Invisibility and diagnosis stigma: disabling factors for female adults with myalgia encephalomyelitis (ME)/chronic fatigue syndrome (CFS) in a small-scale qualitative study in England

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Abstract

Purpose – Female adults diagnosed with myalgia encephalomyelitis (ME) and chronic fatigue syndrome (CFS) often are marginalised because their condition is not fully recognised by medical and health-care systems. The purpose of this small-scale study was to explore the lived experiences of adult females with ME/CFS in England in relation to contributing factors that impact their occupational participation.

Design/methodology/approach – A qualitative study design using semi-structured interviews was used with nine female adult participants who were selected using a purposive sampling method. A Thematic Networks tool was used to analyse data.

Findings – Four organising themes were identified: impairment-, person-, environment- and society-related factors. Two global themes, invisibility and diagnosis stigma, were identified as the overarching issues that female adults with ME/CFS face in occupational participation.

Originality/value – Many of the issues that contribute to lack of participation by this population are associated with environmental factors which are secondary to their illness.

Keywords Stigma, Invisible disability, Thematic analysis, Qualitative study, Occupational participation

Paper type Research paper

Introduction

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a complicated disease that has often been misunderstood and only recognised as an illness since the 1980s (Rubal and Iwanenko, 2004). According to the National Academy of Medicine:

> ME/CFS is a serious, chronic, complex, and systemic disease that frequently and dramatically limits the activities of affected patients. In its most severe form, this disease can consume the lives of those it afflicts (National Academy of Medicine, 2015, p. 5).

The prevalence of ME/CFS is difficult to estimate due to lack of consistency and changes in diagnosis criteria over time and in different countries. According the MEUK Association (2023) the prevalence of ME/CFS is at least 0.2%–0.4% with women diagnosed approximately three times more than men. It is crucial to consider that a significant number of people affected by COVID are diagnosed with ME/CFS afterwards and

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therefore the prevalence of this condition has increased in the recent years (Mirin *et al.*, 2022).

McManimen *et al.* (2018) have highlighted the degree of debilitation in ME/CFS, and its low improvement rate. Individuals with ME/CFS often have challenges in getting their conditions recognised by health-care professionals for reasons, such as the high degree of uncertainty in diagnosis, fluctuating symptoms and the level of restriction adults with ME/CFS experience with participation in day-to-day life (Hughes, 2009; Smith *et al.*, 2015; Weir and Speight, 2021).

Restricting situations may lead to a sense of detachment, not belonging and isolation. Disablement may create a sense of imprisonment and inability to participate in life as others do (Lian and Lorem, 2017). Lack of understanding by significant others is reported as a key aspect of loss of social participation, resulting in more isolation (Pinxsterhuis *et al.*, 2015). Unsupportive social interactions, social distancing and others' minimisation of the illness result in a sense of helplessness similar to that felt by those with terminal illness (McManimen *et al.*, 2018).

Apart from anecdotal evidence, there is a gap in the knowledge of factors that diminish participation and engagement in life situations for adults diagnosed with ME/CFS.

This study explores the lived experiences of adults with ME/CFS from their own perspectives regarding the impact of their condition on their occupational participation; how they feel and how they respond.

Materials and methods

Methodology

A qualitative method was used. Purposive sampling was used with specific eligibility (Ames *et al.*, 2019). Oxfordshire Myalgia Encephalomyelitis Group for Action facilitated recruitment by circulating an invitation to eligible participants. Eligibility was based on official diagnosis of ME/CFS by official medical services. Semi-structured interviews were used as the method of data collection.

The interviewer was an experienced mental health occupational therapist and counsellor with experience of ME, this helped to establish relationships and build trust enabling participants to open up about their experiences (Berger, 2015).

Several strategies were used to manage potential biases and ensure that the interviewer's position had a positive impact on data collection. These strategies enhanced rigor, both in data collection and analysis. Both interviewer and data analyst used reflexive journals, discussing their ideas with each other throughout the process. These discussions aimed to clarify and facilitate in-depth understanding of the participants' experiences to aid interpreting data and supporting researchers to ensure the confirmability (Lysack *et al.*, 2006; Thomas and Magilvy, 2011).

