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Exploring the lived experiences of UK university students with ME/CFS: An Interpretative Phenomenological Analysis

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Abstract

Research regarding students with myalgic encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) has been limited in comparison to the volume of research that has been conducted in relation to other populations with the illness. Exploring the experiences of students with ME/CFS is important due to research reporting that students with invisible illnesses face stigma, discrimination and a lack of empathy, and individuals with ME/CFS face delegitimisation from healthcare professionals and loved ones. This research explored the phenomenological experiences and sense-making processes of eight students with ME/CFS by using online semi-structured interviews, which were enriched by asking participants to think of a metaphor to describe their illness to facilitate the discussion. Interpretative Phenomenological Analysis was used as it enabled the participant's experience of their illness to be explored without imposing a theoretical framework or a pre-conceived focus on their narratives. Three themes were developed: 'University as (de)legitimising', 'Negotiating disclosure' and 'Loss and adaptation'. The theoretical framework of self-esteem was used to explore the findings as it reflected the participants' accounts. This framework, utilising social identity theory and self-discrepancy theory, provided an understanding of how the participants' experiences and sense-making processes occurred on both a personal and social level. These findings have important implications for universities, as they demonstrate that they can play a key role in validating the experiences of students with ME/CFS, as well as providing both formal and informal support. The findings also emphasise the key role of social interactions, adding to the limited research regarding the social level in relation to self-esteem. Suggestions are also made for how social identity theory and self-discrepancy theory could be extended to incorporate key experiences of those with a chronic illness.

Introduction

University students with Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS) are an under-explored population, despite evidence that individuals with ME/CFS have a low subjective well-being (Drachler et al., 2009; McManimen et al., 2018), and students with chronic illnesses experience stigma and discrimination on university campuses (Mills, 2017; Newman et al., 2019). Additionally, the invisibility of ME/CFS can result in students receiving a lack of support and empathy (Chu et al., 2020). This demonstrates the difficulties that students with ME/CFS are likely to encounter and the importance of understanding how they experience and make sense of their illness. ME/CFS is an illness which is subject to debate, as are the terms used to describe it. An overview of the illness is outlined below, along with a discussion of the everyday experiences and challenges that individuals with the illness face. Following this, research investigating experiences of students with chronic and invisible illnesses is outlined. In the final sections, the approach to the current research study will be summarised: the theoretical framework of self-esteem, the methodological approach of Interpretative Phenomenological Analysis (IPA) and how literature used to support the study was found. Finally, the focus of the present research study will be presented.

An Overview of ME/CFS

ME and CFS are terms used interchangeably in the UK to describe the same illness. The lack of a biological marker for ME/CFS makes it a difficult condition to define and decreases the possibility of a diagnosis for individuals experiencing symptoms (Mengshoel et al., 2020). There are currently more than 20 case definitions and criteria used for ME/CFS (Brurberg et al., 2014). These have similarities and differences, but all rely on the absence of other illnesses (Sweetman et al., 2019). The NHS uses the guidelines defined by the National Institute for Health and Care Excellence (NICE; 2007) which state that a patient will

experience new or sudden disabling tiredness which lasts for a long time or is recurring and gets worse after activity. They also state that patients will have some of the following symptoms: problems sleeping, muscle or joint pain, headaches, sore throat, flu-like symptoms, feeling dizzy, sick or having heart palpitations, as well as problems thinking, remembering, concentrating or planning. The cause of ME/CFS is unknown, but it has been linked to infections from viruses such as Epstein-Barr, changes in the immune system, as well as a genetic link (CDC, 2018). Individuals with a diagnosis can experience different symptoms, and individuals can experience variation in their symptoms day-to-day (NHS, 2017).

The history of the terms used to describe ME/CFS illustrate the debated nature of the illness. The term ME was introduced in the UK in 1956 in *The Lancet* after an outbreak of a disease at the Royal Free Hospital (Wojcik et al., 2011). The term ME was coined by Ramsay, head of the hospital's Department of Infectious Diseases, to reflect the muscle pain (myalgic), as well as the damage to the nervous system and inflammation (encephalomyelitis) that was experienced (Acheson, 1956). ME was initially reported in epidemics, but today, endemic cases are mostly reported (Underhill, 2015). In 1988, the term CFS was used in America to describe individuals who did not recover from infections in the timescale expected. The term CFS was developed by the Centers for Disease Control and Prevention (CDC), as they argued it emphasised the fatigue characteristic of the illness, and suggested it was a more neutral term (Holmes et al., 1988). There are ongoing discussions amongst the scientific community, healthcare professionals and patients regarding the correct term. The term CFS has been challenged by patients who argue that it trivialises the illness and perpetuates stigma, as it does not emphasise the severe nature of the fatigue that individuals with the illness experience (Jason & Richman, 2007). The present researcher shares this view, that the term CFS does not capture the intensity nor range of symptoms that can be

experienced. As the international debate is on-going (Jason & Johnson, 2020), the term
ME/CFS will be used throughout this dissertation.

The number of people in the UK with ME/CFS is estimated to be around 0.2% – 0.4%
of the population, equating to around 260,000 people (Walsh et al., 2020). However, without
a biological marker (Bested & Marshall, 2015), and a lack of knowledge about the illness in
the primary care setting (Thomas and Smith, 2005), it is difficult to get an accurate
understanding of how common ME/CFS is in the population (Lim et al., 2020). However, it
is known that the onset of the illness usually occurs in those aged in their early twenties to
mid-forties and it is twice as likely to affect women than men (CFS/ME Working Group,
2002). Therefore, undergraduate and postgraduate students are within the age range of the
condition's likely onset. The NICE (2017) guidelines state that whilst there is no
pharmacological cure for the illness, management strategies and medication should focus on
relieving the symptoms. This illustrates the need to understand how ME/CFS affects
individuals' subjective well-being, and to develop strategies and interventions that can help
patients cope.

The Experience of Living with ME/CFS

Individuals with ME/CFS experience a range of physical, social and emotional
difficulties. The physical impact on individuals varies depending on their symptomology, and
can be focused on issues with pain, cognition or mobility (Collin et al., 2016). The severity of
these symptoms varies and, when most severe, cause profound and prolonged disability
(Horton et al., 2010). Social and emotional difficulties are also serious, with the illness
affecting individuals' social lives and subjective well-being (Nacul et al., 2011). A systematic
review by Drachler et al. (2009) highlighted that individuals often felt excluded from the
social aspect of their lives, lowering their subjective well-being and sense of control. Stigma
and unsupportive social interactions have also been described as a risk factor for depression

in those with ME/CFS (McManimen et al., 2018). The importance of this is shown in a study by Roberts et al. (2016) which found that there was a seven-fold increase in suicide in individuals with ME/CFS, which they argue could be due to the comorbidity of ME/CFS and psychiatric conditions. These issues are often exacerbated due to a lack of clarity regarding the illness which can leave individuals without support from healthcare professionals, as well as friends and family (Dickson et al., 2007). A study by Broughton et al. (2017) found that adequate support is key to improving patients' well-being and therapeutic outcomes. They found that by attending a specialist ME/CFS service and receiving validation of their illness, patients were more accepting of their illness and found ways to adapt.

These physical, social and emotional difficulties can affect an individuals' self-concept and identity. Self-concept is defined as the way in which individuals view themselves and is described as the "the totality of an individual's thoughts and feelings having reference to himself as an object" (Rosenberg, 1979, p.7). Identity has more of a focus on how an individual believes they are perceived by others and describes the nature in which people make sense of themselves by comparison with social categories. It is defined as "an individual's sense of self defined by (a) a set of physical, psychological, and interpersonal characteristics that is not wholly shared with any other person and (b) a range of affiliations (e.g., ethnicity) and social roles" (APA, 2020a). Both self-concept and identity are formed from social interactions (Millward & Kelly, 2003), highlighting how both personal and social factors are key to understanding how people with ME/CFS make sense of their illness and adapt their identity (Dickson et al., 2008).

Research looking into the effect that ME/CFS has on one's sense of self has been undertaken using qualitative approaches, particularly using IPA. A study by Wilde et al. (2020) found that men with ME/CFS struggled to adapt their identity to incorporate their illness, seeing it as a threat to their masculine identity, for example, by no longer being able

to undertake physical activity, or meeting friends for an alcoholic drink. The importance of social context was shown in a study by Dickson et al. (2007), who discussed delegitimisation, which is defined as having one's own perception and definition of an illnesses disconfirmed (Kleinman, 1992). They reported that delegitimisation by loved ones tended to cause individuals to feel personally rejected, affecting their sense of self and self-esteem. It has also been found that individuals with ME/CFS can experience an 'identity crisis' due to the loss of control over their body and personal life (Dickson et al., 2008). Longitudinal studies have provided a unique insight into identity reconstruction over time. Whitehead (2006) found a non-linear trajectory of an individual's identity encompassing the following phases: 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. More recently a study by Arroll and Howard (2013) emphasised the post-traumatic growth that can come about from having ME/CFS, which is the idea that enduring adversity can result in positive growth (Tedeschi & Calhoun, 1996). Aroll and Howard (2013) found that two participants experienced personal growth and entered into a positive phase of their lives. This research illustrates the long-term effect that ME/CFS can have on an individual's identity, which can result in both challenges and positive growth.

Students and Chronic Illnesses

The challenges faced by individuals with chronic illnesses can be amplified in a student environment, due to students moving away from support networks (Fleming et al., 2018), and negotiating a new student identity (Spencer et al., 2018). Students with known disabilities (which includes those with chronic illnesses, such as ME/CFS) made up 13% of the student population in the academic year 2018-2019, representing an increase of 74,090 students from 2015-2016 (HESA, n.d.). The introduction of the 2010 Equality Act resulted in discrimination against someone with a disability being unlawful. Therefore, universities had

to provide reasonable adjustments to students with disabilities in all aspects of their university experience, including academic and support services. Adjustments that students with ME/CFS are likely to receive include being flexible with attendance requirements, deadline extensions and providing additional support for examinations, such as rest breaks and separate rooms (Action for ME, 2013). However, to the researcher's knowledge, the only paper that examines provisions for university students with ME/CFS took place in America and it was argued that universities struggle to support students with fluctuating conditions (Chu et al., 2020).

There is limited research into the everyday experiences of university students with chronic illnesses and how they make sense of it (O'Shea & Kaplan, 2018; Spencer et al., 2018). However, a phenomenological study by O'Shea and Kaplan (2018) found that students with psychiatric illnesses were engaged in a continuous process of meaning-making to understand their disability, and that it was a negotiation at an individual and social level. Research has also shown how the social environment of universities can negatively impact students' self-esteem. For example, research undertaken by Newman et al. (2019) found that stigma and discrimination on university campuses affected the sense of purpose felt by students with disabilities, which is associated with subjective well-being. This reveals how individuals with chronic illnesses are struggling 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 (Mills, 2017), with disclosure a conscious decision (Markoulakis & Kirsh, 2013; Miller et al., 2019). This research acknowledges that students with invisible illnesses and disabilities have the opportunity to present different identities, and that their sense of self can be challenged by the university environment.

Theoretical Framework: Self-esteem

Self-esteem is a person's subjective evaluation of themselves, which is often conceptualised as the "feeling that one is 'good enough'" (Rosenberg, 1965, p.31), and involves acceptance and respect of oneself (Orth & Robins, 2014). Self-esteem differs from self-efficacy, which focuses on an individual's evaluation of their ability to achieve in different situations (Bandura, 1994), and self-confidence which is the trust in one's abilities and judgements (APA, 2020b). Therefore, 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 is also related to self-concept but differs in that one's self-concept focuses on an individual's sense of themselves without evaluation (Rosenburg, 1979). Self-esteem can be measured at multiple levels, with the self being formed at the personal, collective and relational level (Du et al., 2017). The personal level comprises of individual characteristics and traits, the collective level is formed by dyads, and the relational by group membership (Brewer & Gardner, 1996). In the field of psychology, self-esteem has been viewed as the key to predicting a wealth of positive benefits, including health, happiness and prosperity (Baumeister, 2005). However, more recently, it has been subject to criticism that its importance has been over-emphasised (Eromo & Levy, 2017). Despite this, research has found correlations with low self-esteem and negative outcomes for individuals with chronic illnesses, including self-stigma (Corrigan et al., 2006), maladaptive coping strategies (Connell et al., 2012), and psychiatric comorbidities (Sowislo & Orth, 2013). Self-esteem was selected as the theoretical framework for this research as it reflected the accounts of participants and enabled a further understanding of their psychological well-being. Two theories relating to self-esteem will be used, social identity theory (SIT; Tajfel & Turner, 1986) and self-discrepancy theory (SDT; Higgins, 1987), in order to explore the mechanisms underpinning the participants' well-being.

