally, many participants *(n* = 69) experienced HCPs not believing they were ill—disbelieving the existence of their symptoms altogether. For example, participants detailed being told their severe fatigue was normal or that there was nothing physically wrong with them. This often came as a result of inconclusive bloodwork or other laboratory testing. With no definitive illness biomarker, some HCPs seemed to conclude the participant was healthy.

> As for my blood test results, he stated that a small percentage of the general population had similar numbers without being ill, and I was probably one of those people. I was so shocked that I couldn’t respond to what he said, and left the office in tears. It had never occurred to me before that a doctor might not believe me
>
> (Record 411).

Theme 4: Lack of knowledge (17.24%)

Some participants *(n* = 80) reported a simple lack of knowledge about ME and CFS on the part of physicians. These patients described feeling as though it was their duty to educate the physicians about the diagnosis and about symptom management. A few went to great lengths to educate their HCPs by printing information on the most recent research findings, case definitions, and experimental treatments to bring to their appointments. A lack of knowledge on the part of HCPs put an extra burden on the patients, who described having to explain their experiences and related research to their HCPs:

> While compassionate, the doctor does get weary of not having an answer
>
> (Record 650).

> I had to recommend reading material, bring in printouts to educate them. I have to spend hours educating nearly every medical professional I meet
>
> (Record 729).

Theme 5: Insensitivity (51.94%)

Finally, a large number of participants (*n* = 241) reported having experiences with HCPs that were generally insensitive to their needs or disrespectful to them on a personal level.

Attitude

Many participants *(n* = 126) described attitudes that were degrading or rude such as eye-rolling and laughing when the patient talked about their physical limitations. Some patients reported interactions with HCPs that made them feel like a burden.

> I have had frequent derision, dismissal & ridicule from Drs. One even actually laughed in my face when I said that travelling to their office (1 hour away) would be all I could manage that week.
>
> (Record 84).

> Nearly every medical professional I have seen, for ANY ailment other than ME, upon finding out I have ME has changed their attitude to that of either distaste, or just “Oh no—not one of THOSE”
>
> (Record 194).

Treatment refusal

Some participants (*n* = 47) reported instances in which HCPs were not willing to treat them or their complicated illness. These types of experiences included participants being told a treatment they requested “*wasn’t going to help*” (Record 46). A few patients described their HCPs as only willing to prescribe treatments that follow guidelines (e.g. CBT and GET as prescribed by the UK; Baker & Shaw, 2007). The refusal to try alternative treatments or to even see the participant as a patient left them reporting feelings of being left on their own to manage their illness:

> He didn’t have much interest in treating me. I felt like I was a burden to him and was sent a letter asking me not to return!
>
> (Record 171).

> Doctors in the UK are limited in what they can do due to NICE guidelines. Health care for ME in the UK is virtually nonexistent or they will offer CBT & GET. They do not help you manage. It’s up to us to try things in an attempt to improve and then it appears that you are derided for your efforts
>
> (Record 287).

Not listening

In addition to struggling with trivializing and contemptuous demeanors on the part of HCPs, participants (*n* = 103) also reported feeling like the physician was uninterested in hearing about their symptoms. They described HCPs interrupting them in the middle of a sentence, answering questions as they were leaving the exam room, and ignoring the patient as they were describing the limitations their illness has on their life:

> Despite now finally being diagnosed, I now find that I am listened to even less
>
> (Record 313).

Test refusal

Some HCPs reportedly refused to perform certain tests when requested by the participant *(n* = 39). These experiences included participants detailing experiences when they asked the HCP to perform an electrocardiogram or a complete blood count to rule out illnesses with known biomarkers only to have their test suggestion to be immediately dismissed. The participants described feeling as though they were fighting their illness alone, without the support of a medical professional.

> The GPs that I go to have never properly diagnosed me and are very reluctant to do tests or investigate anything
>
> (Record 286).

Insensitive to physical needs

Many ($n = 57$) reported feeling that HCPs were unwilling to help them with disability claims, school accommodations, or mobility devices. This unwillingness on behalf of the HCP to help manage their illness led some patients to reflect on the life events they have missed out on due to the lack of support, including impairment in their ability to work, start a family, or attend a loved one's funeral.

> Still today the GPs refuse to treat the ME/CFS and leave me to my own devices. I have not worked for years and missed out on over a decade of my life
>
> (Record 269).

> A substitute physiotherapist at the same clinic scolded me for getting a mobility scooter, and insisted that I only use it on my bad days. She couldn't comprehend that I would be too sick to use it on bad days, and couldn't get out of the house without help even on good days
>
> (Record 73).