Following each interview, participants were invited to send supplementary information; this aimed to enhance credibility. The interviewer wrote a reflection after each interview which was taken into consideration in the analysis process. Two data analysts separately identified themes which were then discussed to increase credibility (Morrow, 2005).

Participants

Ten eligible participants were invited. The sole male participant later withdrew from the study due to the flair up of his symptoms. Nine female participants were interviewed with the average age of 47, range between 28 and 65. They all had received an official diagnosis and the average illness duration was 14 years, ranging between 4 and 30 years. Two women were retired, three full time, two part time with on and off jobs, one on occasional volunteering jobs and one had to stop working all together. Participants with a full-time job, reported that their type of job had allowed them to have more flexibility around the hours and style of working. All participants reported that the severity of their condition was fluctuating with seven between mild to moderate with occasional severe episodes. Two reported their condition as moderate to severe.

Ethics

Ethics approval was granted by the Research Ethics Committee at Oxford Brookes University (Reference Number 211532).

Analysis process and method

Thematic analysis was used to process interview data and provide basic, organising and global themes. Thematic networks (Attride-Stirling, 2001) and Braun and Clarke's (2006) six steps for thematic analysis were used to provide a realistic view of participants' experiences. Two data analysts separately read transcripts and identified common codes to represent participants' shared experiences. Basic, organising and global themes were identified.

Findings

This section presents the identified basic, organising and global themes. The four organising themes are presented first and the basic themes are briefly explained under each organising theme. Lastly, the two global themes are explained. Thematic networks of the research findings are presented in Figure 1.

Organising theme 1: impairment-related factors

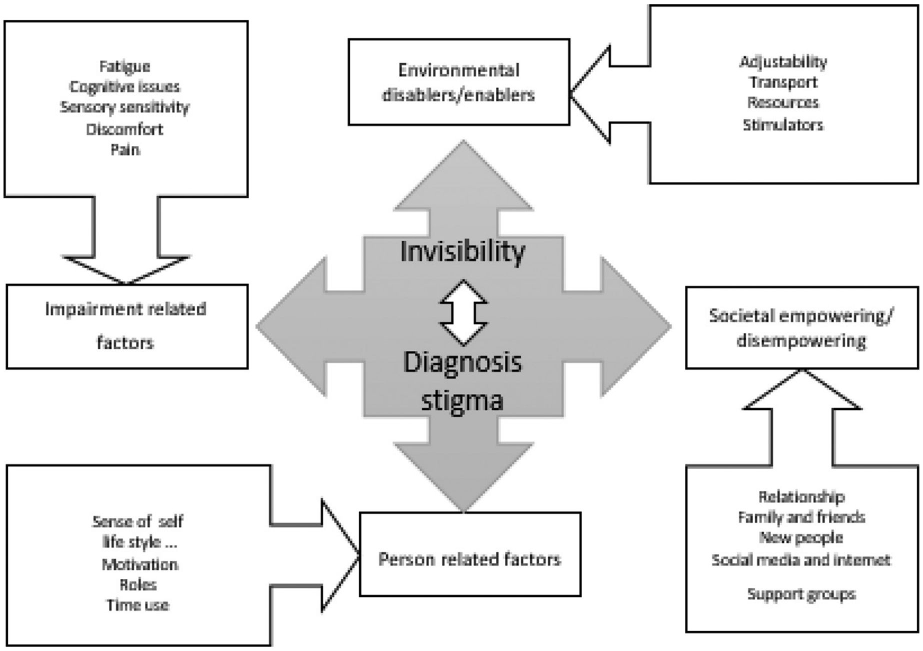
Participants explained the symptoms of their illness and the way these interfered with their ability to do things which they had been able to do prior to their illness. The four categories of symptoms, each of which forms a basic theme (fatigue; cognitive impairment; pain and physical discomfort; sensory sensitivity) commonly considered most debilitating by participants were gathered to form this organising theme.

