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Feeling like 'a damaged battery': exploring the lived experiences of UK university students with ME/CFS

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ABSTRACT

Introduction: Research regarding students with myalgic encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) has been limited. This study aimed to understand how their subjective well-being had been affected by their condition by exploring their experiences and sense-making processes.

Methods: Semi-structured interviews were conducted with eight students using video-calling software and were enriched by asking participants to think of a metaphor to describe their illness. Interpretative Phenomenological Analysis was used to analyze the interviews.

Results: Three themes were developed: *University as (de)legitimizing*, *Negotiating disclosure* and *Loss and adaptation*. Rosenberg's conceptualization of self-esteem was used as a framework to explore the findings as it reflected participants' accounts and provided an insight into their subjective well-being. Participants discussed their reduced self-esteem through experiences of delegitimization and stigma at their universities, as well as how they became more accepting of their illness and increased their self-esteem.

Conclusion: This study provides an understanding of how the lives of students with ME/CFS have been affected by their condition, including their experiences at university and in their social context. Participants raised potential avenues in which universities can act in a supportive manner to be empowering and enhance self-esteem, which is important due to the debated nature of the illness.

Introduction

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/ CFS) is an illness characterized by new or sudden disabling tiredness lasting a long time, or tiredness that is recurring and gets worse after activity [1]. The lack of a biological marker for the illness makes it difficult to define, leading to medical professionals being skeptical about the illness and decreasing the possibility of diagnoses [2]. The prevalence of ME/CFS in the UK is estimated to be 0.2%–0.4%, equating to around 260,000 people [3]. There is a lack of information on how

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many people recover from ME/CFS, but it is known that it is more common for children and young people to do so [4]. The NICE guidelines [1] state that whilst there is no pharmacological cure for the illness, management strategies should be used, such as pacing, and medication can be used to relieve symptoms.

The experience of living with ME/CFS

Individuals with ME/CFS experience physical, social and emotional difficulties. The physical impact depends on an individual's symptomology: it can be focused on pain, cognition or mobility [5] and, at its most severe, can cause profound and prolonged disability [6]. Social and emotional difficulties are common for individuals with ME/CFS. A lack of clarity regarding the illness often means that individuals do not receive support from healthcare professionals, friends and family [7,8], and instead mostly self-manage their illness [9]. Stigma and unsupportive social interactions can affect an individual's self-concept and identity. Self-concept is the way in which individuals view themselves [10], whereas identity focuses on how an individual makes sense of themselves through comparison with social categories [11].

Research into the effect of ME/CFS on one's self-concept and identity has been undertaken using qualitative approaches, particularly using Interpretative Phenomenological Analysis (IPA). Research has highlighted that people with ME/CFS experience delegitimization, which is having one's own perception and definition of an illness disconfirmed [12]. Dickson et al. [7] reported that delegitimization by loved ones tended to cause individuals to feel personally rejected, affecting their sense of self and self-esteem. Additionally, individuals with ME/CFS can experience an 'identity crisis' due to the loss of control over their body and personal life [13]. However, longitudinal studies have provided an insight into how identity can be reconstructed. Whitehead [14] found a non-linear trajectory of an individual's identity: an initial phase of disruption, followed by a medium-term phase, in which individuals desire to go back to their former self, and finally a period of progression to a new self. Likewise, Arroll and Howard [15] found that post-traumatic growth can come about from having ME/CFS, which is the idea that enduring adversity can result in positive growth [16]. This illustrates the long-term effect that ME/CFS can have on an individual's identity, resulting in both challenges and positive growth.

Previous research regarding individuals with ME/CFS has focused on changes in individuals' self-concept and identity. The current research study used self-esteem as the theoretical framework as it reflected the accounts of participants and enabled an insight into their psychological well-being. Self-esteem is a person's subjective evaluation of themselves, which is often conceptualized as the 'feeling that one is 'good enough'' [17 p31] and involves acceptance and respect of oneself [18]. Self-esteem does not necessarily reflect an individual's abilities but rather, high self-esteem correlates to feelings of acceptance of one's capabilities. Self-esteem can be measured at multiple levels, with the self being formed at the personal, collective and relational level [19]. Despite criticism that the importance of self-esteem has been over-emphasized [20], research has found low self-esteem causes negative outcomes for individuals with chronic illnesses, including self-stigma [21], maladaptive coping strategies [22], and psychiatric comorbidities [23]. Therefore, understanding self-esteem is important in understanding an individual's subjective wellbeing and health outcomes.

Students and chronic illnesses

Students with chronic illnesses face unique challenges, as they often move away from support networks [24], negotiate a new student identity [25] and face stigma and discrimination on university campuses [26]. O'Shea and Kaplan [27] found that students with psychiatric illnesses were engaged in a continuous process of meaning-making at an individual and social level to understand their disability. Additionally, Newman et al. [26] found that stigma and discrimination on university campuses affected students with disabilities' sense of purpose. This revealed how individuals with chronic illnesses struggle to make sense of, and accept, their illness. Other research highlights the impact of stigma and discrimination by discussing how students with invisible disabilities often choose to hide their illness to blend in with their peers [28], with disclosure a conscious decision [29,30]. This research acknowledged that students with invisible illnesses and disabilities can present different identities, and that their sense of self can be challenged by the university environment.