Social Identity Theory

SIT (Tajfel & Turner, 1986) proposes that group membership guides the formation of an individual's self-concept (e.g., being disabled or a student), as well as intergroup behaviour. The theory can be used to understand stigma and discrimination through the creation of in-groups and out-groups: in-groups are those which an individual belongs to and identifies with, whereas out-groups are those which an individual does not belong to or identify with. It is argued that individuals seek to increase their self-esteem by attributing a higher value to their own groups (Billig & Tajfel, 1973). The causality of this relationship has been subject to criticisn (Turner, 1999), but on the whole, there is evidence to support the idea that self-esteem is increased when people see their in-group favourably (Brown, 2000). However, the status and power of groups has been found to affect the consistency in which individuals favour in-groups (Sachdev & Bourhis, 1981; Reichl, 1997). Reviews and meta-analyses (Bettencourt et al., 2001; Brewer, 1979; Mullen et al., 1992) have found that higher-status groups are more discriminatory, whilst lower-status groups are more likely to show out-group favouritism in status-related domains. SIT has been applied in research undertaken to understand the psychological well-being of individuals with chronic illnesses (Abraído-Lanza & Revenson) and health-related behaviour (Harwood & Sparks, 2003). SIT has also helped researchers understand how social interventions for people with chronic illnesses can improve psychological well-being, through support and sense of community (Haslam et al., 2012). SIT, rather than identity theory, was chosen to be used in this research due to its focus on individuals' identification with a social group rather than a particular role (Stets & Burke, 2000).

Self-discrepancy Theory

In SDT (Higgins, 1987) different domains of the self are defined: the attributes an individual believes they possess, which come from both self-reflections and feedback from

others (actual self), the way in which an individual wishes to be (ideal self), and the responsibility they feel to act in a certain way (ought self). Higgins et al. (1986) argued that discrepancies between these selves will result in an individual experiencing emotional vulnerabilities. He attributed discrepancies in the actual and ought self to depressive emotions, and the actual and ideal self to anxious emotions. He argued that as these emotions make individuals uncomfortable, they will seek to eliminate or reduce these discrepancies. The discrepancy between the actual and ideal self has been linked directly to an individual's self-esteem (Moretti & Higgins, 1990), and SDT has also been used to understand psychological well-being in individuals with chronic illnesses. Research with women with chronic illnesses (Heidrich and Powwattana, 2004), and individuals with chronic lower back pain (Waters et al., 2004), found that smaller self-discrepancies are linked to higher psychological well-being. SDT has been subject to criticism by researchers who argue that ideal and ought discrepancies are related to both depressive and anxious emotions (e.g., Ozgul et al., 2003; Phillips & Silvia, 2005, 2010), however, support for the theory has been found in multiple studies, including those using university students as the sample population (e.g., Boldero & Francis, 2000; Higgins et al., 1985). SDT was used to interpret the findings of this study, as the negative emotions participants described were similar to those outlined by Higgins (1987). Additionally, unlike similar theories, such as cognitive dissonance theory (Festinger, 1957) and self-awareness theory (Duval & Wicklund, 1972) which also seek to explain imbalances in one's self, it provides a framework to understand the specific emotions associated with self-discrepancies.

Methodological Approach: Interpretative Phenomenological Analysis

IPA provided an approach which allowed the experiences of students with ME/CFS to be captured. It originated as a method within health psychology (Smith, 1996), a discipline which emphasises the importance of patients' perceptions and interpretations of their

illnesses, which IPA is conducive to (Brocki & Wearden, 2006; Smith et al., 1997). IPA has frequently been used to help understand the experiences of individuals with ME/CFS (e.g., Wilde et al., 2020; Arroll & Howard, 2013). It was used in this study to build on this research, as students with ME/CFS are a population which have not yet been explored from a phenomenological perspective. An inductive IPA approach is common in health psychology research (Brocki & Wearden, 2006), and 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 (Howitt, 2019). Other qualitative approaches were considered, including grounded theory and discourse analysis. However, grounded theory aims to reach a more universal conclusion and generate a theory (Howitt, 2019), whereas IPA focuses on the idiographic. This research sought personal accounts in order to understand how students with ME/CFS see the world, providing an insight into their personal thoughts and feelings. Discourse analysis could have been used to understand the experiences of individuals with ME/CFS by interpreting their speech. However, this research was more concerned with individual experiences and how these were enabling a wider sense-making process.

IPA has strong philosophical influences, with the key ones being phenomenology, symbolic interactionism, hermeneutics and ideography. Phenomenology (Husserl, 1982), seeks to understand conscious experiences, and it is argued that these can be understood in the purest form by the researcher bracketing their preconceptions and presumptions. Symbolic interactionism (Mead, 1934), is the idea that the mind and the self are created in relation to social interactions. This is reflected in IPA, which seeks to understand how individuals make sense of a phenomenon in relation to both their personal and social world. Thirdly, the term hermeneutics was developed by Heidegger (1927/1962), who argued that it was an essential component of phenomenology as individuals interpret a particular phenomenon through their own social, cultural and historical context. There is therefore a

'double hermeneutics' in IPA (Smith, 2004), by which the researcher is making sense of a phenomenon that the individual themselves has already made sense of. Finally, in contrast to phenomenology, IPA focuses on the idiographic (Allport, 1963), seeing each individual as a unit of understanding. These philosophies have been central in forming the approach to IPA and are key to understanding how the methodology is enacted.

Article Search

Articles for this research were found by searching all databases on the research platform EBSCOhost. The initial focus was on adults with ME/CFS, conducted using keywords such as "ME or CFS and adults". This was subsequently narrowed using terms related to methodology, such as "qualitative" and finally "IPA". Looking further at the issues that were identified in these articles, such as identity and disclosure, these terms were searched alongside broad terms of illness and disability such as "chronic illness or disability and identity", and articles relating to students and their experiences were found. Searching for articles relating to students with ME/CFS, using keywords covering multiple phrases, such as "students or college students or higher education or further education or university students", one article was found, which focused on support from occupational therapists (Chu et al., 2020). This illustrates the lack of research that has been conducted regarding the experiences of students with ME/CFS.

The Present Research

The number of students declaring a disability at UK universities is increasing, and the challenges facing students with a chronic illness is multiple. Despite universities being legally required to support disabled students, there is evidence to suggest that they find it difficult to support students with ME/CFS (Chu et al., 2020). Moreover, as outlined above, there are additional challenges that individuals with ME/CFS experience, making it difficult for individuals to make sense of their illness. This research study is unique in its focus on the

experiences of university students with ME/CFS. Learning how they experience and make sense of their illness aims to provide an understanding of how their psychological well-being is affected by living with their illness, as well as to understand how university communities can support them. This will, therefore, be 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?*

Methodology

As outlined in the introduction, the current study uses a qualitative approach. IPA was chosen as it allowed the lived experiences of students with ME/CFS to be explored (Smith et al., 2009). The use of IPA informed the approach and design of the study, as discussed below.

Researcher and Reflexivity

The researcher is a 26-year-old female with personal experience of ME/CFS after being diagnosed during her undergraduate degree and experiencing symptoms of the illness for around two years. This was beneficial as it enabled her to empathise with participants, particularly given the debated and stigmatised status of the illness (Dickson et al., 2007; Jason & Johnson, 2020). In order to acknowledge and address her personal experience, the researcher was careful to monitor her personal feelings, and understand where she might be interpreting participants' experiences as similar to her own. A research journal was used to write down initial feelings and perceptions after each interview and whilst carrying out the analysis (Brocki & Wearden; Smith et al., 2009). This provided the researcher with the space to reflect on her thinking and bracket off preconceptions (Gadamer (1960/75).

Participants and Recruitment

In line with IPA's commitment to the idiographic, a small, homogenous sample was used (Brocki & Wearden, 2006; Smith et al., 2009). Eight participants were interviewed, as this number enabled a commitment to each individual, whilst also ensuring there was enough data to analyse due to the decision to interview each participant only once (Smith & Osborn, 2007). The criteria for participant selection were that they were 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. The focus on university students was because there is evidence to suggest that students with disabilities in higher education experience difficulties including stigma on campus (Vaccaro et al., 2019), and a change in the

level of support they receive (Fleming et al., 2018). To ensure similarities in their experiences, all participants saw their diagnosis of ME/CFS as their main health concern and had been diagnosed by a medical professional. There were no parameters on other characteristics, such as age or gender, as the main focus of the research was the similar experience of being a student in with ME/CFS (Smith et al., 2009). Four participants were diagnosed with ME/CFS before they went to university, and four were diagnosed whilst there. 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 adverts posted on the forum Reddit.com; three by an advert posted by the ME Association on their Facebook page. An example advert can be found in Appendix A.

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 years	4 months	FT	PG
Evelyn	F	23	8 years	5 years	FT	UG
Gabriel	M	54	13 years	4 years	PT (and PT work)	PG
Kayleigh	F	21	6 years	7 months	FT	UG
Lottie	F	23	11 years	11 years	FT	PG
Phoebe	F	22	3 years	2.5 years	FT	UG
Ramona	F	23	10 years	6 years	FT	UG
Sophie	F	22	2.5 years	2 years	PT	UG

Materials

Semi-structured interviews were used as they enable rich data to be elicited from participants and are the preferred means of data collection when using IPA (Smith et al., 2009). They also allow the researcher to probe further into topics, as well as allowing participants to convey what they regard to be important (Pietkiewicz & Smith, 2014).

Additionally, one-to-one interviews have the privacy to enable personal discussions to take place and provide participants time to speak at length (Smith et al., 2009). The interview schedule (Appendix B) was developed in relation to the research question. The questions were developed by thinking about different topic areas, such as support and identity, that would enable the research question to be answered. They were also developed to enable participants to speak about what was important to them, by being open, and requiring limited interruption from the researcher (Smith et al., 2009). Additionally, a question asking participants to discuss a metaphor that they felt captured their experience as a student with ME/CFS was added, which they would be asked to think of before the interview. Metaphors can be seen as a reflection of how individuals perceive their reality and can function as a conscious or unconscious understanding of individuals' thoughts and identity (Rees et al., 2009). They have been used in previous research with participants who have health conditions (Mitchell et al., 2011; Smith & Sparkes, 2004), as they are a powerful means of understanding participants' experiences (Schechter & Firuz, 2015). The questions were subsequently arranged in a logical, temporal order, starting with initial experiences with the illness, followed by questions about their current experience as a student. This allowed participants to describe events that had taken place in the past, such as their diagnosis, at the beginning of the interview enabling them to become comfortable with the interview situation (Smith et al., 2009).

Procedure

Pilot Study

Once the initial interview schedule had been drafted, a pilot study was conducted with someone who met the participant criteria. This was conducted to ensure that the questions asked in the interview provided appropriate and rich data (Malmqvist et al., 2019). One question was removed as the pilot participant suggested it could cause a negative emotional

response. Warm-up questions were also added to enable participants to relax. Additionally,

prompts relating to whether family, friends and health professionals understood the illness

and if they accommodated their illness suitably were included, as the pilot participant felt

these were an important aspect of support. Examples of the amendments can be found in

Table 2. The initial interview schedule devised before the pilot study can be found in

Appendix C.

Table 2

Amendments to interview schedule

Original question	Amendment
Can you tell me about the main types of support you receive from friends and family?	Added prompts: Do your friends and family understand your illness? Do you think they accommodate your illness suitably?
No warm-up questions included	Added in: Please could you tell me a bit about the course that you're currently studying? Why did you choose to do this course?
How did your life change after your diagnosis?	Removed question as it was identified as potentially particularly upsetting for participants.

Main Study

Interviews were conducted using the video-calling software Zoom, which was chosen

as it complies with GDPR regulations. The decision to use video-calling was made before

government guidelines due to COVID-19 restricted the use of face-to-face interview. Video-

calling enabled participants to undertake the interview without inducing additional fatigue or

distress from travelling, an approach which has been used in previous research with

participants who have ME/CFS (Aroll & Senior, 2007). It also meant the times of the

interviews were flexible, and participants could be in the comfort of their home. Additionally,

students from across the UK could participate, rather than solely recruiting participants in the

researcher's location. Once participants contacted the researcher, they were asked to read a Participant Information Sheet (Appendix D). This provided them with the required information to understand the procedures and aims of the research, and meant they could provide informed consent, which they did by signing a consent form (Appendix E) before the interview took place. In advance of the interview, participants were also asked to think of a metaphorical description of their experience as a student with ME/CFS. However, it was stated that it was not necessary to do so in order to undertake the interview.

The longest interview was 60 minutes and the shortest 43 minutes. The interviews began with the researcher providing an overview of the research and the nature of the interview. Participants were also reminded of their right to a break during the interview, or termination of the interview without consequence. Participants were then asked warm-up questions to ensure they felt comfortable, and to build up a rapport, which is important to enable participants to feel open to discuss their experiences (Smith & Osborn, 2003). 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 participants discussed to understand what they were feeling and thinking (e.g., "Can you tell me more about that?"/ "How did that make you feel?").

At the end of the interview a question regarding the future was asked, encouraging participants to leave feeling optimistic (Thompkins et al., 2008). If there was time remaining, participants were asked if they would like to add anything to the discussion that was not mentioned previously (McGrath et al., 2019). To conclude the interview, participants were orally debriefed, which is good practice in qualitative research (Howitt, 2019): they were told how they could remove their information from the study, reminded about the charities listed in the Participant Information Sheet and offered the opportunity to ask any questions.

