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Research Article

The Journey Towards Becoming Diagnosed with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome - Patients' Experiences

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Abstract

Background: Myalgic encephalomyelitis/chronic fatigue syndrome is a disease that negatively affects patients' quality of life. Previous research has shown that these patients are commonly not taken seriously when seeking medical attention.

Aim: The aim was to examine the experiences of patients with ME/CFS regarding their interaction with Swedish primary healthcare professionals.

Method: The study used a qualitative and exploratory design, taking place in a specialist clinic in Sweden. Data consisted of interviews with 13 patients with ME/CFS, which were analysed using content analysis.

Findings: For patients, it was Feeling truly connected during the period before they received a diagnosis. Time is an important factor, and in the phase from initial symptoms to diagnosis, Knowledge is power.

Conclusion: Patients with ME/CFS were met with different levels of knowledge and interest from healthcare professionals. These challenges might be related to the relative unawareness and lack of knowledge of the disease and the underlying cultural scepticism still present.

Keywords: *Chronic Fatigue Syndrome; Myalgic Encephalomyelitis; Patient Experience; Primary Healthcare; Relationship*

Implications

- A continued relationship with a specific health care professional is important for patients who waits for a diagnosis
- When a patient consultation is planned, it is important that the patient is given enough time to explain the situation from her/his point of view
- Patients value health care professionals who have specific knowledge of the impact of the disease they are treated for.

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Introduction

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is widely considered to be a neurological disorder with severe dysfunction, including pain and severe fatigue [1]. The diagnosis is made based on the International Consensus Criteria (ICC) from 2011 [2]it is more appropriate and correct to use the term 'myalgic encephalomyelitis' (ME. The prevalence of ME/CFS has not yet been established. Recent studies estimate a prevalence of 857/100.000 [3,4]gender and age of the participants, case definition, diagnostic method, publication year, and country of the study conducted. Prevalence data were collected and counted individually for studies adopted various case definitions. We analyzed and estimated prevalence rates in various angles: average prevalence, pooled prevalence and meta-analysis of all studies. RESULTS: A total of 1291 articles were initially identified, and 45 articles (46 studies, 56 prevalence data. The prevalence is expected to increase substantially due to the Covid pandemic where many patients with Long-Covid develop ME-like symptomatology. The diagnosis may be given within the primary healthcare system, after thorough patient interviews, clinical examinations, and laboratory tests; although, many patients suspected of having the disease are referred to a clinic that specializes in caring for patients in pain.

Patients with ME/CFS report a significantly lower quality of life than the general population [5], and patients struggle with tiredness, fatigue, and exhaustion [6]. These patients need support because they have often gone through numerous and vast changes in their everyday lives, and they feel that they are suffering from a silent and stigmatised condition [7]insomnia, morning stiffness, cognitive impairment, depression, and anxiety. FMS is also accompanied by different comorbidities like irritable bowel syndrome and chronic fatigue syndrome. Although some factors like negative events, stressful environments, or physical/emotional traumas may act as predisposing conditions, the etiology of FMS remains unknown. There is evidence of a high prevalence of psychiatric comorbidities in FMS (especially depression, anxiety, borderline personality, obsessive-compulsive personality, and post-traumatic stress disorder. Healthcare professionals working in primary care can support patients with chronic conditions if they take a holistic approach, thereby contributing to improving patients' quality of life [8]yet few studies have considered their viewpoints in combination. A qualitative study involving healthcare providers and users was thus conducted to examine facilitators and barriers of managing patients with MCCs in the community in Singapore. METHODS: This study involves 26 semi-structured interviews with 10 physicians, 2 caregivers and 14 patients seeking treatment in the polyclinics that provide subsidised primary care services. Topic guides were developed with reference to the literature review, Chronic Care Model (CCM. Research has shown that interaction is a core component of the patient-personnel partnership, as well as the foundation of patient-centred care [9]. However, patients with ME/CFS report being met with negative attitudes, and they experience healthcare professionals in primary healthcare neglecting to take their symptoms seriously [10].

Considering the severity of the disease and the impact on patients' lives, the aim of this study was to examine the interaction between patients referred to a specialised clinic for assessment of ME/CFS and Swedish primary healthcare professionals.

Methods

This study was designed as a qualitative study with an explorative design.