There is a lack of research exploring how universities can support students with chronic illnesses. Students in the UK with known disabilities (which includes those with chronic illnesses, such as ME/CFS) made up 15% of the student population in the academic year 2019–2020, an increase from 11% of students in 2015–2016 [31]. The introduction of the 2010 Equality Act resulted in discrimination against someone with a disability being unlawful. Therefore, universities are required to provide reasonable adjustments to students with disabilities. However, previous research suggests that universities struggle to support students with fluctuating conditions such as ME/CFS [32]. The present study is unique in its focus on the experiences of university students with ME/CFS. Understanding how they experience and make sense of their illness aims to provide an understanding of how their psychological well-being is affected by their illness, as well as to understand how university communities can support them. This was explored using the following research question: *How do university students with a diagnosis of ME/CFS experience and make sense of living with their illness?*

Methods

Design

The present study aimed to build on previous IPA research by exploring a student population with ME/CFS, a population which has yet to be captured from a phenomenological perspective. An inductive IPA approach was chosen as it enabled the researcher to focus on participants' accounts, rather than imposing a theoretical framework or a pre-conceived focus on participants' narratives.

Participants and recruitment

In accordance with IPA's commitment to the idiographic, a small and homogenous sample of eight participants were recruited [33]. The inclusion criteria were for participants to be studying on campus either full or part-time at UK universities. UK students were recruited so all participants would be part of a similar education and healthcare system. All participants saw their diagnosis of ME/CFS as their main health concern and

had been diagnosed by a medical professional. Four participants were diagnosed with ME/CFS before they went to university, and four were diagnosed whilst there. There were no parameters on other characteristics, such as age or gender, as the focus was the similar experience of being a student with ME/CFS [33]. Full participant information is displayed in Table 1. Participants were recruited using a range of online methods: two by a student email distribution list for psychology postgraduate students; three from advertisements posted on the forum Reddit.com; three by an advert posted by the ME Association on their Facebook page.

Materials

Semi-structured interviews enabled rich data to be elicited from participants [33]. The interview schedule was developed by the researchers thinking about topic areas, such as support and identity, that would enable the research question to be answered. Participants were asked to think of a metaphor before the interview to capture their experience, and this was discussed in the interview. Metaphors are a useful way for participants to discuss health conditions [34] and are a powerful means of understanding experiences [35].

Procedure

Once the initial interview schedule had been drafted, a pilot study was conducted to ensure that the questions could generate appropriate and rich data [36], and questions were subsequently adapted. Interviews were conducted by the first author (FW) using the video-calling software Zoom, a decision that was made before COVID-19 government guidelines restricting the use of face-to-face interviews. Video-calling enabled participation without inducing additional fatigue or distress from traveling. The interviews lasted between 43 and 60 min. The questions on the interview schedule were used to structure the conversation, but these were a guide, and probing was used to gain a richer insight into the topics that participants discussed. The interviews were recorded using voice recording software on the researcher's laptop, and subsequently transcribed using Otter.ai and checked manually. Throughout the entire research study, the second author (DLE) served as both a mentor and a critical friend to the first author (FW). Their regular conversations stimulated and prompted deeper reflection and consideration of various possibilities – whether in terms of methods, participant recruitment, and approach to analysis.

Table 1. Participant information.

Pseudonym	Gender	Age	Years experienced symptoms	Time since diagnosis	Full or part-time study	Undergraduate or postgraduate
Clara	F	28	9	4 months	FT	PGR
Evelyn	F	23	8	5 years	FT	UG
Gabriel	M	54	13	4 years	PT (and PT work)	PGT
Kayleigh	F	21	6	7 months	FT	UG
Lottie	F	23	11	11 years	FT	PGT
Phoebe	F	22	3	2.5 years	FT	UG
Ramona	F	23	10	6 years	FT	UG
Sophie	F	22	2.5	2 years	PT	UG

Data analysis

Data was analyzed by the first author (FW) using IPA, and the stages outlined by Smith et al. [33]. Initially, the researcher gained familiarity with the interview transcripts through multiple readings. Exploratory comments were then made in relation to descriptive, linguistic and conceptual aspects of the data. The third and fourth stages involved developing emergent themes based upon these initial notes, and forming connections between them by using abstraction, subsumption, polarization and contextualization. A list of subordinate themes was subsequently developed to categorize the emergent themes. Each case was then analyzed using stages 1–4. Once all cases were analyzed, they were compared, and subordinate themes which occurred in three or more of the cases were included. This resulted in a list of master and emergent themes for all the cases. After the analysis was completed, the theoretical framework outlined in the introduction was explored, aligning with an inductive approach.