Participants were also asked whether they would like to choose a pseudonym to enable them to quickly identify themselves if they read the final report (Mukungu, 2017).

Immediately after the interview, initial thoughts and feelings were recorded in a research diary, which is recommended when undertaking qualitative research in order to bracket off the initial thoughts and feelings (Brocki & Wearden, 2006). Participants were also emailed a debriefing sheet (Appendix F), as a reminder of the discussion in the oral debriefing. The interviews were recorded using voice recording software on the researcher's laptop, as this is more secure than using Zoom's recording service and did not involve video-recording. The interviews were transcribed using the transcription service Otter.ai., and subsequently checked and edited manually by the researcher, and additional information such as pauses, and laughter were added to provide context. All data was stored on the University of Glasgow's secure OneDrive.

Data Analysis

Data was analysed using IPA, using the stages outlined by Smith et al. (2009). However, these were broad stages and the researcher went back and forth between them. The implementation of these stages in the current study is outlined in Table 3. A journal was used by the researcher alongside the analysis process to reflect on her thinking and bracket off preconceptions (Gadamer, 1960/75; Smith et al., 2008). After the analysis was completed, the theoretical framework outlined in the introduction was explored, which aligns with an inductive approach.

Table 3

Stages of analysis based on Smith et al. (2009).

Stage	Implementation within current study
1: Reading and re-reading	The transcripts were read and re-read to gain familiarity with the interview. Looking at the transcripts in this level of detail enabled the researcher to understand the whole interview and move away from focusing on initial reactions and feelings.
2: Exploratory comments	The researcher made initial notes on the transcript. Different comments were made relating to descriptive, linguistic and conceptual aspects. Different colours and fonts were used to highlight the transcript and notes in relation to these different comments (see Appendix G for an example). The metaphors participants discussed were analysed at this stage alongside the interview data.
3: Developing emergent themes	Emergent themes were constructed based on the notes made in stage 2, and the researcher's interpretation of these notes (see Appendix G for an example).
4: Finding connections between emergent themes	Connections between emergent themes were found through different processes. Abstraction (putting similar themes together), subsumption (emergent theme became a superordinate theme), polarisation (finding oppositional relationships between themes), and contextualisation (putting themes together which related to key life events) were used as different methods for forming connections. This resulted in a list of subordinate themes which categorised the emergent themes (see Appendix H for an example).
5: Moving case by case	Each case was analysed using stages 1-4, enabling a focus on the idiographic and ensuring themes were developed from each case.
6: Looking for patterns across the cases	Cases 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 (see Appendix I). If they fitted within the themes developed, the metaphors that participants discussed were also included as evidence. At this stage, the original transcripts were also re-read to ensure that the themes reflected the narratives that participants gave. (Collins & Nicolson, 2002).

Ethics

The research was conducted in line with the British Psychological Society's Code of Ethics and Conduct (2018) and was approved by the School of Education Ethics Committee at the University of Glasgow (Appendix J). To ensure data protection, interview recordings and personal information were stored on the University of Glasgow OneDrive, a secure cloud

software. When the interviews were transcribed, participants were de-identified, and allocated pseudonyms. The key to their real names and contact information was kept on a password protected document. In advance of the interviews the researcher also familiarised herself with the guidelines outlined by Dempsey et al. (2016) to plan in case a participant became distressed during the interview, for example, offering the participant a break and switching off the audio recorder.

Quality of the Research

The quality of qualitative research is difficult to assess, but terms such as credibility and trustworthiness are increasingly being used (Golafshani, 2003). These are terms that are difficult to define in practice, but guidelines have been written regarding how to act on them when conducting qualitative research (e.g., Elliot et al., 1999; Yardley, 2000). Smith (2011) has also outlined quality criteria specifically for IPA research. Table 4 outlines how these criteria have been achieved in this research. These criteria were followed when deciding on the research design, and whilst carrying out the analysis.

Table 4

Quality criteria based on Yardley (2000), and examples from Elliot et al. (1999) and Smith (2011).

Criteria	How this was achieved in the current study
Sensitivity to context	The profile of the participants is outlined in Table 1. The interview questions were designed to ensure that contextual information was collected at the beginning of the interview. Verbatim quotes have also been included in the analysis so that the reader can understand the context of the claims made.
Commitment and rigor	IPA principles were used whilst developing the research question and whilst conducting the analysis. A pilot study was conducted to ensure that the interview would collect appropriate data. Sufficient density of a least three participants for each theme was used in the analysis (Smith, 2011).
Transparency and context	The stages used in the analysis have been outlined in Table 3, and examples of these stages are provided in Appendices G, H and I. The researcher's own interests and experiences are outlined in the reflexivity section (Elliot et al., 1999), and reflected upon throughout the project by using a research diary.
Impact and importance	The topic discussed in this research is one which provides a voice to those who often face stigma and delegitimisation (Dickson et al., 2007). Highlighting the experiences of students with ME/CFS will be of use to university communities.

Analysis

IPA was used to analyse the data in response to the research question: *How do university students with a diagnosis of ME/CFS experience and make sense of living with their illness?* Three superordinate themes with further subordinate themes were developed and are displayed in Table 5. Taken together, these interrelated themes illustrate how the participants' subjective well-being is affected due to their illness, and that making sense of their illness was an ongoing process. As part of the interview, participants were asked to think of a metaphor, and these are displayed in Table 6. Two participants had not remembered about the suggestion of a metaphor before the interview, which was not mandatory for taking part in the research. These metaphors, from six participants, help to understand their individual narratives and experiences. Taken together, they highlight participants' lack of control over their illness and their experience of having to overcome difficulties. Table 6 outlines which of the themes each participant contributed to, and the subordinate themes their metaphors fitted within are shown in bold. The metaphors discussed by Clara and Ramona are broader depictions of their experience, and therefore did not fit into one specific theme.

Table 5
Superordinate and subordinate themes

1. University as (de)legitimising	2. Negotiating disclosure	3. Loss and adaptation
1a. Delegitimisation	2a. Stigma	3a. Academic persona
1b. Legitimisation	2b. Struggling to advocate	3b. Social life
	2c. Deciding to hide	3c. Physical body

Table 6

Metaphors and themes contributed to

Pseudonym	Themes contributed to	Metaphor
Clara	1a, 1b, 2a, 2b, 2c, 3a, 3c	**Image of different selves:** Clara discussed a cartoon image which depicted three people, one which had a frown and was her now, and one which was her in the future who was happy with a PhD. In between the images was another person, which had a scribble on it. She described how in order to get from being sad to happy she had to get through the scribble of her student experience to reach her goal of completing her 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	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	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 hours.
Ramona	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. She also discussed how 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.

1. **University as (de)legitimising**

This superordinate theme describes how universities can act as an authority to both delegitimise and legitimise ME/CFS as a serious illness. The first subordinate theme discusses how participants experienced delegitimisation, which is defined as the concept of having one's own perception and definition of an illness disconfirmed (Kleinman, 1992). The second subordinate theme provides a counter to the first, by highlighting how participants experienced legitimisation, in which an individual's definition of an illness is validated. These two subordinate themes, therefore, reflect the disputed nature of the illness within society, and that often participants did not know how their illness would be received at their university. Further quotes in support of each subordinate theme are in section 1 of Appendix I.

1a. Delegitimisation

Three participants described experiences of delegitimisation, which mostly focused on the disability services and their tutors. Clara describes her experience of having to repeatedly justify herself when she needed support to complete her university work:

> **…** you're just put on the front page it's very much kind of like, 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 kind of feel like you're getting a bit poked and a bit prodded (Clara_28_PG).

Clara discusses how she is regularly being asked to justify and explain her symptoms. Her emphasis on how she has to explain herself "every single time", illustrates how it is likely that she would prefer to only have to tell her story once. This experience makes her feel as though her illness is not valid and makes her feel exposed and vulnerable like she is on the

"front page". Clara's description of being "a bit poked and a bit prodded" brings about 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 described here also depicts the university as more powerful than her, as the expert in the situation rather than Clara. This is likely to lead to Clara feeling disempowered, as she is not seen as an expert on her own illness.

Other participants described specific conversations with university staff who delegitimised their symptoms. Kayleigh describes a conversation she had with her tutor when she went to explain to them why she was not able to complete her major project in the way that she had originally planned:

I just sort of said to her, like, you know, I might have ME, and... I don't want to put too much strain on myself [laughs]. She just kind of said, oh, have you tried taking vitamin B12…she was like my mum had ME, and it's just like, are you sure, you don't seem to know what it is? (Kayleigh_21_UG)

This quote illustrates how Kayleigh is being told to take a supplement, rather than 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 delegitimisation 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 effect that these informal conversations can have on students, as well as the importance of validating students' experiences, and discussing which solutions would work for them.

1b. Legitimisation

Five participants described feelings of legitimisation: one alongside experiences of delegitimisation, and four spoke solely about how their university had legitimised their illness. These experiences of legitimisation were described as a break from other institutions or personal relationships in their lives, in which their illness was often delegitimised. Phoebe describes how she was surprised to find her university more accepting than any other organisation she had been in contact with:

> I've found them…one of the most accepting and…helpful organisations…which has been… quite refreshing…I've never had anything of a debate about whether or not it is an illness or not there was…never that issue. (Phoebe_22_UG).

Phoebe describes her university as "refreshing" as she had not expected the university to accept her illness. This illustrates the critical role that universities can play in students' lives, as a space of safety in which ME/CFS is legitimised, allowing students to seek help and support. In addition, their university can provide a break from other organisations where they have to justify their illness, which Phoebe described later in the conversation by saying the support from her university was "just one less thing that I had to battle to deal with". This illustrates that whilst society has still not reached a point of understanding or acceptance of ME/CFS as a legitimate illness, universities can provide a space of acceptance and support.

Sophie also described her surprise that the university knew about ME/CFS, and did not ask her to explain it:

> …it seemed like they had heard of it…which usually doesn't happen. Um because you say it and somebody's like, oh, no, what's that? But thankfully, they seem to be like

right okay, so we understand you've got ME CFS, what do you need?

(Sophie_22_UG).

Sophie's account also highlights the importance of university as a space of legitimisation, as it is a break from the usual questioning and justification that she has to provide. She also describes how the university asked her what she needed, 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.

This superordinate theme has shown the effect that university support services and tutors can have on the experience of students with ME/CFS. The space of their university has the opportunity to provide a break from other areas of their lives, or it can further perpetuate feelings of delegitimisation. The university, seen as an authority in participants' lives, also helps them to make sense of their illness, by either legitimising their understanding of themselves as someone with a serious chronic illness, or causing them to feel disempowered.

2. Negotiating Disclosure

This superordinate theme has three subordinate themes which describe participants' experiences of disclosing their illness. The first and second subordinate themes describe how concerns of stigma and needing to advocate for themselves were important in their decision to disclose their illness. The final subordinate theme illustrates how these experiences left participants not wanting to disclose their ME/CFS, preferring to hide it instead. Further quotes in support of each subordinate theme are in section 2 of Appendix I.

2a. Stigma

Three participants discussed feeling stigmatised 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 has not increased her symptoms, but rather highlighted them:

> I feel it's basically like, what do you call it, spotlights? So it's kind of like it was already there. But…now like its centre stage [laughs] 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_PG)

Clara describes how people finding out about her illness leaves her feeling stigmatised, 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 marginalised. The question she describes people asking of "why did you come back to university?" is likely to make her feel as though she is being marginalised from all areas of her life, as she describes later in the conversation that "work places are worse [than] universities". This is likely to leave her feeling as though there is no space in which her illness is accepted.

2b. Struggling to Advocate

The interactions participants had 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, as well as on behalf of the illness itself. Gabriel

discusses how he sent the disability services at his university a brochure explaining ME/CFS:

> …I've sent them you know, there's an Action for ME brochure that I've sent them, but
> I'm not sure, well 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_PG)

Gabriel's act of sending a brochure suggests that he was almost lost for words when trying to

explain his illness, as he does not have the words to explain a condition which is "not... well

understood". Instead of explaining his own personal account, Gabriel decided to refer the

disability services to a more accredited information source. 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:

> … this nervousness of like what to actually say in order for it to come across in the
> best way for everybody because I also feel quite conscious that you're speaking on
> behalf of like a community…but I think because 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

it, as she is worried that she has to prove that ME/CFS is a real illness in order to advocate on

behalf of others with ME/CFS. This leaves her feeling under considerable pressure to

disclose and educate those around her, but she does not feel capable that she alone can convince them that ME/CFS is a legitimate illness.

2c. Deciding to Hide

The active decision to not disclose their illness was discussed by four participants. This is due, in part, to the stigma and difficulties they experienced advocating for themselves and their illness. Lottie disclosed her experience of hiding her illness as an undergraduate student:

> So I didn't tell any of my friends that there was anything wrong with me, um 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_PG)

The length of time that Lottie did not tell her friends 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 discusses her comparison with others as "not necessarily a healthy thought process", highlighting how the desire to be normal was making her unhappy. Now a postgraduate student, Lottie said she had been able to tell two friends on her course, which 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 was perpetuating Lottie's negative feelings towards it.