The COREQ checklist for qualitative studies was used to guide reporting of the study.

Participants were patients diagnosed with ME/CFS according to the ICC at a ME/CFS specialist clinic in Stockholm, Sweden. Inclusion criteria were being over 18 years old and speaking and understanding Swedish. Thirty consecutively sampled patients, who had recently been referred to the clinic, were sent a letter inviting them to participate in the study. This letter included information about the study and forms for informed consent. Of the 30 patients, 15 accepted the invitation to participate. One did not answer a confirmatory telephone call, and one patient later withdrew consent. Thus, 13 participants, in the age range of 28 to 64 years, living in different cities around Sweden were included.

The study was approved by the Swedish regional ethics committee (Dnr 2018/1123-31/2). All participants gave informed consent and were assured of the possibility to withdraw from the study.

Data collection

Individual interviews were conducted and audio recorded. One interview took place via a video call, three were face-to-face, and the other nine interviews were conducted as telephone interviews, all according to participants' own choices. Two of the members of the research team conducted the interviews, which lasted 14 - 46 minutes, performed using a semi-structured interview guide.

Data analysis

All interviews were transcribed and analysed, being guided by content analysis [11]. The interviews were read several times to get an overall picture of the content. Codes and preliminary categories were then discussed among the researchers. Repeated discussions took place between the researchers in order to reach a mutual understanding of the data and determine categories. The process of going back and forth in the analytic process continued until a consensus was reached.

Findings

In this study about the experiences of the patients, three categories emerged. For patients it was important to Feeling truly connected; in the period before they received a diagnosis, Time is an important factor; and in the phase from initial symptoms to diagnosis, Knowledge is power.

Feeling truly connected

The informants described encounters with healthcare professionals where they felt connected, as well as situations where they had not. When patients suspected that there was no interest from the health care professionals, it made them feel like they were not being seen. These interactions resulted in the patient experiencing feelings of flatness, contempt, lack of respect, or disinterest. According to one of the patients, the physician involved did not ask follow-up questions or listen to the patient, did not give suggestions for future actions, and did not take blood samples or other tests for several years. This created a sense of not being taken seriously, as described by the patient: "Hard to put into words. It is this 'little girl attitude', like it's something bothersome for them to investigate, which gives you the feeling that they don't believe you." (Informant 2). This kind of care was described as dishonest and disrespectful. When the only feedback from physicians was that all test results looked good, even though the informant still did not feel well and did not get any help, the patient felt poorly treated, resulting in some patients avoiding further contact with primary care for many years.

In contrast, when patients experienced being welcomed into the context of the assessment by the healthcare professional, feeling that their contribution to the consultation was valued, they reported feeling content and well cared for. This experience meant having their competence in the matters acknowledged and openly listened to: "The regular physician is great. He listens and often asks me 'What is new in research?' He's very open." (Informant 7). One participant described how one day he suddenly felt different after a visit to his physician; he felt good but did not know why. He described how he later realized that he felt good as a result of being met with interest by the physician. Some participants experienced a more positive dialogue with their physician in those instances where a spouse, friend, or relative accompanied them to their appointments. One participant described her experience when her father, on one occasion, came with her on a visit to the physician. On this occasion, the physician approached her completely differently: "It feels quite strange that you need to have a person with you at the visit to be taken seriously." (Informant 12). The feeling of being heard was important, together with the notion of being treated from a more holistic angle. The patients wished for the primary care sector to improve their interactions with them because it was where they had their initial contact: "You visit each physician with one body part. Sometimes you would like to visit a physician who had a holistic view of you as a patient, instead of being one body part here, and one body part there." (Informant 4).

These experiences were also described concerning contact with nurses. A patient described her contact with nurses at the healthcare centre where she had been treated for more than 20 years. Receiving help, when the need emerged, gave the patient faith to rely on the relationship, a trust that the nurse cared for her as a person, and a feeling of being treated with respect.

Patients were grateful when healthcare professionals confirmed their physical symptoms, and there was genuine gratitude involved in meeting healthcare professionals who wanted to help. When physicians legitimised symptoms, patients felt that it legitimised their life with ME/CFS. For patients, being referred to a specialist or offered treatment was more important than just legitimising symptoms, and this led to patients increasing their confidence in their physician. Receiving a referral to a specialist clinic and getting a diagnosis was described as being the most important because they were now finally being seen, enabling hope for the future.