Ethics

The research was approved by the School of Education Ethics Committee at the University of Glasgow, which guided the carefully followed ethics protocol for this study.

Results

Three superordinate themes with further subordinate themes were developed. These interrelated themes illustrate how the participants' self-esteem and subjective well-being was affected due to their illness, and that making sense of their illness was an ongoing process. The metaphors which the participants discussed in the interviews, which help to understand the participants' individual narratives and experiences, are displayed in Table 2. Overall, they describe their lack of control over their illness and the difficulties they have needed to overcome. Table 2 also outlines which of the subordinate themes each participant contributed to, and the theme their metaphor fits in is in bold. Quotes from participants are presented alongside their pseudonym, as well as their age and the qualification they were pursuing when the interview was conducted.

1. University as (de)legitimizing

1a. Delegitimization

Three participants described experiences of delegitimization at university. This focused on the disability services and their tutors. Clara describes her experience of having to repeatedly justify herself:

> you're just put on the front page it's very much … you have chronic fatigue so tell us what it's like … I don't really want to do that every single time I need a week off, extension, so I … feel like you're getting a bit poked and a bit prodded (Clara, 28, PGR).

Clara's emphasis on how she must explain herself 'every single time', illustrates her preference for only needing to tell her story once. This experience makes her feel as though her illness is not valid and leaves her feeling exposed and vulnerable as though she is on the 'front page'. Clara's description of being 'a bit poked and a bit prodded' brings about

Table 2. Metaphors and themes contributed to.

Pseudonym	Themes contributed to	Metaphor
Clara[b]	1a, 1b, 2a, 2b, 2c, 3a, 3c	Image of different selves: Clara discussed a cartoon image which depicted three people. One person had a frown and was her now, one was her in the future who was happy with a PhD and in between the images was another person, who had a scribble on it depicting her journey to reaching her goal of completing a PhD.
Evelyn	1a, 2a, 2b, 3a, 3b, 3c	Damaged battery: Evelyn used the metaphor of a damaged battery to describe the unknown and fluctuating nature of the illness, and the lack of control she has over her symptoms.
Gabriel[a]	2b, 3a	-
Kayleigh	1a, 2a, 2c, 3a, 3b, 3c	Constantly hungover: Kayleigh described her experience as similar to being hungover, as she often feels groggy, exhausted and has a pounding headache.
Lottie[a]	1b, 2c	-
Phoebe	1b, 2b, 2c, 3a, 3b, 3c	Bed: Phoebe discussed the importance of her bed as a place in which she finds comfort and security. This was a big change in her life, as she described how before she got ill, she would only sleep for 5 or 6 h.
Ramona[b]	1b, 2b, 3a, 3c	Really big set of hills: Ramona discussed her university experience as a hilly range, where small problems transform into a big hill that she had to overcome. There were times in which she felt as though she was going downhill, but there were never any periods of stability.
Sophie	1b, 3b, 3c	Puzzle piece: Sophie spoke about how she pictured her life as a puzzle. She described herself with ME as a single puzzle piece which had been removed from the context of her life.

[a]Two participants had not remembered about the suggestion of a metaphor before the interview, which was not mandatory.
[b]The metaphors discussed by these participants are broader depictions of their experience and did not fit into one specific theme.

an image of her as a patient being invasively examined, with the university in charge of deciding what is in fact 'wrong' with her. The power dynamic depicts the university as more powerful than Clara, and as the expert in the situation, which is likely to lead to Clara feeling disempowered.

Other participants described specific conversations with university staff. Kayleigh described a conversation she had with her tutor when she explained why she was not able to complete her project in the way she had planned: 'I … said to her … I might have ME, and … I don't want to put too much strain on myself. She just kind of said, oh, have you tried taking vitamin B12' (Kayleigh, 21, UG). This illustrates how Kayleigh is not being listened to as an expert on her own illness. Kayleigh later mentions that she does take 'a lot of vitamins but it's not … going to cure everything', reiterating how Kayleigh has not been given the space to explain her illness and how she is managing it. This experience of delegitimization left Kayleigh feeling as though she 'couldn't really go to my tutors and be like, oh, I'm struggling right now'. This highlights the importance of validating students' experiences through informal conversations and discussing which solutions would work for them.

1b. Legitimization

Five participants described feelings of legitimization at university: one alongside experiences of delegitimization, and four spoke solely about how their university had legitimized their illness by not questioning the status of their illness and treating them as an expert about it. These experiences of legitimization were described as a break from other institutions or personal relationships in their lives. One of the participants, Phoebe, shares: 'I've found them … one of the most accepting and … helpful

organizations … which has been … quite refreshing … I've never had anything of a debate about whether or not it is an illness' (Phoebe, 22, UG). This illustrates the critical role that universities can play in students' lives, as a space of safety in which ME/CFS is legitimized, allowing students to seek help and support. Additionally, their university can provide a break from justifying their illness. Phoebe asserted that receiving support from her university meant that it was 'just one less thing that I had to battle to deal with'. This illustrates that whilst other aspects of society have still not reached a point of understanding or acceptance of ME/CFS, universities can provide a space of acceptance and support.