Basic theme 1.1. fatigue

Fatigue was mentioned by all participants as their main symptom. Two forms of fatigue were identified: physical and mental. Participants emphasised emotional frustration, feeling drained psychologically as well as lack of concentration, poor memory and inability to cognitively manage a task. Mental fatigue was explained as sudden thought blocking or feeling overwhelmed, which led them to stop their activities and rest which further exacerbated isolation. Participant 3 said: "[the] worst thing is when you cannot talk, when I'm so tired that I cannot talk or I cannot explain, or I cannot answer phone calls".

The word "fatigue" seemed to be misinterpreted by health-care and medical professionals: it did not portray the intensity of the experience, therefore, the debilitating impact was

Figure 1 Thematic networks presentation of the research findings



Source: Authors' own work

underestimated. Participant 1 explained: "people say oh we all get tired, I got tired the other day". Advice to "get some rest" added to the level of frustration.

Basic theme 1.2. cognitive impairment

Participants referred to the cognitive impact of the condition as "cognitive fatigue" or "brain fog". This appeared to be one of the most debilitating aspects of the condition because it affected their ability to work. Participant 1 said: "the worst thing is fatigue and cognitive functioning" and "lack of concentration and brain fog [. . .] is difficult for me to handle".

Memory deficit, when mentioned, significantly impacted functioning. Participants mentioned strategies to help them. Participant 2 described severe memory problems, and said she wrote things down to aid herself. Cognitive dysfunction seemed to be a very restricting factor for managing work-related tasks and the main reason for leaving/losing jobs.

Basic theme 1.3. pain and physical discomfort

Physical discomfort was widely reported in many forms: discomfort from certain positioning, physical exertion or even as a result of the cognitive demands of an activity. Their level of discomfort was acknowledged by close friends and family but not understood or acknowledged by people further from them, including professionals. The lack of appreciation of the level of pain and the delayed consequences of exertion were the main causes of being misunderstood. The fact that participants were able to walk but as P7 said: "faced pain and discomfort later" disadvantaged receipt of support services such as parking benefits. Fatigue, pain and discomfort-triggered factors with delayed consequences were judged negatively by others. Participant 4 said: "I stopped particular social engagements which resulted in becoming bed- or housebound sometimes for days afterwards". While some activities could be managed with certain strategies, ME/CFS meant that peripheral activities were not manageable. The fact that participants might look fine at the point of contact with others but faced consequences later was not easy to explain.

Basic theme 1.4. sensory sensitivity

Most participants relayed decrease tolerance to sensory input following the onset of their illness often related to the intensity of the stimuli or the period of exposure. Participant 1 said: "I can do short periods for instance but if I'm put in a situation with lots of lights, sounds, lots of people, and stimuli (not only people talking but also the topic of conversation and how cognitively and emotionally demanding they were), it will be half an hour before I feel unwell". Some senses were more affected than others were. Participant 3 noticed an increase in sensory sensitivity to lights and smell saying, "what is really the worst, and if I'm tired it makes me mad, is sound". She emphasised that this impact of sound had ended her career as a musician.

Organising theme 2: person factors

The second organising theme shows how participants' symptoms affected their being and selfhood as an individual and what it meant to them to be ill and live with their condition. The following basic themes (sense of self; motivation; lifestyle, hopes and aspirations; roles; time use; and resourcefulness) illustrate participants' perceptions of their pre- and post-illness status.

Basic theme 2.1. sense of self

Participants presented their view of themselves, describing what had/had not changed due to their condition. There was an emphasis on their abilities prior to illness, and a desire to retain the characteristics related to that identity. They felt these were challenged by both the social and professional remarks received. Participant 3 said: "a lot of people with ME have been hard workers, achievers until we become ill". While they still identified with the person they were prior to their illness, they were sometimes described as "lazy" or it was implied that they had chosen to be unwell.

Participants described how their changing activities and patterns of activities affected self-views. Participant 5 said: "camping, rock climbing, and mountaineering so all of my social activities were actually super active [...] I feel like a completely different person than I was before". Participants' views fluctuated between hope and despair due to lack of evidence about diagnosis and treatment of their illness.