Clara introduces 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, you know, make yourself a bit vulnerable and…tell people things if it's not going to be of use. (Clara_28_PG)

Clara's experience of having to explain and advocate for herself has not been positive, as telling her story often leaves her feeling worse due to the experience evoking feelings of vulnerability. Therefore, she only sees telling people around her to be worth it if she receives support in return, which has not been happening.

This superordinate theme has illustrated how participants are constantly negotiating whether to disclose their illness. Their experience of the illness was, therefore, one which included being fearful of stigma and struggling to advocate for themselves, which left them feeling as though it was easier to hide their illness. This illustrates how the participants made sense of their ME/CFS as a part of them which should be hidden from others, and their coping mechanism was to hide their illness.

3. Loss and Adaptation

This final superordinate theme explores how participants saw their diagnosis of ME/CFS as leading to loss in their life. The loss they experienced was discussed around three central areas: their academic persona, their social life and loss of control over their body. There were also instances in which participants discussed how they had come to terms with this loss and adapted their sense of self. Further quotes in support of each subordinate theme are in section 3 of Appendix I.

3a. Academic Persona

Six participants discussed how becoming ill changed their ability to achieve academically. They told stories about how they had been in the past, citing examples of being

top of the class or perfectionists in their academic work. Ramona explains how her poorer

academic performance has changed her view of herself as a student:

> …when I was younger, I was always the best at everything. I was like, top of the class
>
> of everything, and it's really hard now to be like middle to bottom with grades
>
> because I just don't have the energy to make it any higher or revise four times a day so
>
> that…makes you feel like, yeah, less of a worthy student. (Ramona_23_UG)

Ramona explains 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, two participants spoke about this loss, but then also about how they had

adopted a kinder attitude to themselves:

> …but since being ill the focus and the ability to concentrate on something has just
>
> gone. And so sometimes sitting and thinking, right look, you can't like, not beating
>
> myself up about it, basically. And so, accepting that if you get a 2:1, it's not like the
>
> end of the world [laughs]. (Phoebe_22_UG).

Phoebe describes how she is trying to adapt to be kinder to herself. Later in the conversation,

she explains 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, which is an ongoing process of negotiation with herself about whether

to be kinder to herself in relation to her grades. This shows how participants are managing to

adapt and learn to accept their illness. It also highlights changes in how participants are assessing their achievements, and therefore how they feel 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 in order to prioritise studying, housework and resting. Sophie explains how she is currently missing a social context in her life:

> I feel like I've missed out on so much so it's almost like an incomplete puzzle…would be the way I kind of picture it, just because certainly 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 discusses 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 socialising is encouraged and seen as an important aspect of student life.

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

> …whereas the friends that I've got now it's understood that 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 describes how the friends she has now understand that she would "move the bit of 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 was feeling disconnected and frustrated with their bodies, as though they had lost control over them. Many participants discussed how, prior to becoming ill, they were very active and had since 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 a 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. Um so that's, it more kind of unpredictable, and is based on the idea of something just not quite doing what it's supposed to. (Evelyn_23_UG)

Evelyn describes her body as a "damaged battery" showing how she sees her energy levels as unpredictable, and she has lost her control over her body. Relating her body to a material object makes it seem 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 my sport was my stress relief and when you don't have a stress relief, it's just like right, I need something…so um my go to became, adult paint by numbers, because it was just, it was getting you sitting not really thinking about anything, and it's really relaxing (Sophie_22_UG)

Sophie describes 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 it has helped her to feel better about her illness.

This final superordinate theme explored how adapting to life with ME/CFS was a process for participants, one which was often defined by a sense of loss, but one which also provided opportunities for them to be more accepting of their illness. It also highlights how participants made sense of their illness by comparing themselves to how they were before they became ill.

Discussion

The present study aimed to explore how university students with a diagnosis of ME/CFS experienced and made sense of living with their illness. Using IPA to analyse the data, three interconnected themes were developed: 'University as (de)legitimising', 'Negotiating disclosure' and 'Loss and adaptation'. The theoretical framework of self-esteem, which is an individual's subjective evaluation of themselves (Rosenberg, 1965), provides an understanding of how the participants' diagnosis of ME/CFS affects their subjective well-being. This framework, utilising social identity theory (SIT; Tajfel & Turner, 1986) and self-discrepancy theory (SDT; Higgins, 1987) provides an understanding of how the participants' experiences and sense-making processes occurred on both a personal and social level. Additionally, SIT and SDT enable the mechanisms influencing participants' psychological well-being to be explored. Figure 1 summarises the findings of the present study by illustrating participants' experiences and sense-making processes, and how these are both increasing and decreasing their self-esteem. Each theme will be discussed in turn, in light of this theoretical framework, and alongside literature in the field.
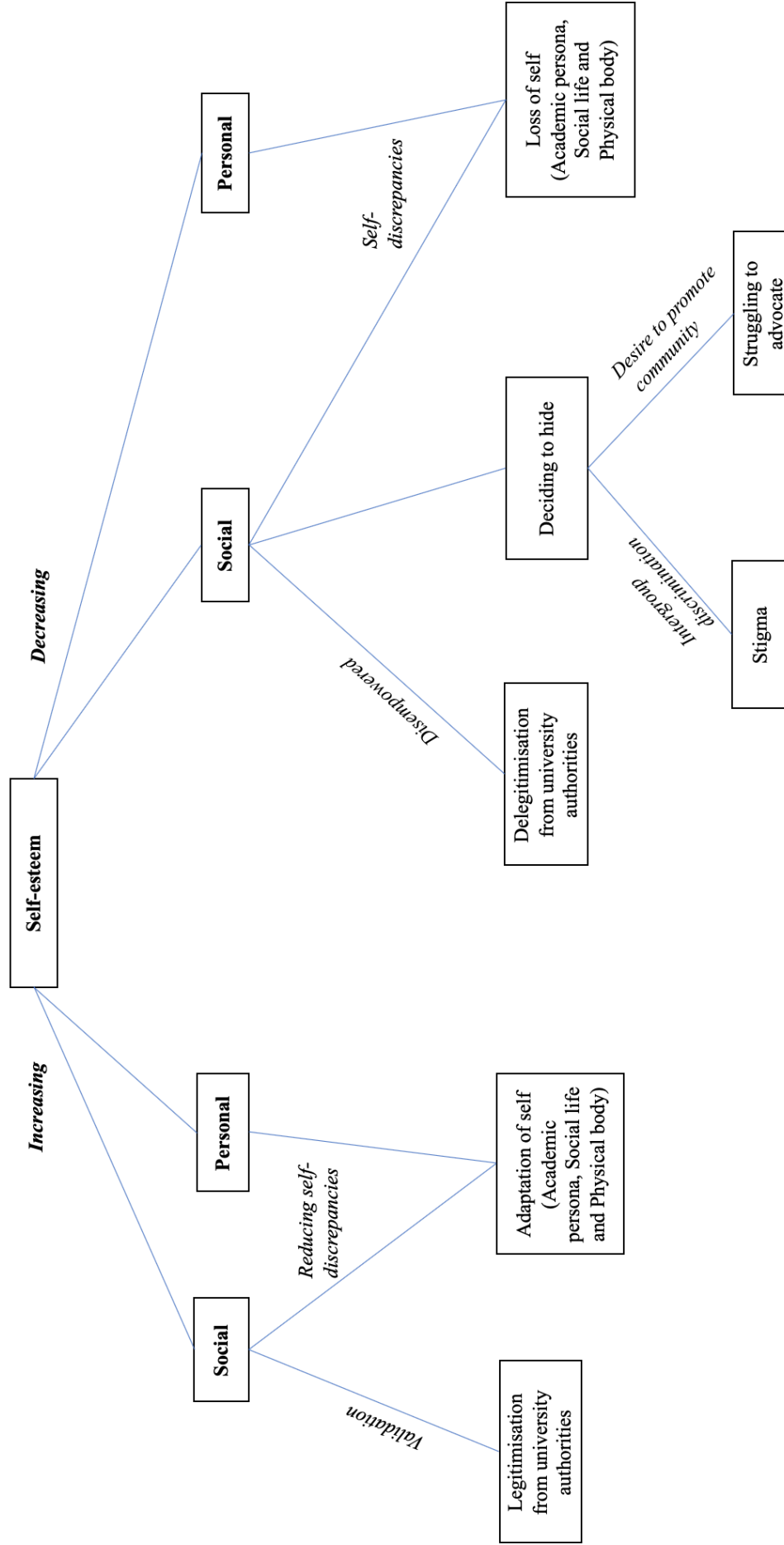
Figure 1. The experiences and sense-making processes participants discussed and how these affected their self-esteem.

Participants discussed how their universities were both delegitimising and legitimising of their illness. Delegitimisation is the concept of having one's own perception and definition of an illness disconfirmed (Kleinman, 1992). 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 delegitimisation have been described in research with adults who have ME/CFS, in relation to their interactions with healthcare professionals and loved ones (Clarke & James, 2003; Dickson et al., 2007; Edwards et al., 2007). However, by focusing on a student population, this research added a new form of delegitimisation to the current literature. Participants' accounts also suggested that delegitimisation 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. Similar effects of delegitimisation have been reported in previous research, for example, Wilde et al. (2020) found that men with ME/CFS preferred to distance themselves from those who they felt did not understand their illness, and research has also emphasised the subsequent feelings of worthlessness (Dickson et al., 2007; McManimen et al., 2018).

Participants' accounts of legitimisation offered a different perspective, providing an understanding of how universities can act as an important authority of 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 them what support they required, thus treating them as an expert on their own illness. This is likely to have enabled them to feel empowered and increased their self-esteem. Experiences of legitimisation, and the subsequent positive outcomes on well-being and sense of self have also been found in previous research (Wilde et al., 2020; Brady et al., 2016). Research

conducted by Broughton et al. (2017) investigated the impact of specialist support services for adults with ME/CFS and found that by having their illness validated participants experienced an increase in their subjective wellbeing and therapeutic outcomes. 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 (Chu et al., 2020). These experiences of delegitimisation and legitimisation, therefore, highlight how participants' self-esteem is likely to have been affected by interactions at a social level within their universities.

Participants' descriptions of negotiating the disclosure of their illness to university staff and peers also suggests that their social environment had a large effect on how they felt about their illness. Participants discussed stigma and the struggles they experienced advocating for themselves. This illustrated how participants felt judged and marginalised, suggesting that they felt as though they could not convince those around them that they have a legitimate illness. SIT (Tajfel & Turner, 1986) proposes that stigma and discrimination can be understood by in-groups and out-groups. This idea of intergroup dynamics can help to explain why students are being judged and stigmatised by others in the university community. Experiences of stigma have also been found in previous research with individuals with ME/CFS (Drachler et al., 2009; McManimen et al., 2018), as well as for students with disabilities (Newman et al., 2019). Tajfel and Turner (1986) also propose that groups aim to promote a positive group identity. This can be seen in participants' descriptions of their desire to advocate for the ME/CFS community. However, whilst this was the participants' aim, they often found it difficult, which could be explained by research that has proposed that there is more in-group bias within higher-status groups (Brown, 2000). The difficulties they disclosed regarding advocating for themselves have also been found in previous research with individuals who have ME/CFS, for example, in a study by Wilde et al.

(2020) 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, in their synthesis of research regarding students with mental health problems Markoulakis and Kirsh (2013) found that participants' perceptions of stigma 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 being 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's (2013) synthesis of research regarding students with mental health problems found that disclosure was often avoided due to the fear of discrimination. Similarly, Miller et al. (2019) conducted research with LGBTQ students with disabilities in America and found that disclosure was a conscious decision. The participants' experiences of hiding an aspect of their identity is 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.

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 (Aroll & Howard, 2013; Whitehead, 2006). 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 body's capabilities (Dickson et al., 2008; Wilde et al., 2020). 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 (Dickson et al., 2008; Gray & Fossey, 2003; Wilde et al., 2020). These experiences of loss, and the subsequent emotions, have parallels with the ideas proposed in SDT (Higgins, 1987). This theory proposes that it is differences between one's actual self and their ideal or ought self that results in depressive and anxious emotions. Therefore, it could be argued that participants, whose actual selves now incorporate their illness, have experienced an increased discrepancy between their actual and ideal or ought selves. Moreover, participants used their knowledge of how they used to be, before they became ill, in order to form their ideal self. For example, participants recounted how they wished they could still achieve academically to the same level they used to or undertake the same physical activities, which resulted in participants feeling less worthy. These findings, therefore, can be understood in light of the hypothesis put forward by Moretti and Higgins (1990) that a discrepancy between the actual and ideal self, results in a reduction in self-esteem.