Another participant, Sophie, highlighted how her university treated her as an equal: 'thankfully, they seem to be like right okay, so we understand you've got ME CFS, what do you need?' (Sophie, 22, UG). Sophie describes how the university enquired about her specific needs, and therefore how they are treating her as an expert on her own illness, rather than imposing their suggestions for support on to her. This is particularly important for an illness such as ME/CFS in which individuals will experience differences in their symptoms, and therefore different solutions will be helpful for each individual.

2. Negotiating disclosure

2a. Stigma

Three participants discussed feeling stigmatized when others found out about their illness. This stigma was either explicit or more oblique. During the interview Clara was asked if her symptoms of ME/CFS had increased when she went back to university to study for her PhD. She describes how being in a university environment had not increased her symptoms, but rather highlighted them:

> I feel it's basically like … spotlights […] it's kind of like it was already there, but … now its center stage for everyone to see … I feel like people look at me in a weird way and say things like that and they're thinking, if you have chronic fatigue, why did you come back to university? (Clara, 28, PGR)

Clara describes how people finding out about her illness leaves her feeling stigmatized, as she believes that those around her are questioning why she is a student if she has ME/CFS. Her change in speech from 'say things like that' to 'they're thinking', illustrates how she almost hears people saying these comments to her, when in fact these are her thoughts about what those around her are thinking. Being in a university environment has resulted in Clara feeling judged and marginalized, which has made her feel that there is no space in which her illness is accepted.

2b. Struggling to advocate

Participants' interactions with others in the university community about their illness illustrated how they struggled to explain it. Five participants discussed how they struggled to advocate for themselves and justify the illness itself. Gabriel discusses how he sent the disability services a brochure explaining ME/CFS: 'there's an Action for ME brochure that I've sent them, but … I'm pretty sure that most of the people at the university won't understand what it is because it's not a well understood condition' (Gabriel, 54, PGT). Instead of giving his own personal account, Gabriel decided to refer the disability

services to a more accredited information source, suggesting he was lost for words when trying to explain his illness. This highlights how participants found it hard to disclose their illness to others because of concerns that they would be unable to fully explain it and would not be seen as a credible source of information. Phoebe adds another layer to this: 'I also feel quite conscious that you're speaking on behalf of like a community … there's so much negativity around it, you almost feel a bit of a pressure to like, act a certain way or say the right thing' (Phoebe, 22, UG). Phoebe discusses how the debated nature of the illness means she finds it difficult to disclose, as she is worried that she must prove that ME/CFS is a real illness in order to advocate on behalf of others. This leaves her feeling under pressure to disclose and educate those around her but does not feel capable that she alone can convince them that ME/CFS is a legitimate illness.

2c. Deciding to hide

The decision not to disclose their illness was discussed by four participants. This was due, in part, to the stigma and difficulties they experienced advocating for themselves and their illness. Lottie disclosed her experience of hiding her illness: 'So, I didn't tell any of my friends that there was anything wrong with me, for the first two years of my undergrad degree … I just had a massive desire for people to think that I was normal' (Lottie, 23, PGT). The length of time it took Lottie to disclose her illness illustrates how strong her desire had been to hide her illness, and her use of the phrase 'normal' depicts how she was comparing herself to a standard that she believed ME/CFS did not fit within. Later in the conversation she discussed her comparison with others as 'not necessarily a healthy thought process' and described how, as a postgraduate student, she had told two friends on her course. This made her feel more positive about herself because they could 'accept that it is just a part of who I am but not something that defines who I am'. This illustrates how the act of hiding her illness perpetuated Lottie's negative feelings towards it.

Clara introduced the theme of vulnerability in relation to hiding her illness: 'I've just gotten used to struggling in silence because you don't really want to … make yourself a bit vulnerable and … tell people things if it's not going to be of use' (Clara, 28, PGR). Clara's experience of having to explain her illness and advocate for herself has evoked feelings of vulnerability, and she has decided that is only worth telling others if she receives support in return.

3. Loss and adaptation

3a. Academic persona

Six participants discussed how becoming ill changed their ability to achieve academically. They provided examples of being top of the class or perfectionists in their academic work before they became ill. Ramona explained how her lower academic performance had changed her view of herself as a student:

> when I was younger, I was always the best at everything … it's really hard now to be like middle to bottom with grades because I just don't have the energy … so that … makes you feel like, yeah, less of a worthy student. (Ramona, 23, UG)

Ramona explained how she feels a divide in how she used to be and how she is now as a student. She has lost her ability to be the 'best at everything', which was when she was worthy of being a student. This highlights how her illness has resulted in her losing her identity as a high academic achiever, leaving her feeling despondent.