Basic theme 2.2. motivation

All participants had experimented with interventions thought to help with their condition. Participant 1 explained: "This is not depression; I do have the will to do things. I want to go out [...] go shopping, go to the cinema, and go to my friends. I just can't move, you know". All participants were motivated to change their situation by engaging with a variety of programmes varying from those offered by health services, e.g. cognitive behavioural therapy (CBT), and others that participants tried themselves including different types of massage, acupuncture and special diets. There was agreement that suggested health service interventions were not helpful. Some considered them to exacerbate their condition. Two participants acknowledged that CBT had helped with secondary emotional problems but not ME/CFS symptoms.

Basic theme 2.3. lifestyle, hopes and aspiration

Participants talked about how their life plans had changed because of their condition. Participant 4 described her retirement plan to sing in a choir with her partner: "that's another thing I thought I'd be able to do". For Participant 5, a young woman with ME, the ability to manage pregnancy and child care was a concern: "[the] biggest emotionally challenging thing I see for my future is that I would really like to be a mother". Poor evidence about the illness, its prognosis and fluctuating symptoms created uncertainty, making it difficult and for some impossible to plan for the future.

Basic theme 2.4. roles

Participants highly valued their supporting and caring roles within their family and/or friendship groups but expressed feelings of despair, guilt and frustration about being unable to continue due to ME/CFS. Participant 1 explained: "where it hurts really is when I can't do as much as I want to with my son", adding that helping other people with ME and disabilities "is something that keeps me going".

Basic theme 2.5. time use

Participants mentioned how their concept and use of time had changed, due largely to low energy and fatigue, which impacted their social interactions and commitment to tasks with or for others. Participant 4 said she had: "lots of other friends I'd like to meet up with and it's just difficult when you say 'well I can only manage half an hour' when it used to be kind of an hour and I feel like it's dwindling". Participants mentioned how starting the day was daunting. Participant 3 explained: "slow dressing and getting ready in the morning and those morning chores took about two hours" which impacted on the type of job she could manage.

Basic theme 2.6. resourcefulness

Participants showed a diverse range of strategies to help them manage their lives. Some had stopped working due to their condition, which had made it difficult to meet job requirements. Participant 1, who was still working at the time of the interview, described a wide range of adjustments. For instance, she recorded conversations with colleagues, to aid her memory problem. She also had a mattress at work and requested a room where she could rest during the day. Participant 5 explained how her home was adjusted: "we set up the house to be pretty comfortable, so we have a daybed in the living room so I can lay down [...] I don't need to be in the bedroom". Other participants were unable to make such modifications, partly because of lack of support from services.

Organising theme 3: environment enabling/debilitating factors

The third organising theme is environment. The basic themes are transport, stimuli and resources, which play significant roles in enabling or disenabling social and other activities.

Basic theme 3.1. transport

Participants reported difficulty in using public transport. Problems with noise, vehicle motion and crowds related to hypersensitivity. Whereas participants using their own vehicles detailed fatigue, nausea, lack of energy and pain. Participants had limited capacity to travel and most had established the maximum distance they could manage. Participant 6 said: "my contacts with loved ones were restricted by the limited distance she could drive".

Basic theme 3.2. stimuli

Participants presented examples of the limiting impact of hypersensitivity to stimuli, notably visual and auditory stimuli. Probing revealed discomfort with movement, speed, spinning and other sensations which presented as vertigo, discomfort, nausea and body aches. Participant 5 said: "I couldn't visit my family in their place as the light, TV noise, even cooking smell was intolerable for me". Avoiding or limiting certain stimuli enabled participants to engage in many activities

Basic theme 3.3. resources

Pursuing independence was difficult due to lack of environmental resources, such as parking badges. Their acquisition proved difficult for some while others were criticised for not being visibly disabled when using them. Electric scooters or bikes were useful to those who qualified for formal mobility support although some participants mentioned that ME/CFS did not receive the same support as other conditions. Fluctuations in symptoms created confusion for healthcare professionals evaluating the need for aids and services. Participant 7 said that: "not receiving support was so upsetting because the mobility with ME is very fluctuating". Participant 2, who had a dual diagnosis and found more support services were available for her other medical condition than for the ME, said: "I don't think he fully understands the extent [of my problem] because he sees me on a better day because obviously I plan".