Participants also discussed adapting their sense of self to allow for their ME/CFS. Higgins (1987) outlined that individuals will attempt to reduce discrepancies, in order to decrease the resulting negative emotions. 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, which is likely to increase their self-esteem. A change in self-evaluation over time has been reported previously in qualitative research with adults with ME/CFS (Reynolds et al., 2008; Whitehead, 2006). Additionally, in a study by Arroll and Howard (2013) 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 in the current study, who had a mean age of 27, and six participants 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 study's findings should, however, be considered within the context of its limitations. Firstly, sometimes online interviews are unable to achieve the same level of interaction and rapport as face-to-face interviews (Bohannon et al., 2013; Lo Lacono et al., 2016). Video-calling software also means participants see their own image on the screen, which can increase feelings of self-consciousness (Deniers, 2019). Additionally, as participants were not known to the interviewer, this could have reduced the amount of information they were willing to disclose. However, video-calling was used as it enabled the researcher to speak to individuals from across the UK, as well as ensuring that taking part did not induce additional fatigue (Aroll & Howard, 2013). The participants also shared personal insights during the interview, and the fact that the researcher did not know the participants beforehand may have allowed them to feel more comfortable speaking about these personal topics. Another limitation is in relation to gender, as all but one of the participants were female. In previous research with individuals with ME/CFS it has been identified that men go through specific experiences relating to a loss of masculinity (Wilde et al., 2020), which could not be captured in this research due to an emphasis on shared experiences. However, only one male offered to participate in the research.

Differences in the research design could have enabled more in-depth data to be elicited from participants, for example, by asking participants to complete a diary to explain their experiences (Morrell-Scott, 2018). Additionally, interviewing participants more than

once would have retained IPA's idiographic focus, while enabling richer and more detailed data to be collected (Hefferon & Gil-Rodriguez, 2011). However, these were not included due to time and resource limitations. Instead metaphors were included as they only required a limited additional time commitment from participants but enabled an in-depth insight into their experiences (Mitchell et al., 2011). Lastly, due to the subjective approach of IPA, the researcher's own preconceptions from having had the illness could have influenced the analysis (Brocki & Wearden, 2006). However, the researcher aimed to bracket off her preconceptions (Gadamer, 1960/75), and be transparent by stating her own interests and experiences in the reflexivity section (Elliott et al., 1999). It also allowed her to understand participants' experiences and empathise with them during the interview.

Implications

The present study presents theoretical and practical implications. The participants' emphasis on their social context in relation to how they made sense of their illness, and the use of SIT to explain their experiences, 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 (Du et al., 2017). Additionally, SDT was used in a new context: it helped to explore how participants could have used their knowledge of how they used to be, before they became ill, to form their ideal self, thus perpetuating the discrepancy between their actual and ideal self. Perhaps there is therefore a need to extend SDT to include the psychological processes that perpetuate discrepancies in individuals who have gone through a significant life change, such as being diagnosed with a chronic illness. Additionally, SIT was applied to understand why students experienced stigma, and their desire to advocate for the ME/CFS community. However, future research could look at extending SIT in order to

understand the mechanisms influencing disclosure of group membership for those with chronic illnesses.

The findings of this research also suggest that further support should be provided by universities. The delegitimisation that students experienced could be mitigated by providing tutors, support staff and students with information about ME/CFS. This could be 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 (Wroe & Bowers, 2019). 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 and put on a student's file, and with the student's permission, provided to university staff so students do not need to repeat their story to multiple people. It would then be the responsibility of academic staff to read this information and ensure that they speak to students regarding how they can best support them. Receiving this legitimisation could result in students experiencing less of a discrepancy between their actual and ideal selves, particularly in relation to their academic persona, increasing their self-esteem (Moretti & Higgins, 1990). Additionally, support groups for students with chronic illnesses could help students form a group identity (Tajfel & Turner, 1986), enabling them to feel empowered and increase their self-esteem. Lastly, the use of metaphors in this study helped participants succinctly explain how they were feeling; universities could use similar techniques to understand the impact ME/CFS was having on students.

Future Research

Additional insight into this topic could be gained by conducting further research. Longitudinal research would provide a further understanding of how students with ME/CFS adapt over time. Additionally, the students that took part in this study were those who were

well enough to remain on their university course. Further insight may be provided by speaking to students who left university due to ME/CFS, to understand what interventions, if any, could have been put in place by the university to support them. It would also be useful to conduct research on the effectiveness of policies and practices that universities have in place, for example, to evaluate systems that inform tutors that a student has ME/CFS.

Conclusion

The present study provides insights into the phenomenological experiences and sense-making processes of students with ME/CFS. The findings suggest that participants' self-esteem was affected by changes in their self-concept at both a personal and social level. Participants' accounts suggested that their self-esteem was predominately negatively affected by their illness, however, there were also experiences and opportunities for participants to increase their self-esteem. The implications of these findings are that universities can play a significant role in supporting students with ME/CFS. The findings demonstrate that there are two key interventions that could be put in place: the academic staff and disability services knowing about and legitimising the illness, as well as setting up support groups for students to informally connect with others in a similar situation and form a group identity. The emphasis on social context in this research highlights how students are making sense of their illness through social interactions, which has also theoretical implications for understanding the self-esteem of individuals with chronic illnesses. This research lends itself to further exploration as there are opportunities to find out more about the strategies that could enable students with ME/CFS, and other chronic illness, to achieve at university.

References

Acheson, E.D. (1956) A new clinical entity? *Lancet*, *267*(6926), 789–790.

    https://doi.org/10.1016/S0140-6736(56)91252-1

Abraído-Lanza, A. F., & Revenson, T. A. (2006). Illness intrusion and psychological

    adjustment to rheumatic diseases: a social identity framework. *Arthritis and*

    rheumatism, *55*(2), 224–232. https://doi.org/10.1002/art.21849

Action for ME (2013). *M.E./CFS and Higher Education*.

    https://www.actionforme.org.uk/uploads/pdfs/how-might-me-affect-studying.pdf

Allport, G. (1963). *Pattern and Growth in Personality*. Holt, Rinehart and Winston.

APA (2020a). Identity. In *APA Dictionary of Psychology*. https://dictionary.apa.org/identity

APA (2020b). Self-confidence. In *APA Dictionary of Psychology*.

    https://dictionary.apa.org/self-confidence

Arroll, M. A. & Howard, A. (2013) 'The letting go, the building up, [and] the gradual process

    of rebuilding': identity change and post-traumatic growth in myalgic

    encephalomyelitis/chronic fatigue syndrome. *Psychology & Health, 28*(3), 302-318.

    https://doi.org/ 10.1080/08870446.2012.721882

Arroll, M. A., & Senior, V. (2008). Individuals' experience of chronic fatigue

    syndrome/myalgic encephalomyelitis: An interpretative phenomenological analysis,

    Psychology and Health, 23(4), 443-458. https://doi.org/10.1080/14768320701246469

Bandura, A. (1994). Self-efficacy. In R. J. Corsini (Ed.), *Encyclopedia of psychology (2nd*

    ed., Vol. 3, pp. 368-369). Wiley.

Baumeister, R. (2005). Rethinking self-esteem: Why nonprofits should stop pushing self-

    esteem and start endorsing self-control. *Stanford Social Innovation Review, 3*, 34–41.

    Retrieved from: http://www.academia.edu

Bested, A. C., & Marshall, L. M. (2015). Review of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: an evidence-based approach to diagnosis and management by clinicians, *Reviews on Environmental Health, 30*(4), 223-249. https://doi.org/10.1515/reveh-2015-0026

Bettencourt, B.A., Dorr, N., Charlton, K., Hume, D.L. (2001). Status differences and in-group bias: A meta-analytic examination of the effects of status stability, status legitimacy, and group permeability. *Psychological Bulletin, 127*(4), 520–542. https://doi.org/10.1037/0033-2909.127.4.520

Billig, M., & Tajfel, H. (1973). Social categorization and similarity in intergroup behaviour. *European Journal of Social Psychology, 3*(1), 27–52. https://doi.org/10.1002/ejsp.2420030103

Bohannon, L.S., Herbert, A.M., Pelz, J.B. and Rantanen, E.M. (2013). Eye contact and video-mediated communication: A review, *Displays*, *177*(185), 177-185. https://doi.org/10.1016/j.displa.2012.10.009.

Boldero, J., & Francis, J. (2000). The relation between self-discrepancies and emotion: The moderating roles of self-guide importance, location relevance, and social self-domain centrality. *Journal of Personality and Social Psychology, 78*, 38-52. https://doi.org/10.103//0022-3514.78.1.38

Brady, E., Segar, J. & Sanders, C. (2016). "I Always Vet Things": Navigating Privacy and the Presentation of Self on Health Discussion Boards Among Individuals with Long-Term Conditions. *Journal of Medical Internet Research, 18*(10), e274. https://doi.org/:10.2196/jmir.6019

Brewer, M. B. (1979). In-group bias in the minimal intergroup situation: A cognitive-motivational analysis. *Psychological Bulletin, 86*(2), 307-324. https://doi.org/10.1037/0033-2909.86.2.307

Brewer, M. B., & Gardner, W. (1996). Who is this "we"? Levels of collective identity and

    self representations. *Journal of Personality and Social Psychology, 71*(1), 83-93.

    https://doi.org/10.1037/0022-3514.71.1.83

British Psychological Society (2018). *Code of Ethics and Conduct*. Retrieved from

    https://www.bps.org.uk/sites/www.bps.org.uk/files/Policy/Policy%20-

    %20Files/BPS%20Code%20of%20Ethics%20and%20Conduct%20%28Updated%20J

    uly%202018%29.pdf

Brocki, J.M. & Wearden, A.J. (2006). A critical evaluation of the use of interpretative

    phenomenological analysis (IPA) in health psychology. *Psychology & Health, 21*(1),

    87-108. https://doi.org/10.1080/14768320500230185

Brown, R. (2000). Social identity theory: Past achievements, current problems and future

    challenges. *European Journal of Social Psychology, 30*(6), 745-778.

    https://doi.org/10.1002/1099-0992(200011/12)30

Broughton, J., Harris, S., Beasant, L., Crawley, E., & Collin, S. M. (2017). Adult patients'

    experiences of NHS specialist services for chronic fatigue syndrome (CFS/ME): A

    qualitative study in england. *BMC Health Services Research, 17*(1), 384-12.

    https://doi.org/10.1186/s12913-017-2337-6

Brurberg, K.G., Fønhus, M.S., Larun, L., Flottorp, S., & Malterud, K. (2014). Case

    definitions for chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): a

    systematic review. *BMJ Open, 4*, e003973. https://doi.org/10.1136/bmjopen-2013-

    003973

CDC. (2018). *Possible Causes*. https://www.cdc.gov/me-cfs/about/possible-causes.html

CFS/ME Working Group. (2002, January). *A Report of the CFS/ME Working Group*.

    https://www.meresearch.org.uk/wp-

    content/uploads/2013/05/WorkingGroupReport.pdf

Chu, L., Fuentes, L. R., Marshall, O. M., & Mirin, A. A. (2020). Environmental accommodations for university students affected by myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). *Work, 66*(2), 315-326. https://doi.org /10.3233/WOR-203176

Clarke, J. N., & James, S. (2003) The radicalized self: The impact on the self of the contested nature of the diagnosis of chronic fatigue syndrome. *Social Science & Medicine, 57*, 1387–1395. https://doi.org/10.1016/s0277-9536(02)00515-4

Collin, S.M., Nikolaus, S., Heron, J., Knoop. H., White, P.D., & Crawley, E. (2016). Chronic fatigue syndrome (CFS) symptom-based phenotypes in two clinical cohorts of adult patients in the UK and The Netherlands. *Journal of Psychosomatic Research, 81*, 14–23. https://doi.org/10.1016/j.jpsychores.2015.12.006

Collins, K., & Nicolson, P. (2002). The meaning of 'satisfaction' for people with dermatological problems: Reassessing approaches to qualitative health psychology research. *Journal of Health Psychology, 7*, 615–629. https://doi.org/ 10.1177/1359105302007005681

Connell, J., Brazier, J., O'Cathain, A., Lloyd-Jones, M., & Paisley, S. (2012). Quality of life of people with mental health problems: A synthesis of qualitative research. *Health and Quality of Life Outcomes, 10*(1), 138-138. https://doi.org/10.1186/1477-7525-10-138

Corrigan, P. W., Watson, A. C., & Barr, L. (2006). The self-stigma of mental illness: Implications for self-esteem and self-efficacy. *Journal of Social and Clinical Psychology, 25*(8), 875–884. https://doi.org/10.1521/jscp.2006.25.8.875

Dempsey, L., Dowling, M., Larkin, P., & Murphy, K. (2016). Sensitive interviewing in qualitative research. *Research in Nursing & Health, 39*(6), 480-490. https://doi.org/10.1002/nur.21743

Deniers, C. (2019). Experiences of receiving career coaching via Skype: An interpretative phenomenological analysis. *International Journal of Evidence Based Coaching & Mentoring*, *17*(1), 72–81. https://doi.org/10.24384/r4j8-hm94

Dickson, A., Knussen, C. & Flowers, P. (2007) Stigma and the delegitimation experience: An interpretative phenomenological analysis of people living with chronic fatigue syndrome, *Psychology & Health, 22*(7), 851-867, https://doi.org/10.1080/14768320600976224

Dickson, A., Knussen, C., & Flowers, P. (2008) '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, *Psychology & Health, 23*(4), 459-476. http://doi.org/10.1080/08870440701757393

Drachler, M., Leite, J. C., Hooper, L., Hong, C. S., Pheby, D., Nacul, L., Lacerda, E., Campion, P., Killett, A., McArthur, M., & Poland, F. (2009). The expressed needs of people with chronic fatigue syndrome/myalgic encephalomyelitis: a systematic review. *BMC public health, 11*(9), 458. https://doi.org/10.1186/1471-2458-9-458

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

Duval, T.S., & Wicklund, R.A. (1972). *A theory of objective self-awareness*. Academic Press.