However, while two participants spoke about this loss, they also commented about how they had adopted a kinder attitude to themselves. Phoebe said that she was 'not beating myself up about it, basically … accepting that if you get a 2:1, it's not like the end of the world' (22, UG). Later in the conversation, she explained that she does not want to think of her illness as an excuse but 'then I have to remember that it is like a, I see it as like a disability'. She is trying to come to terms with the severity of the illness, an ongoing process of internal negotiation about whether to be kinder to herself in relation to her grades. This shows how participants adapted and learned to accept their illness. It also highlights changes in how participants assessed their achievements, and therefore how they felt about themselves.

3b. Social life

Another key area of loss mentioned by four participants was their social lives. This had largely been lost since becoming ill to prioritize studying, housework and resting. Sophie explained how she is currently missing a social context in her life:

> I've missed out on so much so it's almost like an incomplete puzzle … would be the way I kind of picture it … over the last kind of year and a bit I feel like I've missed out on so much, um because I felt I had to cut myself back a lot with like, the … social side of things. (Sophie, 22, UG)

Sophie discussed how she has been removed from a social context, which has left her feeling as though her illness has caused her to lose an important part of who she is. This is likely to have been reinforced by the generally accepted idea of university as an environment in which socializing is encouraged and seen as an important aspect of student life.

One participant, Evelyn, discussed how she has adapted her social life by becoming friends with other people with disabilities, as they understand how she is feeling:

> the friends that I've got now … we would … move the bit of the world for each other, but if we have the energy … out of my four or five friends, three of them have active mobility or fatigue issues, and one of them used to have it, so nowadays, like the people I surround myself with are very much in the same boat. (Evelyn, 23, UG)

Evelyn described how her current friends understand that she would 'move … the world' for them, but that she does not always have the capacity to do so due to her illness. By surrounding herself with people who are in the same situation, and who understand what she is going through, she has removed some of the pressure to live up to expectations placed on her friendships. This adaptation of her social life has enabled her to have a more positive view of herself.

3c. Physical body

The final area that six participants discussed related to feeling disconnected and frustrated with their bodies. Many participants discussed how, prior to becoming ill, they

were very active and had found it difficult to adapt to a new identity of not being able to do activities that had previously contributed to their definition of themselves. Evelyn described, through her metaphor of a damaged computer battery, the unpredictable relationship she now has with her body:

> … if you have a damaged battery, even if it's fully charged when you first start using it, it might suddenly jump down to 40%, or it might still not turn on, like your computer might turn on, but then keep having alerts and going dim and doing like that sort of thing … kind of unpredictable and is based on the idea of something just not quite doing what it's supposed to. (Evelyn, 23, UG)

Evelyn described how she sees her energy levels as unpredictable and that she has lost control over her body. By using a metaphor of a material object, it seems as though she is so detached from her body that she struggles to see herself as a functioning human being, highlighting the level of loss she has experienced.

One participant, Sophie, described how she has had to adapt to her body's capabilities: 'before … sport was my stress relief … [then] my go to became, adult paint by numbers' (22, UG). Sophie described how as a result of having to play less sport she needed to find something that would provide her with some of the same positive benefits. By adapting, and taking up new creative and artistic hobbies, she has managed to retain these benefits and has helped her to feel better about her illness.

Discussion

The present study explored how university students with a diagnosis of ME/CFS experienced and made sense of living with their illness. Using IPA to analyze the data, three interconnected themes were developed: *University as (de)legitimizing*, *Negotiating disclosure* and *Loss and adaptation*. The theoretical framework of self-esteem provided an understanding of how the participants' diagnosis of ME/CFS affected their subjective well-being.

University as (de)legitimizing

Participants discussed how their universities were both delegitimizing and legitimizing of their illness. This was demonstrated in participants' accounts of experiencing a lack of understanding and validation from their tutors and the disability services at their university. Similar experiences of delegitimization have been described in research with adults who have ME/CFS, in relation to their interactions with healthcare professionals and loved ones [7,8,37]. However, by focusing on a student population, this research added a new form of delegitimization to the current literature. Participants' accounts suggested that delegitimization affected their self-esteem, as interactions with authority figures made them feel as though they were not an expert on their own illness, leaving them disempowered. They also discussed distancing themselves from authorities at the university, instead preferring to self-manage their illness.

Participants' accounts of legitimization offered a different perspective, providing an understanding of how universities can act as an important authority for support. Participants disclosed how acceptance and validation provided a break from their usual

encounters, leading to surprise and relief. One participant discussed how the disability services asked her what support she required, treating her as an expert on their own illness. This is particularly important for ME/CFS as individuals experience differences in their symptoms, so it is important to understand each individual's story. This legitimization is likely to have led to a feeling of empowerment, and increased self-esteem. Experiences of legitimization, and the subsequent positive outcomes on well-being and sense of self have also been found in previous research [38,39]. The findings of the current study also add to recent literature that recommends students with ME/CFS need to experience a compassionate understanding of their illness at university [32].