Organising theme 4: society empowering/disempowering factors

The fourth organising theme, participants' connections to others, the roles others play in their life and the support others give, embraces understanding ME/CFS, validating the presence and limiting extent of symptoms and providing care and support emotionally and financially. Participants expressed frustration regarding how some people showed doubt about their illness. As Participant 1 stated:

> That lack of social acknowledgement gets into you and you start doubting yourself and when you can't get out of bed and you start thinking maybe if I try harder maybe if I push. And that is horrendous.

Basic theme 4.1. relationships

A long-term relationship with a supportive partner was a strong empowering factor. Participant 6 talked about her husband doing all the chores and Participant 2 showed how supportive her partner was by: "knowing that he will never judge me for not being able to do stuff". Alternatively, other participants ended a relationship because of their illness. Participant 3 said that her partners in different relationships had not understood her illness. Participants without partners spoke about how difficult it was to find a relationship because of their condition.

Basic theme 4.2. selection-based connections

Participants distinguished between two types of relationship; those with family and friends, and those who they chose to remain connected with. The terms "supportive family", "negative" and "distant" family, "close friend" and "distant friend" were used to describe levels of interaction, togetherness and connection to other significant people. Generally, immediate family were identified as understanding.

Participant 7 stated that: "my friends and family have been amazingly supportive [. . .] they essentially act as my mini carers when I am around them so I can feel independent". Whereas Participant 1 said that those family and friends who did not understand "detach themselves progressively because they think it's too weird to understand". The fluctuation of the symptoms and sudden changes in the level of energy were confusing for others. There seemed to be explicit and implicit, gradual decisions made around the possibility of continuing relationships with family and friends.

Participant 4 said: "I'm almost ashamed to tell [friends], because I know they can't really understand and I don't really bother them about it [. . .] so I end up not even meeting them". It was clear that participants had a group of family and friends that they could identify as "understanding". The fact that others could not manage the situation was understood and accepted by participants even though it could be hurtful.

Basic theme 4.3. health-care professionals

Interactions and relationships with health-care professionals varied. Some participants had positive accounts and others were left feeling invalidated. Participants indicated that their relationship with GPs, consultants and other professionals influenced the resources available to them.

Several participants described lack of understanding, doubt and confusion, suggesting that some health-care professionals do not believe that ME/CFS exists while others think it as purely psychological. Symptoms were dismissed, ignored or attributed to underlying mental health and psychological problems and personality characteristics. Participant 5 stated: "I had been going to the doctors [. . .] they just kept telling me there was nothing wrong and refusing to give me a doctor's certificate to let me put my thesis on hold". Participants had to manage the attitudes towards their symptoms alongside the aches and fatigue they were experiencing. They felt frustration at having to deal with both the illness and the stigma. A sense of unfairness caused secondary problems due to the pressure of the psychosocial consequences of their diagnosis. Other participants indicated the significance of their GPs' understanding in opening pathways of help, hope and support.

Basic theme 4.4. new people

Meeting new people is particularly challenging when there is an invisible disability. Participants described needing to explain themselves constantly and even to apologise when they have to limit an encounter, stop a conversation or reposition their body. Managing sensory sensitivity was especially difficult because communicating the discomfort around people's conversation volume, or a cognitively or emotionally demanding conversation topic, could be interpreted as impolite or self-centred. Participant 1 said she feels the need to say:

> Forgive me if I look like I'm not paying attention to you. Forgive me if I have to cut the conversation short, forgive me if I do not remember your name or your face. So, my ME takes over.

The difficulty of explaining, inevitable when the illness is not well recognised, then more explaining creates a cycle of fatigue, disappointment and the desire to avoid contact distance. However, it is difficult to avoid spontaneous socialising, for example, when shopping.