Edwards, C. & Thompson, A., & Blair, A. (2007). An 'Overwhelming Illness': Women's Experiences of Learning to Live with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis. *Journal of health psychology, 12*, 203-14. https://doi.org/10.1177/1359105307071747

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38*(3), 215-229. https://doi.org/10.1348/014466599162782

Eromo, Tamara & Levy, David. (2017). The Rise, Fall, and Resurgence of "Self-Esteem": A Critique, Reconceptualization, and Recommendations. *North American Journal of Psychology, 19*(2), 255-302.

Festinger, L. (1957). *A Theory of cognitive dissonance*. Stanford University Press.

Fleming, A. R., Edwin, M., Hayes, J. A., Locke, B. D., & Lockard, A. J. (2018). Treatment-seeking college students with disabilities: Presenting concerns, protective factors, and academic distress. *Rehabilitation Psychology, 63*(1), 55–67. https://doi.org/10.1037/rep0000193

Fonte, D., Lagouanelle-Simeoni, M., & Apostolidis, T. (2018). "behave like a responsible adult" - relation between social identity and psychosocial skills at stake in self-management of a chronic disease. *Self and Identity, 17*(2), 194-210. https://doi.org/10.1080/15298868.2017.1371636

Gadamer, H. (1960/1975). *Truth and Method* (Trans. G. Barden & J. Cumming). Sheed & Ward.

Golafshani, N. (2003). Understanding Reliability and Validity in Qualitative Research. *The Qualitative Report, 8* (4), 597-607. Retrieved from https://nsuworks.nova.edu/tqr/vol8/iss4/6

Gray, M.L., Fossey, E.M. (2003). Illness experience and occupations of people with chronic fatigue syndrome. *Australian Occupational Therapy Journal, 50*(3),127–36. https://doi.org/10.1046/j.1440-1630.2003.00336.x

Harwood, J. & Sparks, L. (2003). Social Identity and Health: An Intergroup Communication Approach to Cancer. *Health communication, 15*, 145-59. https://doi.org/10.1207/S15327027HC1502_3.

Haslam, C., Jetten, J., & Haslam, A. (2012). Advancing the social cure: Implications for theory, practice and policy. In J. Jetten, C. Haslam & S.A Haslam (Eds.), *The social cure: identity, health and wellbeing* (pp. 319-343). Psychology Press.

Hefferon, K. & Gil-Rodriguez, E. (2011). Reflecting on the rise in popularity of interpretive phenomenological analysis. *The Psychologist. 24*(10), 756-759.

Heidegger, M. (1927/1962). *Being and Time* (Trans. J. Macquarrie & E. Robinson). Blackwell.

Heidrich, S.M., Powwattana, A. (2004). Self-Discrepancy and Mental Health in Older Women with Chronic Illnesses. *Journal of Adult Development 11*, 251–259. https://doi.org/10.1023/B:JADE.0000044528.54943.5f

HESA (n.d.). *Who's studying in HE?* https://www.hesa.ac.uk/data-and-analysis/students/whos-in-he

Higgins, E. T. (1987). Self-discrepancy: A theory relating self and affect. *Psychological Review, 94*(3), 319–340. https:// https://doi.org/10.1037/0033-295X.94.3.

Higgins, E. T., Bond, R. N., Klein, R., & Strauman, T. (1986). Self-discrepancies and emotional vulnerability: How magnitude, accessibility, and type of discrepancy influence affect. *Journal of Personality and Social Psychology, 51*(1), 5–15. https://doi.org/10.1037/0022-3514.51.1.5

Higgins, E.T., Klein, R., & Strauman, T. (1985). Self-Concept Discrepancy Theory: A Psychological Model for Distinguishing among Different Aspects of Depression and Anxiety. *Social Cognition. 3*, 51-76. https://doi.org/10.1521/soco.1985.3.1.51.

Holmes, G.P., Kaplan, J.E., Gantz N.M., Lomaroff, A. L., Schonberger, L.B., Straus, S. E., Jones, J.F., Dubois, R.E., Cunningham-Rundles, C., Pahwa, S. Tosato, G., Zegans, L. S., Purttilo, D. T., Brown, N., Schooley, R. T. & Brus. I. (1988) Chronic fatigue syndrome: a working case definition. *Annals of Internal Medicine, 108*(3), 387-389. https://doi.org/10.7326/0003-4819-108-3-387

Horton, S. M., Poland, F., Kale, S., Drachler, M. d. L., de Carvalho Leite, Jose Carlos, McArthur, M. A., Campion, P. D., Pheby, D. & Nacul, L. (2010). Chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) in adults: A qualitative study of perspectives from professional practice. *BMC Family Practice*, 11(1), 89-89. https://doi.org/10.1186/1471-2296-11-89

Howitt, D. (2019). *Introduction to Qualitative Research Methods in Psychology: Putting theory into practice* (4th ed.). Pearson Education Limited.

Husserl, E. (1982). *Ideas Pertaining to a Pure Phenomenology and to a Phenomenological Philosophy* (F.Kersten, Trans.). Kluwer.

Jason, L. A. & Johnson, M. (2020) Solving the ME/CFS criteria and name conundrum: the aftermath of IOM. *Fatigue: Biomedicine, Health & Behavior.* https://doi.org./10.1080/21641846.2020.1757809

Jason, L., & Richman, J. (2007). How Science Can Stigmatize: the Case of CFS. J*ournal of Chronic Fatigue Syndrome. 14*, 85-103. https://doi.org/10.3109/10573320802092146

Kleinman, A. (1992). Pain and resistance: The delegitimation and religitimation of local worlds. In M. J. D. Brodwin, B. J. Good & P. E. A. Kleinman (Eds.), P*ain as human experience: An anthropological perspective.* University of California.

Larun, L., & Malterud, K. (2007). Identity and coping experiences in chronic fatigue syndrome: A synthesis of qualitative studies. *Patient Education and Counseling, 69*(1), 20-28. https://doi.org/10.1016/j.pec.2007.06.008

Lim, E., Ahn, Y., Jang, E., Lee, S., Lee, S., & Son, C. (2020). Systematic review and meta-analysis of the prevalence of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). *Journal of Translational Medicine, 18*(1), 100-15. https://doi.org/10.1186/s12967-020-02269-0

Lo Iacono, V., Symonds, P., & Brown, D. H. K. (2016). Skype as a Tool for Qualitative Research Interviews. *Sociological Research Online*, *21*(2), 103–117. https://doi.org/10.5153/sro.3952

Malmqvist, J., Hellberg, K., Möllås, G., Rose, R., & Shevlin, M. (2019). Conducting the Pilot Study: A Neglected Part of the Research Process? Methodological Findings Supporting the Importance of Piloting in Qualitative Research Studies. *International Journal of Qualitative Methods*, *18,* 1-11. https://doi.org/10.1177/1609406919878341

Markoulakis, R., & Kirsh, B. (2013). Difficulties for university students with mental health problems: A critical interpretive synthesis. *The Review of Higher Education, 37*, 77–100. http://doi.org/10.1353/rhe .2013.0073

McGrath, C., Palmgren, P. J., Liljedahl, M. (2019). Twelve tips for conducting qualitative research interviews. *Medical Teacher, 41*(9), 1002-1006. https://doi.org/10.1080/0142159X.2018.1497149

McManimen, S. L., McClellan, D., Stoothoff, J., & Jason, L. A. (2018). Effects of unsupportive social interactions, stigma, and symptoms on patients with myalgic encephalomyelitis and chronic fatigue syndrome. *Journal of Community Psychology, 46*(8), 959-971. https://doi.org/10.1002/jcop.21984

Mead, G. H. (1934) *Mind Self and Society.* University of Chicago Press.

Mengshoel, A. M., Helland, I. B., Meeus, M., Castro-Marrero, J., Pheby, D., & Strand, E. B. (2020). Patients' experiences and effects of non-pharmacological treatment for myalgic encephalomyelitis/chronic fatigue syndrome – a scoping mixed methods

review. *International Journal of Qualitative Studies on Health and Well-being, 15*(1), 1-16.

Miller, R. A., Wynn, R. D., & Webb, K. W. (2019). "This really interesting juggling act": How university students manage disability/queer identity disclosure and visibility. *Journal of Diversity in Higher Education, 12*(4), 307-318. https://doi.org/10.1037/dhe0000083

Mills, M. L. (2017). Invisible disabilities, visible service dogs: The discrimination of service dog handlers. *Disability & Society, 32*, 635– 656. http://doi.org/10.1080/09687599.2017.1307718

Millward, L.M., & Kelly, M.P. (2003). Incorporating the biological: chronic illness, bodies, selves and the material world. In S.J. Williams, G.A. Bendelow, & L .Birke (Eds.)., *Debating Biology: Sociological Reflections on Health Medicine and Society* (pp. 157-68). Routledge.

Mitchell, K., Skirton, H., & Monrouxe, L. (2011). Amelioration, regeneration, acquiescent and discordant: an exploration of narrative types and metaphor use in people with aphasia. *Disability & Society, 26*(3), 321–335. https://doi-org. /10.1080/09687599.2011.56041

Moretti, M. M., & Higgins, E. T. (1990). Relating self-discrepancy to self-esteem: The contribution of discrepancy beyond actual-self ratings. *Journal of Experimental Social Psychology, 26,* 108 – 123. https://doi.org/10.1016/0022-1031(90)90071-S

Morrell-Scott, N. (2018). Using diaries to collect data in phenomenological research. *Nurse Researcher, 25*(4), 26-29. https://doi.org/10.7748/nr.2018.e1527

Mukungu, K. (2017). "How can you write about a person who does not exist?": Rethinking pseudonymity and informed consent in life history research. *Social Sciences, 6*(3), 86. https://doi.org/10.3390/socsci6030086

Mullen, B., Brown, R., & Smith, C. (1992). Ingroup bias as a function of salience, relevance, and status: An integration. European Journal of Social Psychology, 22(2), 103-122. https://doi.org/10.1002/ejsp.2420220202

Nacul, L.C., Lacerda, E.M., Campion, P., Pheby, D., de L Drachler, M., Leite, J. C., Poland, F., Howe, A., Fayyaz, S. & Molokhia, M. (2011). The functional status and well being of people with myalgic encephalomyelitis/chronic fatigue syndrome and their carers. *BMC Public Health 27*(11), 402. https://doi.org/10.1186/1471-2458-11-402

Newman, B. M., Kimball, E. W., Vaccaro, A., Moore, A., & Troiano, P. F. (2019). Diverse Pathways to Purpose for College Students With Disabilities. *Career Development and Transition for Exceptional Individuals, 42*(2), 111–121. https://doi.org/10.1177/2165143418758985

NHS (2017, May 16). *Chronic Fatigue Syndrome.* https://www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/

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

O'Shea, A., & Kaplan, A. (2018). Disability identity and use of services among college students with psychiatric disabilities. *Qualitative Psychology,* 5(3), 358-379. https://doi.org/10.1037/qup0000099

Olney, M., & Brockelman, K. (2003). Out of the disability closet: Strategic use of perception management by select university students with disabilities. *Disability & Society, 18*(1), 35–50. http://doi.org/10.1080/ 713662200

Orth, U., & Robins, R. W. (2014). The Development of Self-Esteem. *Current Directions in Psychological Science*, *23*(5), 381–387. https://doi.org/10.1177/0963721414547414

Ozgul, S., Heubeck, B., Ward, J., & Wilkinson, R. (2003). Self-discrepancies: Measurement and relation to various negative affective states. *Australian Journal of Psychology, 55*, 56-62. https://doi.org/10.1080/00049530412331312884

Phillips, A, G. & Silvia, P. J. (2005). Self-Awareness and the Emotional Consequences of Self-Discrepancies. *Personality & social psychology bulletin. 31*, 703-13. https://doi.org/10.1177/0146167204271559.

Phillips, A. G., & Silvia, P. J. (2010). Individual differences in self-discrepancies and emotional experience: Do distinct discrepancies predict distinct emotions? *Personality and Individual Differences, 49*, 148-151. https://doi.org/ 10.1016/j.paid.2010.03.010

Pietkiewicz, I. & Smith, J. (2014). A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology. *CPPJ. 20*, 7-14. https://doi.org/10.14691/CPPJ.20.1.7.