Negotiating disclosure

Participants' descriptions of negotiating the disclosure of their illness to university staff and peers also suggest that their social environment had a large effect on how they felt about their illness. The invisible nature of the illness meant that participants were actively deciding whether to disclose their illness. Participants discussed stigma and the struggles they experienced advocating for themselves. This illustrated how participants felt judged and marginalized. Experiences of stigma have also been found in previous research with individuals with ME/CFS [40], as well as for students with disabilities [26]. Participants' descriptions of their desire to advocate for the ME/CFS community highlighted how they often found it difficult. The difficulties they disclosed regarding advocating for themselves have also been found in previous research. In a study by Wilde et al. [38] one participant discussed how individuals with ME/CFS do not like to discuss their illness for fear of being seen as someone who complains. Additionally, Markoulakis and Kirsh [29] found that the stigma students with mental health problems perceived resulted in them finding it difficult to advocate for themselves.

The participants responded to these experiences by hiding their illness from those around them. They described their desire to fit in, be seen as normal, and protect themselves from feeling vulnerable. Hiding an aspect of one's identity has been reported previously in research with students in their university environments. For example, Markoulakis and Kirsh [29] found that disclosure was often avoided due to the fear of discrimination. Similarly, Miller et al. [30] conducted research with LGBTQ students with disabilities and found that disclosure was a conscious decision. The participants' experiences of hiding an aspect of their identity are likely to have decreased their self-esteem. This was explored by one participant who disclosed how she felt more accepted after she was able to tell her friends about her illness.

Loss and adaptation

Lastly, the participants' journey of making sense of their illness is depicted in their description of initially losing their sense of self, and for some, the subsequent adaptation in order to accept their illness. This is a trajectory that has been explored in previous qualitative research with individuals who have ME/CFS [14,15]. Participants discussed how the loss of their social life and control over their physical body left them without a context to their lives, as well as feelings of detachment from their bodies. Similar to the findings of this study, research has identified that individuals with ME/CFS face difficulties in

relation to the loss of their social life and their bodies' capabilities [7,38]. This study added to the current literature by describing the participants' sense of loss of their academic persona, as they could no longer achieve the high standards they were used to. However, similar ideas have been discussed in research with adults who have ME/CFS, such as the loss of their occupational identity [7,38,41].

Participants also discussed adapting their sense of self. Six participants reported adapting to their new capabilities, such as not setting themselves such high academic standards, making friends with those who did not have such high expectations, and taking up less strenuous relaxation activities. This led to participants describing that they felt happier and more accepting of their illness, increasing their self-esteem. A change in self-evaluation over time has been reported previously in qualitative research with adults with ME/CFS [14,42]. Additionally, in a study by Arroll and Howard [15] two participants experienced post-traumatic growth. However, in the present study, participants predominately felt resentment towards their illness. This could have been due to the age of participants, as the majority were in their early twenties, compared to a mean age of 39.5 in the above study. This shows that, by adapting their sense of self, participants are likely to increase their self-esteem, compared to the sense of loss they often felt when first diagnosed with ME/CFS.

Limitations

The findings of the study should be considered alongside its limitations. All but one of the participants were female. In previous research it has been identified that men with ME/CFS go through specific experiences relating to a loss of masculinity [38], which could not be captured in this research. Additionally, the students who took part were those well enough to remain on their university course and to take part in an interview, so the experiences of students in more difficult situations have not been captured. Additionally, future research could also evaluate strategies that are used to help students with ME/CFS achieve at university, which this study was not able to fully consider.

Implications

There are theoretical and practical implications that arise from this study. The participants' emphasis on their social environment in relation to how they made sense of their illness has illuminated the importance of the social level in determining one's self-esteem. Previous research on self-esteem has often focused on the personal and collective level, with only limited research conducted in relation to social experiences [43]. The practical implications of this research are that universities need to provide further support. Tutors, support staff and students could be provided with information about ME/CFS, delivered in the form of workshops, information sessions or information booklets, and could cover a range of similar illnesses which are also subject to stigma, such as fibromyalgia [44]. It is important that universities enable students to be the expert on their own illness, by asking them what symptoms they have, and what support they require. This information should be collected by the disability services, put on a student's file and, with the student's permission, provided to university staff to prevent students needing to repeat their story. Receiving this legitimization could result in an increase in students' self-esteem and subjective wellbeing.

Conclusion

The present study provided an insight into the phenomenological experiences and sense-making processes of students with ME/CFS. It has elucidated the experience of a group of people who have ME/CFS to gain an in-depth understanding of how their life has been affected by their condition, including the de-legitimization and powerlessness they experienced at university and in their social context, due to the debated and hidden nature of the illness. Participants also discussed instances in which their self-esteem had increased, including being treated as an expert in their condition and consciously deciding to accept their condition and adjust their lives accordingly. Potential avenues in which universities can act in a supportive manner to be empowering and enhance self-esteem have been discussed. This is important due to the debated and invisible nature of the illness, and the fact that individuals can experience different symptoms, meaning they need to be treated as an expert on their own illness and their individual experience validated.

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Disclosure statement

Data not available due to ethical restrictions

Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data is not available.