Time as an important factor

Time was a central factor in the experiences of the informants. The visits at the primary care centres were short. Many participants reported feeling that the system was inefficient, stating that nothing happened for half a year after their first appointment. Some participants had to wait over two years before being admitted at the specialist clinic they had been referred to. This could trigger anger due to the feeling that their lives and resources were being wasted. However, regular meetings with a nurse could ease the anger of waiting: "She takes the charge … when I get the help I need instantly, It´s less difficult for me." (Informant 4). Patients who were only given short appointments with their physician experienced a lack of confidence in their physicians, as they thought this was too short a time to make a proper examination or give a diagnosis. Many consultations were only ten minutes long. Some participants were prescribed medication, which they felt were used as a way for the physician to avoid giving a real diagnosis. This experience could also trigger, to an even greater extent, feelings of neglect when the patient met different physicians or when it took a very long time before they received any help. One participant described the experience of waiting: "The feeling was desperation, I was desperate, I told myself, now I will do ANYTHING. If I have to run naked around the earth, I will do it." (Informant 1). Short meetings also generated stress among patients because they then felt that they had no time to address the problems that they wanted to address. The experience of the treatment in primary care was affected by the level of knowledge of ME/CFS among healthcare professionals. If the physician did not know the physical symptoms and explained that the symptoms were due to mental illness, or prescribed antidepressant drugs even though the informants did not feel depressed, the patient experienced a rising sense of frustration: "Yes, I have tried antidepressants before, but it took several visits before he realised that it's not because I want to sit at home that I sat at home. I want to do things, but it just doesn't work." (Informant 6. The interactions with primary care were sometimes complicated by the difficulty of merely getting in contact with healthcare professionals. First, you had to call them, and then they were supposed to call you. When they did call, the person you were talking to might not be knowledgeable about ME/CFS.

Knowledge is power

The experience of the treatment in primary care was affected by the level of knowledge of ME/CFS among healthcare professionals: "I think it is great that nothing is taboo about mental disorders anymore [...] but it must not lead to that as soon as you do not know what the physical symptoms are, then it becomes a mental illness. This can easily be a shortcut." (Informant 10). Patients also reported feeling frustration when given an unsuitable training programme by a physiotherapist and were made to follow it for several days, as this was interpreted as a lack of knowledge by the physiotherapist.

There was a wish for increased competence and knowledge among healthcare professionals:

"She does not know ME, or I mean... as a general practitioner, she can't know everything, that I understand. But an important thing is also that she should be able to recognise areas where her knowledge is insufficient and then refer to others." (Informant 3)

Often patients felt the need to seek information about ME/CFS via the internet and YouTube, alongside that given by healthcare professionals, and because of this, they felt that they became experts of their own. Participants described feeling like they had to take the lead in their treatment, and that they felt like the physicians conducted tests which they did not believe to be necessary, simply to appease the patient. Powerlessness was described and a feeling that the consultations were of no value. This was also seen by the patients as ignorance, leading them to move away from primary care to private care, with physicians who knew how to diagnose ME/CFS and how to treat pain: "The reason I got away from primary care was that I felt like... how should I describe it?...that you didn't get the responses that felt good and I guess that is due to ignorance. " (Informant 2). When there was attention to ME/CFS in the media, or if the primary healthcare professionals received relevant education, patients experienced a more responsive consultation with the physician.

Discussion

In this study, patients presented their experiences regarding interactions with healthcare professionals in primary care; the patients expressed that it was important to feel truly connected with the physician. It has been recommended that healthcare professionals-in their efforts to help normalise ME/CSF as a chronic condition-work towards early diagnosis, address all symptoms the patient might experience, and engage in continued education to stay updated on current treatment options [12]. These recommendations may be appropriate for the patients in our study, as the amount of time it took to confirm the ME/CFS diagnosis was important to the patients, as was the experience of being taken seriously regarding all the symptoms the patient experienced. A recent synthesis of patients' reporting of harm in the medical encounter concludes that conflicts between healthcare professionals and patients might be avoided if a patient-centred approach is taken, allowing for the patient's narrative to guide care [13]there has been a strong impetus to tackle the illness utilizing a biopsychosocial model. However, many sufferers of this disabling condition report distress and dissatisfaction following medical encounters. This review seeks to account for this discord. METHODS: A narrative review methodology is employed to synthesize the evidence for potential iatrogenesis. RESULTS: We identify seven potential modalities of iatrogenesis or harm reported by patients: difficulties in reaching an acceptable diagnosis; misdiagnosis, including of other medical and psychological conditions; difficulties in accessing the sick role, medical care and social support; high levels of patient dissatisfaction with the quality of medical care; negative responses to controversial therapies (cognitive behavioral therapy and graded exercise therapy.