It should be noted that some participants reported positive, empathetic experiences with physicians as well. These physicians, although caring for the well-being of the patient, were often still perceived as being weary of treating ME and CFS. Participants reported reluctance on the part of the HCPs to try off-label uses for medications or even prescribe pain relievers for symptom management:

> I've only had one decent GP in all these years—someone who listens but cannot help/prescribe as he is constrained by the guidelines he operates under. He is too frightened to prescribe off-label but tries to support me regardless
>
> (Record 324).

Gender differences

There was no statistically significant difference between the overall proportions of male and female participants who reported a dismissive experience versus those who did not, $p > .05$. As shown in Table 1, there were some significant differences in the frequency of certain themes related to specific dismissive experiences as reported by male and female participants. Women reported higher rates of feeling as though the HCP did not believe them in both the general "Disbelief' category [$\chi^2(1) = 4.71$, $p < .05$] and the "ME and CFS is not Real" subtheme [$\chi^2(1) = 4.28$, $p < .05$] compared to male participants. Additionally, female participants described significantly higher rates of experiences related to "Insensitivity" [$\chi^2(1) = 17.33$, $p < .001$] and "Attitude" [$\chi^2(1) = 4.71$, $p < .05$] than male participants. The remaining themes and subthemes were not significantly different, $p > .05$ across gender (see Table 1).

Discussion

Our findings of this patient-focused study echo those of prior physician-focused researchers. Many participants reported being told their ME or CFS symptoms were the consequences of a psychological issue, with depression being the most frequent inappropriate attributed cause. This is similar to the findings of Jason, Taylor, Plioplys, Stepanek, and Shlaes (2002) that showed 43% of medical trainees believed CFS was stress-related, and 37% believed it was primarily cause by depression. Indeed, over a third of patients in the present study reported that their physician suggested a psychological treatment for their symptoms and quarter were told to increase physical activity. Taylor, Jason, Kennedy, and Friedberg (2001) found that practitioners were more likely to perceive a patient as disabled when they had a history of treatment with Ampligen, a non-psychotropic medication, than if they were treated with a combination of CBT and GET. Unfortunately, this suggests that even if a patient chooses to switch doctors in an effort to seek alternative diagnoses and treatments, they may continue to experience delegitimization from HCPs as a result of past inappropriate treatment suggestions. This notion is supported by Tidmore, Jason, Chapo-Kroger, Brown, and Silverman (2015) who found that 71% of patients had to see four or more physicians before receiving an accurate diagnosis.

Our findings in this study strongly suggest that there is a need for further training and education for HCPs. Chew-Graham, Cahill, Dowrick, Wearden, and Peters (2008) found that physicians felt the training and continuing education they received was not sufficient enough to give them confidence in treating ME and CFS. Researchers found that physicians who were more knowledgeable about the illness also had better attitudes toward it (Scheeres, Wensing, Mes, & Bleijenberg, 2007). It may also be beneficial to include improved training on managing illnesses with an unclear etiology. Raine et al. (2004) found physicians tend to stereotype patients with ME and CFS as having more undesirable traits due to the absence of a precise anatomical location for the illness, its various name changes over time, and continuing disagreement over etiology and treatment/illness management. Furthermore, these physicians reported experiencing caring for these patients as a burden. Scott, Deary, and Pelosi (1995) found that patients with ME and CFS were viewed by HCPs as likely to cause difficulty and take a significant amount of time in treating. Thus, more comprehensive training regarding the symptomatology, management, and effect ME and CFS have on a patient is integral to improving the patient-physician relationship.

Physicians report professional journals, continuing education programs, and the Internet as the most prominent sources from which they obtained information on CFS (Brimmer, Fridinger, Lin, & Reeves, 2010). It would be beneficial to increase the reporting of ME and CFS research in professional journals and create more continuing education programs for physicians. Additionally, physicians may want to take a more patient-centered approach to treatment as it has been linked to improved health status (Stewart et al., 2000). One way to do this would be to be more mindful in communicating around mental health issues. For example, is possible that a psychiatric diagnosis can occur because of or in conjunction with the ME or CFS diagnosis (Sharpe, 1998), rather than as a precipitating cause of the illness. Similarly, other chronic illness patient populations such as fibromyalgia and chronic Lyme disease have also experienced a lack of understanding from their HCP. Physicians' lack of knowledge, lack of medical training, financial pressures on primary care clinicians' time, complexity of the diseases with similar symptoms, and no medical specialty embracing these diseases have all contributed to a large unmet medical need for patients with neuro-endocrine-immune diseases (Tidmore et al., 2015). Prior research on AIDS, has shown empathy plays an integral role in improving attitudes towards a group of individuals with a stigmatizing illness (Batson et al., 1997). Thus, a patient-centered, empathetic, informed treatment approach would likely be beneficial to improving the doctor-patient relationship, which has been fraught with perceived delegitimization due to a predisposition to psychological diagnoses and treatment approaches.