Rakib, A., White, P.D., Pinching, A.J., Hedge, B., Newbery, N., Fakhoury, W.K., & Priebe, S. (2005). Subjective quality of life in patients with chronic fatigue syndrome. *Quality of Life Research, 14*(1), 11-19. https://doi.org/10.1007/s11136-004-1693-y

Rees, C.E., Knight, L.V. and Cleland, J.A. (2009). Medical educators' metaphoric talk about their assessment relationships with students: 'You don't want to sort of be the one who sticks the knife in them'. *Assessment & Evaluation in Higher Education, 34*(4), 455–67. https://doi.org/10.1080/02602930802071098

Reichl, A. J. (1997). Ingroup favouritism and outgroup favouritism in low status minimal

    groups: Differential responses to status-related and status-unrelated

    measures. *European Journal of Social Psychology, 27*(6), 617-633.

    https://doi.org/10.1002/(SICI)1099-0992(199711/12)27

Reynolds, F., Vivat, B., & Prior, S. (2008) Women's experiences of increasing subjective

    well-being in CFS/ME through leisure-based arts and crafts activities: A qualitative

    study. *Disability and Rehabilitation, 30*(17), 1279-1288.

    https://doi.org/10.1080/09638280701654518

Roberts, E., Wessely, S., Chalder, T., Chang, C. K., & Hotopf, M. (2016). Mortality of

    people with chronic fatigue syndrome: A retrospective cohort study in England and

    Wales from the South London and Maudsley NHS Foundation Trust Biomedical

    Research Centre (SLaM BRC) Clinical Record Interactive Search (CRIS) Register.

    The Lancet, 387(10028), 1638–1643. https://doi.org/10.1016/S0140-6736(15)01223-4

Rosenberg, M. (1979). *Conceiving the self.* Basic Books.

Sachdev, I., & Bourhis, R. Y. (1991). Power and status differentials in minority and majority

    group relations. *European Journal of Social Psychology, 21*(1), 1-24.

    https://doi.org/10.1002/ejsp.2420210102

Schechter, C. & Firuz, F. (2015) How mentor principals interpret the mentoring process

    using metaphors, *School Leadership & Management, 35*(4), 365-387.

    https://doi.org/10.1080/13632434.2015.101050

Smith, J.A. (1996) Beyond the divide between cognition and discourse: using interpretative

    phenomenological analysis in health psychology, *Psychology and Health, 11*(2), 261–

    71. https://doi.org/10.1080/08870449608400256

Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology, 1*(1), 39–54. https://doi.org/10.1191/1478088704qp004oa

Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review: Advancing and Extending Qualitative Research in Health Psychology, 5*(1), 9-27. https://doi.org/10.1080/17437199.2010.510659

Smith, J. A., Flowers, P. & Larkin, M. (2009) *Interpretative Phenomenological Analysis: Theory, Method and Research*. Sage.

Smith, J.A., Flowers, P., and Osborn, M. (1997) Interpretative phenomenological analysis and health psychology. In L. Yardley (Ed.), *Material Discourses and Health* (pp. 68–91). Routledge.

Smith, J.A. & Osborn. M. (2003) Interpretative phenomenological analysis. In J.A. Smith (Ed.), *Qualitative Psychology: A practical guide to research methods* (2nd ed., pp.57-80). Sage.

Smith, B. and Sparkes, A.C. (2004). Men, sport, and spinal cord injury: An analysis of metaphors and narrative types. *Disability & Society, 19*(6), 613–26. https://doi.org/10.1080/0968759042000252533

Sowislo, J. F., & Orth, U. (2013). Does low self-esteem predict depression and anxiety? A meta-analysis of longitudinal studies. *Psychological Bulletin, 139*(1), 213-240. https://doi.org/10.1037/a0028931

Spencer, G., Lewis, S., & Reid, M. (2018). Living with a chronic health condition: Students' health narratives and negotiations of (ill) health at university. *Health Education Journal, 77*(6), 631–643. https://doi.org/10.1177/0017896917738120

Stets, J., & Burke, P. (2000). Identity Theory and Social Identity Theory. *Social Psychology Quarterly, 63*(3), 224-237. https://doi.org/10.2307/2695870

Sweetman, E., Noble, A., Edgar, C., Mackay, A., Helliwell, A., Vallings, R., Ryan, M. & Tate, W. (2019). Current Research Provides Insight into the Biological Basis and Diagnostic Potential for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). *Diagnostics, 9*(3), 73. https://doi.org/10.3390/diagnostics9030073

Tajfel, H., & Turner, J. C. (1986). Social Identity Theory of Intergroup Behavior. In S. Worchel, S. and W.G. Austin (Eds.), *Psychology of Intergroup Relations* (pp.7-24). Hall Publishers.

Tedeschi, R. G., & Calhoun, L. G. (1996). The posttraumatic growth inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress, 9*(3), 455-471. https://doi.org/10.1002/jts.2490090305

Thomas, M. A., & Smith, A. P. (2005). Primary healthcare provision and Chronic Fatigue Syndrome: a survey of patients' and General Practitioners' beliefs. *BMC family practice, 6* (49). https://doi.org/10.1186/1471-2296-6-49

Thompkins, C. N. E., Sheard, L., & Neale, J. (2008). Methodological reflections on closing qualitative interviews with women drug users. *Methodological Innovations, 2*(3), 18-29. https://doi.org/10.4256/mio.2008.0003

Tuffour, I. (2017). A Critical Overview of Interpretative Phenomenological Analysis: A Contemporary Qualitative Research Approach. *Journal of Healthcare Communications, 2*(4), 52. https://doi.org/10.4172/2472-1654.100093

Turner, J.C. (1999). Some current issues in research on social identity and self categorization theories. In N. Ellemers, R. Spears, and B. Doosje (Eds.), *Social Identity* (pp.6-34). Blackwell.

Underhill, R. A. (2015). Myalgic encephalomyelitis, chronic fatigue syndrome: An infectious disease. *Medical Hypotheses, 85*(6), 765-773. https://doi.org/10.1016/j.mehy.2015.10.011

Vaccaro, A., Moore, A., Kimball, E., Troiano, P.F & Newman, B. M. (2019) "Not Gonna

    Hold Me Back": Coping and Resilience in Students with Disabilities, *Journal of*

    Student Affairs Research and Practice, 56(2), 181-

    193, https://doi.org/10.1080/19496591.2018.1506793

Walsh, R. S., Denovan, A., Drinkwater, K., Reddington, S., & Dagnall, N. (2020). Predicting

    GP visits: A multinomial logistic regression investigating GP visits amongst a cohort

    of UK patients living with myalgic encephalomyelitis. *BMC Family Practice, 21*(1),

    1-8. https://doi.org/10.1186/s12875-020-01160-7

Waters, S. J., Keefe, F. J., & Strauman, T. J. (2004). Self-discrepancy in chronic low back

    pain: Relation to pain, depression, and psychological distress. *Journal of Pain and*

    Symptom Management, 27(3), 251-259.

    https://doi.org/10.1016/j.jpainsymman.2003.07.001

White, P.D. (2004). What causes chronic fatigue syndrome? *BMJ, 329*(7472), 928–929.

    https://doi.org/10.1136/bmj.329.7472.928

White P. D. (2007). How common is chronic fatigue syndrome; how long is a piece of

    string?. *Population health metrics*, *5*(6). https://doi.org/10.1186/1478-7954-5-6

Whitehead, L. (2006). Toward a trajectory of identity reconstruction in chronic fatigue

    syndrome/myalgic encephalomyelitis: A longitudinal qualitative study. *International*

    Journal of Nursing Studies, 43(8), 1023-1031.

    https://doi.org/10.1016/j.ijnurstu.2006.01.00

Wilde, L., Quincey, K., & Williamson, I. (2020). "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, 21(2), 309–320. https://doi.org/10.1037/men0000220

Willig, C. (2013). *Introducing qualitative research in psychology* (3rd ed.). Open University Press.

Wojcik, W., Armstrong, D., & Kanaan, R. (2011). Is chronic fatigue syndrome a neurological condition? A survey of UK neurologists. *Journal of Psychosomatic Research, 70*(6), 573 - 574. https://doi.org/10.1016/j.jpsychores.2011.02.007

Worchel & W. G. Austin (Eds.) *Psychology of intergroup relations* (pp. 7–24). Nelson-Hall.

Wroe, A. L., & Bowers, H. M. (2019). Beliefs about sharing illness experiences: Development of a scale and relationship with symptoms of fibromyalgia. *British Journal of Health Psychology, 24*(3), 687-703. https://doi.org/10.1111/bjhp.12376

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health, 15*(2), 215-228. https://doi.org/10.1080/08870440008400302

Appendices
Appendix A: Example Advertisement

Hi everyone,

I'm a current MSc Psychology student at the University of Glasgow. I'm looking for students who are diagnosed with Chronic Fatigue Syndrome (CFS)/ Myalgic Encephalomyelitis (ME) to take part in my research looking at students' experiences who have a diagnosis of CFS/ME.

I am looking for students who are aged over 18 in either full or part-time study at a university or college to share their experiences.

If you would like to participate, you would be invited to complete an interview via video-calling which will ask about your experience with CFS/ME, including:

- Receiving a diagnosis
- Your social support networks
- How you see yourself
- Expectations and hopes for the future.

Your participation would take no longer than one hour, and the findings will be written up in my dissertation for my MSc. I hope that you would find it a useful experience, and an opportunity to reflect on your experiences.

If you would like more information, please see the Participant Information Sheet, which can be viewed online using the following link: https://bit.ly/372k7FW

If you would like to participate or require any further information, please contact me, Frances, on 2505892W@student.gla.ac.uk or my supervisor Dr Dely Elliot on Dely.Elliot@glasgow.ac.uk. I am happy to have a chat over the phone or via email if you are considering taking part and would like further information.

The study has been approved by the University of Glasgow's ethics board (402190253).

Please feel free to share this email with anyone you think might be interested in taking part.

Best wishes,
Frances Waite

Appendix B: Interview Schedule

Warm up questions

1) Please could you tell me a bit about the course that you're currently studying? Why did you choose to do this course?

Initial experience

2) Please could you tell me about the period of time when you first realised you were feeling unwell or different from your usual self?

   Prompts: How long ago was this? What else was happening in your life at this point?

3) Could you tell me about your experience of being diagnosed?

   Prompts: What kind of interactions with health care professionals did you have? What was your initial reaction? Can you tell me how it happened, for example where you were and who was with you?

Current experience

4) Can you describe what a good day and a bad day are like in terms of your illness?

   Prompts: Do you have any further examples?

5) Can we discuss the image or object you selected as a metaphor for your experience? Why did you select this to represent your experience as a student with CFS/ME?

   Prompts: Could you tell me a bit more about your experience as a student with CFS/ME?

Support

6) Can you tell me about the main types of support you receive from friends and family?

   Prompts: Do you have any examples? How do you feel about this support? Do your friends and family understand your illness? Do you think they accommodate your illness suitably?

7) Can you tell me about the main types of more formal support you receive, such as from your university or healthcare professionals?

   Prompts: Do you have any examples? How you feel about this support? Do you think these professionals understand your illness? Do you think they accommodate your illness suitably?

Identity

8) How do you think your diagnosis has changed how you see yourself?

   Prompts: How does this relate to how you see yourself as a student?

9) How do you think your diagnosis has changed how those around you see you?

   Prompts: Do you have any examples? How do you feel about that?

10) What do you imagine your life would be like if you were fully recovered from your illness?

   Prompts: Can you describe what type of activities you would be doing, or what type of relationships you would have with others?

Conclusion

11) Is there anything else you would like to discuss, or you think is important that we didn't cover?

Appendix C: Draft Interview Schedule

Initial experience

1) Please could you tell me about the period of time when you first realised you were feeling unwell or different from your usual self?

   Prompts: How long ago was this? What else was happening in your life at this point?

2) Could you tell me about your experience of being diagnosed?

   Prompts: What kind of interactions with health care professionals did you have? What was your initial reaction? Can you tell me how it happened, for example where were you and who was with you?

3) How did your life change after your diagnosis?

   Prompts: Please could you tell me some more similarities and differences before and after your diagnosis.

Current experience

4) Can you describe what a good day and a bad day are like in terms of your illness?

   Prompts: Do you have any further examples?

5) Can we discuss the image or object you selected as a metaphor for your experience? Why did you select this to represent your experience as a student with CFS/ME?

   Prompts: Could you tell me a bit more about your experience as a student with CFS/ME?

Support

6) Can you tell me about the main types of support you receive from friends and family?

   Prompts: Do you have any examples? How do you feel about this support?

7) Can you tell me about the main types of more formal support you receive, such as from your university or healthcare professionals?

   Prompts: Do you have any examples? How you feel about this support?

Identity

8) How do you think your diagnosis has changed how you see yourself?

   Prompts: How does this relate to how you see yourself as a student?

9) How do you think your diagnosis has changed how those around you see you?

   Prompts: Do you have any examples? How do you feel about that?

10) What do you imagine your life would be like if you were fully recovered from your illness?

    Prompts: Can you describe what type of activities you would be doing, or what type of relationships you would have with others?

Conclusion

11) Is there anything else you would like to discuss, or you think is important that we didn't cover?

Appendix D: Participant Information Sheet

Title of research project: The experiences of students who have a diagnosis of CFS/ME
Researcher: Ms Frances Waite
Supervisor: Dr Dely Elliot
Programme: Psychological Studies (MSc)

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part. Thank you for reading this.