The patient-healthcare relationship is important for patients with ME/CFS [14]management, and relational continuity. METHODS: This cross-sectional study uses questionnaire data collected from members of The Norwegian ME Association. Descriptive statistics and logistic regressions were used to estimate experiences of continuity, and associations with age, education, self-rated degree of CFS/ME, duration of the GP relation (GP duration, and findings in our study can contribute to defining this relationship. In our study, a sense of connection in the interaction with healthcare professionals was powerfully facilitated by elements of teamwork, where the patient's competence or viewpoint was validated by the healthcare professional, either explicitly or implicitly. Scheffelaars., *et al*. [15] illustrated this in terms of equality: personnel should treat patients as equals and value their expert knowledge. This also emerged in our study, where patients were attentive to signals of whether they were seen as someone who played an active role in the process and given the chance to add their influence.

A multi-professional care team working in primary care and a patient-centred framework might be one approach, reducing over-testing and diagnostic delay, while also improving the outcome for patients [16]. When a patient is diagnosed late, this also impacts healthcare professionals' ability to follow recommended guidelines for treatment, as patients then have a variety of symptoms and rely on high doses of both prescribed and over-the-counter medications to ease their symptoms [17]. Patients in our study felt that knowledge of the specific disease was important and that this could be difficult to find among healthcare professionals. Perceived quality of care and its correlation with self-rated health was also found in a study from Norway [18]and CFS/ME patients' assessment of quality of primary care, specialist care and coordination of care. DESIGN: Cross-sectional study. SETTING: Self-reported questionnaire data from women members of The Norwegian ME Association obtained in 2013. PARTICIPANTS: 431 women with CFS/ME aged 16-73 years. MAIN OUTCOME MEASURE: The participants' assessment of quality in primary care, specialist care and in coordination of care (good/very good or poor/very poor, indicating similarities in outcome. When patients' experiences are validated, it enables the journey towards an improved quality of life [19].

Patients' knowledge includes their own understanding, as well as knowledge among healthcare professionals. It has been shown that only 23% of general practitioners report having sufficient knowledge about the disease [20]general practitioners (GPs. When healthcare professionals lack the knowledge, and are also sceptical of the diagnosis, it impacts the speed of diagnosis as well as the openness towards multiple treatment possibilities, which can lead to epistemic injustice when patient testimony is discredited [21]there is continued debate about how best to conceive of CFS/ME, including disagreement about how to interpret clinical studies of treatments. Against this background, robust qualitative and quantitative research from a range of countries has found that many doctors (and medical students. This creates a situation with ethical consequences in healthcare, and it also enables the stereotyping of patients among healthcare authorities that may increase their marginalisation [22]. These are also mechanisms seen among patients with other illnesses, such as multiple chemical sensitivity [23] and medically unexplained physical symptoms [24], as well as among patients from other cultural contexts [25] four women. When patients are marginalised, it might negatively impact the progression of their disease [26], which again can have a socioeconomic impact.

Methodological considerations

Participants in this study were in a vulnerable situation, and the findings might only reflect the experiences of those who were well enough to participate in our study. The transferability of our findings must be viewed in light of this possibility.

Conclusion

In this study, we found that patients with ME/CFS were met with different levels of knowledge and interest from healthcare professionals. These challenges might be related to the relative rareness of the disease and the underlying cultural scepticism still present among healthcare professionals. As patients' well-being is related to their relationships with healthcare professionals, further research is important to develop more patient-centred approaches.

Conflict of Interest

None.

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None.

Author Contribution

All authors (KT, PC, GB, BCB and HK) contributed to the design, analysis and interpretation of data. KT and PC collected data and drafted the manuscript together with GB and HK. All authors (KT, PC, BCB and HK) gave their final approval of the manuscript and agree to be accountable for all aspects of the work.

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