Our findings also revealed differences in the ways men and women with ME and CFS tended to perceive their interactions with HCPs. Women were more likely to report experiencing disbelief and insensitive treatment from HCPs. These results are consistent with research in general medical settings, where researchers have found that men's and women's complaints are viewed differently by medical professionals, with men's complaints being taken more seriously (Colameco, Becker, & Simpson, 1983). Weir, Browne, Tunks, Gafni, and Roberts (1996) found men were more likely to be immediately referred to a specialty pain clinic while women had to be examined by a general practitioner and a specialist before receiving the same referral, suggesting that women are subjected to more disbelief from their HCPs compared to men. In a similar fatiguing illness, fibromyalgia, physicians were shown to perceive women's pain as less serious than men's, resulting in the minimization illness and the patient being viewed as less worthy of treatment (Oldfield, 2013). Additionally, Foss (2002) found in a Norwegian study of patients that had been treated for a variety of ailments, female patients, compared to male patients, perceived their HCPs as being less caring and committed.

Our study is not without limitations. Most importantly, it is subjected to selection bias. The question used for the current study was part of a larger investigation titled "Demoralization and Depression-like Symptoms in ME and CFS," which could have resulted in a participant sample that experienced exceptionally high levels of dismissive HCP interactions. Those that had more positive relationships with HCPs may have participated in smaller numbers, having less interest in completing a questionnaire on demoralizing experiences. While the percentage of patients that reported experiencing dismissive attitudes from HCPs may be inflated due to selection bias, the characteristics of the negative interactions that were described continue to be a cause for concern.

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Table 1.

Number of participants who discussed each theme and subtheme.

	Female (n = 407)		**Male (n = 56)**		**Total (N = 464)**		
	%	**(n)**	**%**	**(n)**	**%**	**(n)**	***p* Value**
Inappropriate causes	69.04	(281)	64.29	(36)	53.45	(248)	
General psychological	30.96	(126)	35.71	(20)	28.23	(131)	
Depression	16.46	(67)	8.93	(5)	14.66	(68)	
Lying or faking illness	11.30	(46)	5.36	(3)	9.91	(46)	
Anxiety	4.67	(19)	8.93	(5)	5.17	(24)	
Lazy or lack motivation	4.42	(18)	3.57	(2)	4.31	(20)	
Inappropriate treatments	61.67	(251)	55.36	(31)	44.61	(207)	
Psychological treatment	25.55	(104)	33.93	(19)	22.84	(106)	
Physical activity	18.92	(77)	28.57	(16)	18.10	(84)	
Unable to help	10.07	(41)	5.36	(3)	8.84	(41)	
Resolve on its own	4.18	(17)	3.57	(2)	3.88	(18)	
Disbelief	36.12	(147)	21.43	(12)	29.74	(138)	*
Patient not ill	17.69	(72)	10.71	(6)	14.87	(69)	
ME or CFS is not real	15.72	(64)	5.36	(3)	13.58	(63)	*
Lack of knowledge	18.92	(77)	17.86	(10)	17.24	(80)	
Insensitivity	77.64	(316)	51.79	(29)	51.94	(241)	**
Attitude	36.12	(147)	21.43	(12)	27.16	(126)	*
Not listening	26.78	(109)	17.86	(10)	22.20	(103)	
Insensitive to physical needs	15.48	(63)	8.93	(5)	12.28	(57)	
Treatment refusal	11.30	(46)	10.71	(6)	10.13	(47)	
Test refusal	9.83	(40)	7.14	(4)	8.41	(39)	

[*] $p < .05$,

[**] $p < .001$.

Table 2.

Summary of themes.

Theme	Summary
Inappropriate causes	The HCP attributed symptoms to psychological causes (e.g. anxiety or depression), faking illness, and lack of motivation to participate in daily activities
Inappropriate treatments	The HCPs treatment plan consisted of psychological therapy, increases in physical activity, or waiting for the illness to resolve on its own. Additional experiences included the HCP telling the participant there was nothing that could be done to help them with their illness
Disbelief	The HCP told the participant that they did not consider ME and CFS to be a true illness or that they were not ill or the symptoms were within normal range
Lack of knowledge	The HCP did not know about ME and CFS, which often left the participant in the position to educate the HCP on their illness
Insensitivity	The HCP displayed a negative attitude after learning of the ME or CFS diagnosis, refused treatments and laboratory testing at the participant’s request, appeared uninterested in listening or ignored the participant, or refused to assist with disability claims