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References

[1] NICE. (2007, August 01). *Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): Information for the public.* https://www.nice.org.uk/guidance/cg53/resources/chronic-fatigue-syndromemyalgic-encephalomyelitis-or-encephalopathy-pdf-254691886021.

[2] Bayliss K, Goodall M, Chisholm A, et al. Overcoming the barriers to the diagnosis and management of chronic fatigue syndrome/ME in primary care: a meta synthesis of qualitative studies. BMC Fam Pract. 2014;15(44):1–11. doi:10.1186/1471-2296-15-44.

[3] Walsh RS, Denovan A, Drinkwater K, et al. Predicting GP visits: A multinomial logistic regression investigating GP visits amongst a cohort of UK patients living with myalgic encephalomyelitis. BMC Fam Pract. 2020;21(1):1–8. doi:10.1186/s12875-020-01160-7.

[4] NHS. (2021, January 29). *Chronic Fatigue Syndrome.* https://www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/.

[5] Collin SM, Nikolaus S, Heron J, et al. Chronic fatigue syndrome (CFS) symptom-based phenotypes in two clinical cohorts of adult patients in the UK and The Netherlands. J Psychosom Res. 2016;81:14–23. doi:10.1016/j.jpsychores.2015.12.006.

[6] Horton SM, Poland F, Kale S, et al. Chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) in adults: A qualitative study of perspectives from professional practice. BMC Fam Pract. 2010;11(1):89–89. doi:10.1186/1471-2296-11-89.

[7] Dickson A, Knussen C, Flowers P. Stigma and the delegitimation experience: An interpretative phenomenological analysis of people living with chronic fatigue syndrome. Psychol Health. 2007;22(7):851–867. doi:10.1080/14768320600976224.

[8] Geraghty K. The negative impact of the psychiatric model of chronic fatigue syndrome on doctors' understanding and management of the illness. Fatigue: Biomed Health Behav. 2020;8(3):167–180. doi:10.1080/21641846.2020.1834295.

[9] Pinxsterhuis I, Strand EB, Sveen U. Coping with chronic fatigue syndrome: a review and synthesis of qualitative studies. Fatigue: Biomed Health Behav. 2015;3(3):173–188. doi:10.1080/21641846.2015.1035519.

[10] Rosenberg M. Conceiving the self. New York: Basic Books; 1979.

[11] APA. Identity. In: *APA dictionary of psychology*; 2020. https://dictionary.apa.org/identity

[12] Kleinman A. Pain and resistance: The delegitimation and religitimation of local worlds. In: MJD Brodwin, BJ Good, PEA Kleinman, editors. P*ain as human experience: An anthropological perspective.* Berkeley and Los Angeles, California: University of California; 1992. p. 169–197.

[13] Dickson A, Knussen C, Flowers P. 'That was my old life; it's almost like a past-life now': identity crisis, loss and adjustment amongst people living with chronic fatigue syndrome. Psychol Health. 2008;23(4):459–476. doi:10.1080/08870440701757393.

[14] Whitehead L. Toward a trajectory of identity reconstruction in chronic fatigue syndrome/myalgic encephalomyelitis: A longitudinal qualitative study. Int J Nurs Stud. 2006;43(8):1023–1031. doi:10.1016/j.ijnurstu.2006.01.003.

[15] Arroll MA, Howard A. 'The letting go, the building up, [and] the gradual process of rebuilding': identity change and post-traumatic growth in myalgic encephalomyelitis/chronic fatigue syndrome. Psychol Health. 2013;28(3):302–318. doi:10.1080/08870446.2012.721882.

[16] Tedeschi RG, Calhoun LG. The posttraumatic growth inventory: measuring the positive legacy of trauma. J Trauma Stress. 1996;9(3):455–471. doi:10.1002/jts.2490090305.

[17] Rosenberg M. Society and the adolescent self-image. Princeton, New Jersey: Princeton University Press; 1965.

[18] Orth U, Robins RW. The development of self-esteem. Curr Dir Psychol Sci. 2014;23(5):381–387. doi:10.1177/0963721414547414.

[19] Du H, King RB, Chi P. Self-esteem and subjective well-being revisited: The roles of personal, relational, and collective self-esteem. PLoS ONE. 2017;12(8):e0183958. doi:10.1371/journal.pone.0183958.

[20] Eromo T, Levy D. The rise, fall, and resurgence of "self-esteem": A critique, reconceptualization, and recommendations. N Am J Psychol. 2017;19(2):255–302.