Basic theme 4.5. social media and internet

Some participants described how the internet helped them to stay connected with friends and support groups. Mostly, the internet had created a means of staying connected with learning, education and entertainment, meeting friends and family and raising awareness about their condition. Participant 7 found it meaningful and purposeful as: "[online] raising awareness and learning about ME and other health conditions gives [me] satisfaction". Many used the internet for socialising. Participant 2's internet use entailed: "a lot of answering emails, catching up with friends, keeping up with what they're doing". However, Participant 1 also highlighted how it made her feel more disconnected: "when you see on Facebook, people doing things, you know people taking a day out with children".

Basic theme 4.6. support groups

Meeting people with the same condition empowered and supported those with self-doubt. Most participants lived too far away to take part in face-to-face support groups but found online groups useful. Participant 1 appreciated: "seeing other people struggling in the same ways" and Participant 6 felt: "that definitely makes me feel connected and be part of [. . .] we've got something in common". Because the illness is invisible there is often doubt whether it is real, and support groups give people a space to talk openly with others who have MS/CFS.

Global theme 1: invisibility, unpredictability and fluctuation triad

The first global theme was the incongruency between visibility and lived experience: participants felt they were not understood because the illness is invisible. The subjectivity of the main symptoms (fatigue and pain), and their fluctuating severity and unpredictable patterns of manifestation, made understanding the illness difficult for the participant and others.

Global theme 2: stigmatised diagnosis

Unhelpful responses by others regarding the condition, such as denying its existence or refusing to give access to support services, were debilitating. Participants felt that their symptoms were not always believed by society and medical professionals. There was a sense of injustice about how lack of understanding of the illness led to its denial and the sometimes pejorative labelling of people diagnosed with ME/CFS. For participants, the problem was not so much the lack of knowledge as the unwillingness to explore it further and research it properly. Disbelief among medical and health-care services appeared to bear on the way newly notified illness was handled. The lack of a scientifically established aetiology and pathology concerned participants less than the resistance to accept the illness as a phenomenon that needed to be investigated. Some medical professionals seemed to make up for their lack of understanding by fitting the illness within existing medical science. Participants found such resistance to accepting that existing knowledge is unable to fully explain the illness curious.

Discussion

This small-scale study identified factors contributing to the participation patterns of female adults in England diagnosed with ME/CFS. The relationships between the four organising and the two global themes were explored and linked to the existing literature. The main finding is the significance of the approach and attitude of the medical system in empowering/disempowering those with ME/CFS through facilitating or blocking resources that enable participation in day-to-day activities. According to the International Classification of Function, Disability and Health (ICF), impairment on its own is not an indicator of disability or its level. Rather, limitations and restrictions on activity and participation play a large part in causing disability (World Health Organisation, 2001).

There is no doubt that the symptoms of ME/CFS are debilitating by their nature; however, medical and social service responses to the condition have not always helped people diagnosed with ME/CFS return to participation (Raine *et al.*, 2004). Some interventions offered to adults with ME/CFS overlook aspects of the condition. For instance, the negative impact of cognitive problems associated with ME/CFS makes it difficult for those diagnosed to benefit from intervention plans focused on self-management coping strategies (Pinxsterhuis *et al.*, 2015).

In a metasynthesis of findings from 53 papers about chronic illness, Schulman-Green *et al.* (2016) argued that factors such as family, work and health-care services influence self-management of the condition. In this study, participants also showed that their pre-illness situation, established relationships, secure job, social status and good finance interactively contributed to a more supportive basis for handling complications of the illness. Partners and family support, and healthy personal finance, provided opportunities for participants with ME/CFS to modify home and work environments to allow flexibility around activities. For example, supportive partners who could take responsibility for household chores, drive their partners around and purchase useful equipment were indicators of the significance of the environment in enabling adults with ME/CFS to manage day-to-day life and in some cases remain working, at least part time.