[21] Corrigan PW, Watson AC, Barr L. The self-stigma of mental illness: implications for self-esteem and self-efficacy. J Soc Clin Psychol. 2006;25(8):875–884. doi:10.1521/jscp.2006.25.8.875.
[22] Connell J, Brazier J, O'Cathain A, et al. Quality of life of people with mental health problems: A synthesis of qualitative research. Health Qual Life Outcomes. 2012;10(1):138–138. doi:10.1186/1477-7525-10-138.
[23] Sowislo JF, Orth U. Does low self-esteem predict depression and anxiety? A meta-analysis of longitudinal studies. Psychol Bull. 2013;139(1):213–240. doi:10.1037/a0028931.
[24] Fleming AR, Edwin M, Hayes JA, et al. Treatment-seeking college students with disabilities: presenting concerns, protective factors, and academic distress. Rehabil Psychol. 2018;63(1):55–67. doi:10.1037/rep0000193.
[25] Spencer G, Lewis S, Reid M. Living with a chronic health condition: students' health narratives and negotiations of (ill) health at university. Health Educ J. 2018;77(6):631–643. doi:10.1177/0017896917738120.
[26] Newman BM, Kimball EW, Vaccaro A, et al. Diverse pathways to purpose for college students with disabilities. Career Dev Transit Except Individ. 2019;42(2):111–121. doi:10.1177/216514341875898.
[27] O'Shea A, Kaplan A. Disability identity and use of services among college students with psychiatric disabilities. Qualitative Psychol. 2018;5(3):358–379. doi:10.1037/qup0000099.
[28] Mills ML. Invisible disabilities, visible service dogs: The discrimination of service dog handlers. Disabil Soc. 2017;32:635–656. doi:10.1080/09687599.2017.1307718.
[29] Markoulakis R, Kirsh B. Difficulties for university students with mental health problems: A critical interpretive synthesis. Rev High Ed. 2013;37:77–100. doi:10.1353/rhe.2013.0073.
[30] Miller RA, Wynn RD, Webb KW. "This really interesting juggling act": How university students manage disability/queer identity disclosure and visibility. J Divers High Educ. 2019;12(4):307–318. doi:10.1037/dhe0000083.
[31] HESA. (n.d.). Who's studying in HE? https://www.hesa.ac.uk/data-and-analysis/students/whos-in-he.
[32] Chu L, Fuentes LR, Marshall OM, et al. Environmental accommodations for university students affected by myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Work. 2020;66(2):315–326. doi:10.3233/WOR-203176.
[33] Smith JA, Flowers P, Larkin M. Interpretative Phenomenological Analysis: theory, method and research. London: Sage; 2009.
[34] Mitchell K, Skirton H, Monrouxe L. Amelioration, regeneration, acquiescent and discordant: an exploration of narrative types and metaphor use in people with aphasia. Disabil Soc. 2011;26(3):321–335. doi:10.1080/09687599.2011.56041.
[35] Schechter C, Firuz F. How mentor principals interpret the mentoring process using metaphors. School Leadership Manage. 2015;35(4):365–387. doi:10.1080/13632434.2015.1010500.
[36] Malmqvist J, Hellberg K, Möllås G, et al. Conducting the pilot study: A neglected part of the research process? methodological findings supporting the importance of piloting in qualitative research studies. Int J Qual Methods. 2019;18:1–11. doi:10.1177/1609406919878341.
[37] Edwards C, Thompson A, Blair A. An 'overwhelming illness': women's experiences of learning to live with chronic fatigue syndrome/myalgic encephalomyelitis. J Health Psychol. 2007;12:203–214. doi:10.1177/1359105307071747.
[38] Wilde L, Quincey K, Williamson I. "The real me shining through M.E.": visualizing masculinity and identity threat in men with myalgic encephalomyelitis/chronic fatigue syndrome using photovoice and IPA. Psychology of Men & Masculinities. 2020;21(2):309–320. doi:10.1037/men0000220.
[39] Brady E, Segar J, Sanders C. "I Always Vet Things": navigating privacy and the presentation of self on health Discussion boards among individuals with long-term conditions. J Med Internet Res. 2016;18(10):e274. doi:10.2196/jmir.6019.
[40] McManimen SL, McClellan D, Stoothoff J, et al. Effects of unsupportive social interactions, stigma, and symptoms on patients with myalgic encephalomyelitis and chronic fatigue syndrome. J Community Psychol. 2018;46(8):959–971. doi:10.1002/jcop.21984.

[41] Gray ML, Fossey EM. Illness experience and occupations of people with chronic fatigue syndrome. Aust Occup Ther J. 2003;50(3):127–136. doi:10.1046/j.1440-1630.2003.00336.x.

[42] Reynolds F, Vivat B, Prior S. Women's experiences of increasing subjective well-being in CFS/ME through leisure-based arts and crafts activities: A qualitative study. Disabil Rehabil. 2008;30 (17):1279–1288. doi:10.1080/09638280701654518.

[43] Du H, King RB, Chi P. Self-esteem and subjective well-being revisited: The roles of personal, relational, and collective self-esteem. PLoS ONE. 2017;12(8):e0183958. doi:10.1371/journal.pone.0183958.

[44] Wroe AL, Bowers HM. Beliefs about sharing illness experiences: Development of a scale and relationship with symptoms of fibromyalgia. Br J Health Psychol. 2019;24(3):687–703. doi:10.1111/bjhp.12376.