Flexibility in physical and social arrangements was an important factor empowering female adults with ME/CFS to retain independence. While physical support such as the provision of areas and time for rest were helpful, the attitudes and belief of people around those diagnosed with ME/CFS were key in facilitating the physical environment. Elements of trust and empathy that seemed to be present for people with other kinds of invisible disabilities, were felt missing for adults with ME/CFS. The problem was not just that the illness is invisible to others (which is often true of other illnesses), but that the symptoms fluctuate. Due to fluctuating symptoms, friends, family and colleagues often see stepping back from strenuous work and pacing as a choice rather than necessity, which further isolates the person (Taylor, 2005). When someone says that they have a condition, they normally expect others to understand that there is an issue to be considered. However, the diagnosis of ME/CFS often not only fails to evince reactions that show understanding, but may also elicit a negative response, due to myths that it is not being a real illness (Weir and Speight, 2021). Such issues can cause obstacles to participation for adults with ME/CFS, particularly outside their home environment.

As with any health condition, the severity of the illness plays a part in limiting activity, but an additional challenge for those with ME/CFS is that sensory triggers can lead to sensory overload and overwhelming responses. Noise, smell, motion, speed and changes in position, particularly in crowds and around others (which makes it more difficult to control), are examples of triggers that exacerbate other symptoms, such as pain and fatigue. The interaction of these factors is difficult to handle for someone who is already experiencing low energy. Therefore, the natural response is avoidance of participation and engagement in any situation that may trigger or exacerbate symptoms.

Previous lifestyle, habits and related skills and capacities play a role cognitively, physically and emotionally in the level of disability that ME/CF causes. For instance, for adults who engaged in a lot of outdoor activities, or whose jobs were more cognitively demanding, the new physical and cognitive impairments made a more dramatic change to their lifestyle, demanding more effort, strategies and plans to manage their post-illness situation.

Established trustworthy relationships with employers, partners and friends are more conducive to understanding a person's limitations and needs for adjustments. At post-diagnosis, it is harder to form this type of relationship that facilitates trust, respect for needs and eagerness to provide for them. Taylor describes how this rapport should be developed over time to build trust (2005). Clair *et al.* (2005) describe the challenge and related stigma of "passing or revealing" invisible illness to employers. That was one of the main reasons that adults with ME/CFS found encountering new people very challenging, for instance in a new relationship, friendship or job.

The two global themes emerging from the small-scale study presented in this paper highlight the significance of interaction between some characteristics of the illness and professional and social responses to them. This interaction was the foundation of most problems raised by participants.

ME/CFS as a condition is not well understood and attracts little attention in terms of further investigation and research meaning that participants living with the condition face doubt and disbelief by friends, family and health professionals. Goldberg (2017), explains the historical background of pain stigma and how pains that could not be linked to a lesion were stigmatised or and seen as Semitism, writing that:

> In Western contexts of increased anxiety about deception and corresponding efforts to discern the truth of the matter via forensic investigation of the natural world, pain without lesion was increasingly problematic.

According to Goldsberg, the issue of pain complaints were increasingly sites of doubt and contest between illness sufferers and physicians. The issue with ME/CFS is that fatigue can be equally stigmatised, but is it not time that medical science reflects on understanding pain and similar human experiences of illness rather than stigmatising the unknown?

Conclusion

This small-scale qualitative study of female adults diagnosed with ME/CFS, has the usual limitations of studies of this kind. However, it does present issues about the current status of adults with a diagnosis of ME/CFS that raise ethical and disability rights questions. At times, frustrated individuals with ME/CFS may sound frustrated from health professionals and others who don't believe them; a qualitative paper using the words and the voices of these individuals gives a first-person account of "what really is".

Implications for practice

Health-care professionals need to be mindful that the limitations of science and lack of knowledge about ME/CFS should be considered and emphasised in interaction with patients. Lack of empathy arising from disbelief of the issues this population encounters may cause harm, and is neither ethical nor professional. Many issues that contribute to lack of participation by this population are secondary to their illness and are preventable through establishing the right approach, and advocating for the right policies that support patients with ME/CFS.

Limitations of the research

Due to differences in the time of diagnosis and locations where the diagnosis has happened, diagnostic criteria may have been different for the participants.

Future research

A comparative study to investigate the impact of a supportive health-care system against one that lacks supportive services could provide a greater understanding of the role of contextual facilities in managing ME/CFS in female adults.

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