What is the purpose of the study?
The study is seeking to understand the experiences of students at university or college with a diagnosis of Chronic Fatigue Syndrome (CFS)/ Myalgic Encephalomyelitis (ME). To understand these experiences, I am looking for students who currently have a diagnosis of CFS/ME and are in full-time or part-time study who willing to participate in an interview. I am interested in learning more about 1) your experience of diagnosis, 2) your social support networks, such as friends and family, 3) how you see yourself with your illness and 4) your hopes and expectations for the future. There may also be other aspects of your experience that you would like to discuss and can also be covered.

What's involved if I agree to take part?
We are keen to support you to decide whether this research study is suited to you. If upon reading this information sheet, you have more questions, please do not hesitate to get in touch (contact details below). If you would like to take part, you will be asked to sign a consent form. You are free to withdraw from this study at any time up until the analysis has begun, even if you have signed the consent form.

This research will use interviews to generate an understanding about the experience of students who have a diagnosis of CFS/ME. The interview will use broad and open-ended questions giving you the chance to talk about your own experiences. The interviews will be conducted via video-calling using Zoom, which complies with data regulation laws (GDPR). The interviews will be audio recorded so that the interview can be typed up. The interview questions and discussion will last for no longer than one hour. You will be able to take breaks whenever you want, and you can decide to terminate the interview at any point.

Will my taking part in this study be kept confidential (privacy notice)?
Everything will be in place to protect your privacy. We will remove specific references in the write up of the interview which may reveal your identity. However, due to a small sample size, confidentiality cannot be guaranteed. In addition, a time and space where you can speak confidentiality will be arranged with you.

The following steps will be taken to maintain your confidentiality:
1. Changing your name, and the names of other people, places or organisations you mention during the interview.
2. All transcribed interviews will be securely stored for up to ten years, which is in line with the open access policies at University of Glasgow. They will only be made accessible to future researchers or used in future publications without any names, contact details or any other personal information.
3. All personal and research data will be stored securely on University of Glasgow's secure OneDrive facility and all personal data will be destroyed once the research project is completed, which would be at the latest December 2021.

Please note that if evidence of wrongdoing or potential harm is uncovered, this information may need to be passed on to the relevant authority.

What are the possible disadvantages and risks of taking part?
We hope that you will find taking part in this research a useful experience and provide an opportunity to reflect on your experience. We consider your views and experiences as extremely valuable. We will ensure your own welfare and comfort throughout the video-interview using Zoom. You are free to end the interview at any time and you will be able to ask for breaks as necessary. You are also free to withdraw from the research at any point without giving any reason why.

What will happen to the results of the research study?
A summary of experiences and views will be presented in a dissertation. Findings for this study may also be published in an academic journal or presented at a conference. If you would like a written summary of results and/ or a copy of the final dissertation this can be sent to you.

Who has reviewed the study?
The study has been reviewed and approved by The University of Glasgow's School of Education Ethics Committee.

Contact for Further Information
If you have any questions about this study, you can ask me, Frances Waite at 2505892W@student.gla.ac.uk, or my supervisor, Dr Dely Elliot at Dely.Elliot@glasgow.ac.uk.

If you have any concerns regarding the conduct of this research project, you can contact the School of Education Ethics Officer, Dr Barbara Read, at Barbara.Read@glasgow.ac.uk.

If you would like support regarding any issues raised by reading this participant information sheet, or if you take part in the interview, please see contact details for charities that can provide support and advice below.

ME Association	**Samaritans**
Contact number 0344 576 5326	Contact number 116 123
Website https://www.meassociation.org.uk/	Website https://www.samaritans.org/

Appendix E: Consent Form

University | School of
of Glasgow | Education

Consent Form

Title of Project: The experiences of students who have a diagnosis of CFS/ME

Name of Researcher: Ms Frances Waite
Name of Supervisor: Dr Dely Elliot

I confirm that I have read and understood the Participant Information Sheet for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

I acknowledge that participants will be referred to by pseudonym.

Data usage and storage
- All names and other material likely to identify individuals will be anonymised.
- The material will be treated as confidential and kept in secure storage at all times.
- The material will be retained in secure storage for use in future academic research.
- The material may be used in future publications, both print and online.
- I agree to waive my copyright to any data collected as part of this project.

I acknowledge the provision of a Privacy Notice in relation to this research project, which is outlined in the Participant Information Sheet.

I consent to undertaking the interview using Zoom and interviews being audio- recorded ☐

I agree to take part in this research study ☐

I do not agree to take part in this research study ☐

Name of Participant ………………………. Signature …………………………………………

Date …………………………………

Appendix F: Debriefing Sheet

Title of project: The experiences of students who have a diagnosis of CFS/ME

Thank you for taking the time to take part in this research. Your time and responses are greatly appreciated.

The aim of the study is to understand the experiences of students at university or college with a diagnosis of Chronic Fatigue Syndrome (CFS)/ Myalgic Encephalomyelitis (ME). The findings of the study can hopefully help to improve experiences for students whilst at university and college.

If you have been affected by speaking about your experiences, please contact the below charities.

ME Association	**Samaritans**
Contact number 0344 576 5326	Contact number 116 123
Website https://www.meassociation.org.uk/	Website https://www.samaritans.org/

The findings will be written into a dissertation for an MSc, and possibly published in an academic journal or presented at a conference. Please remember to contact me in the next week if you would like to remove your data from the project.

If you have any questions, please contact me by email on 2505892W@student.gla.ac.uk

If you would like the results of the study communicated to you, either as a summary, or of the full dissertation document please let me know.

Thank you again for your time.

Appendix G: Exploratory Comments and Emergent Themes

Example of Stages 2 and 3 of the analysis

Code of exploratory comments: normal = descriptive, *italics* = language, underlined = conceptual

Code of transcript highlights: blue = descriptive, pink = language, green = conceptual

Emergent Themes	Transcript	Exploratory Comments
Self-management Not showing true self, hiding vulnerabilities Negotiating disclosure	been like I don't really know what we could do for you. And it's like, that's really disheartening to hear because it's kind of like I've just spent all this time telling you my life story. And you basically say, well, you know, we can't do anything for you. Um so that's been quite a tricky part of my university experience, particularly this academic year. Um just normally I wouldn't even go down the disability route because I just I feel like I've just gotten used to struggling in silence because you don't really want to, you know, make yourself a bit vulnerable and, you know, tell people things if it's not going to be of use. So, yeah, I think I had a bit of a bullet this year and was like, okay, you know, just try and see what the disability team can do. And unsurprisingly, they couldn't really do much. So I think that's been really really hard for me to kind of just adjust to the fact that you know, I tried something I didn't really want to try it and it worked out how my negative side told me it would and also because I feel like that's gonna impact on my degree.	Spent time explaining story and it hasn't gone anywhere Feeling vulnerable *Life story: invasive so she doesn't want to do it repeatedly* Finds it difficult to navigate support aspect of university Wouldn't normally tell people, used to managing it on her own *Doesn't want to be vulnerable and open up to people* Doesn't want to show her true self Forced herself to go and speak to someone Felt like it wasn't worth it for her to go and speak to someone Reinforcing negative thoughts in her mind Worry about degree, disability service not providing her with adequate support

Appendix H: Subordinate and Emergent Themes

Example of Stage 4 of the analysis

Subordinate Theme	Emergent Themes	Quotes
1: Loss of self	1.1: Academic persona	Okay, so basically, it has like a little um man or person should I say, [laughs] badly drawn person. So it's literally like a circle with legs and eyes. So it's got a little circle man with eyes erm and then feet, err, kind of like a, I don't know what you call it. I suppose it's a frown. Beside, you've got the same man but he's smiling. Erm and then in between those two little men was the same person is like a scribble. It's a scribble and it says, it has the letters PhD on it, and the first image of him frowning is me. It says me underneath it. Erm second image says Dr. me, so obviously, it's kind of like me kind of like sad and then I go through this, like scribble and then I come out and then I'm a doctor, and then I'm happy basically. (180-187) Yeah, so I'm in the scribble right now. Like it's literally, it's like a child's done that all over the paper, so I feel like I'm in that middle bit right now where it's kind of like, you can see the beginning and you can see the end, but you literally can't see anything beyond that. That's it. (192-194) So I think it did take quite a bit of thinking actually, before I went back to university I wasn't sure if err it's hard because you think is university a place for me like even if you want to do your course, it's kind of like the demands of being a university student are so intense and it's even though yes you have other students that are on your cohort or might be on your class or on your course I think it's different for every individual like everyone has their own kind of different kind of university experience and also their own life outside of university as well. (46-51) Um just because I just feel like universities are not built for people with chronic fatigue in, in in all honesty, they're really not because everything you have to do things within a certain time frame. You have to do team group work, you have to do independent work, you have to manage your life. You have to do all of these things at the same time and it's kind of like that is like the most anti chronic fatigue, [laughs] lifestyle anyone could ever have. (342-347)

	1.2: Body	Um, because it's literally like you could wake up one day and be bed bound for a month. And I feel like university or not, that is a very worrying thing to have to live in fear of, I think. (422-424)
2: Disclosure	2.1: Trying to hide vulnerabilities	Um just normally I wouldn't even go down the disability route because I just I feel like I've just gotten used to struggling in silence because you don't really want to, you know, make yourself a bit vulnerable and, you know, tell people things if it's not going to be of use. So, yeah, I think I had a bit of a bullet this year and was like, okay, you know, just try and see what the disability team can do. And unsurprisingly, they couldn't really do much. So I think that's been really really hard for me to kind of just adjust to the fact that you know, I tried something I didn't really want to try it and it worked out how my negative side told me it would and also because I feel like that's gonna impact on my degree. (207-214) Um but I think outside of I suppose my GP, it is quite lonely because people don't they don't they just don't get it. You know you can explain it and people are literally just kind of like it's just another label that you're putting on yourself kind of thing. So yeah, and I think that can make it more isolating when people think it's a fake condition. It's kind of just like if they didn't understand it, that would be bad enough but for them to kind of just be like, well, I have that as well, and I'm like [laughs], I don't wanna explain it basically. (248-253)
	2.2: Stigma	I feel it's basically like, what do you call it? Spotlights? So it's kind of like it was already there. But it's kind of like, now like it's centre stage [laughs] for everyone to see… Just kind of feel like, university isn't really the place where you say things like that. Because people will just kind of 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? I feel like that's what they're saying, I feel like they're judging me [laughs]. (334-340)
	2.3 Struggling to advocate	So um I feel like having to be an educator of what chronic fatigue syndrome, and people are just like isn't that just extreme tiredness, and I'm just like ah, now I have to be you know, the neurologist that explains it to you as well as the person that's suffering from it [laughs]. Um, so yeah it's it's tricky, it is a tricky one. (233-236)

3: De(legitimisation) at university	3.1: Delegitimisation	…um people just either don't understand it or just kind of brush it off. Um and I think that makes it really, really hard as well, you know, being at uni where people are kind of just like, oh, are you sure that you don't just have um an iron deficiency, that's the one that I get all the time. You're not just iron deficient, you might be anaemic everyone's like, and I'm just like I'm not, I have regular blood tests, regular blood tests, and I'm definitely I know I'm definitely not anaemic. (509-514) …you're just put on the front of, you're just put on the front page it's very much kind of like, you have chronic fatigue so tell us what it's like and it's just like, I don't really want to do that every single time I need a week off, extension, so I kind of feel like you're getting a bit poked and a bit prodded, and it's like, you know, I don't know. It makes your life very difficult in a nutshell. I think it makes it extremely difficult simply because the institution isn't designed to support people with chronic fatigue, amongst other conditions. (399-404)
	3.2: Legitimisation	Work places are worse [laughs] universities it's weird because workplaces have a legal duty, as well, but I just kind of feel like you get lost in it…At university, it's a bit more like, you know, it's kind of like school, you have to safeguard me, you have to do something about it, at least be seen to be doing something about it. Whereas at work it can just get swept under the rug. Or, you know, they may not even ask you. That way they don't have a legal obligation, whereas at university, it's more kind of like you apply, do you have a disability? Yes or no, you know, it's more, it's less hidden I think. (450-458)
4: Questioning legitimacy of diagnosis	6.1: Herself	Because when I first started feeling like this, and obviously the diagnosis, before the formal diagnosis when kind of the word CFS was flying around, I was kind of like, do I actually have this? Is it actually a condition? Have I made this up? Or is it a thing where I've just got really poor um what do you call it like sleep hygiene? Is it because I don't have a blue light filter? Is it because I'm not going to bed on time and just thinking about all these things, that I'm probably doing that's making my sleep worse. (306-311) Just because I just I'm not really I'm not convinced about whether my personal case of chronic fatigue is a disability. I'm kind of on the fence really, if it is or if it isn't, just because when it is a bad day, it feels it's definitely disability. But other than that, I kind of just live a relatively normal existence. (465-468)

	6.2: Family	I feel like my dad, he's one of those just typical people, though. He's very much like, what is this condition? [laughs] Why are you saying that you have it? What are the symptoms? And then like, I'll tell him the symptoms, and then he'll decide whether or not I have it [laughs]. (273-276)
		Like he's, he just doesn't get it, and I think it's quite challenging for particularly for people like my parents, and people in their generation where it was like everything was work work work. You know, I had three jobs. I did this and I looked after children and I went to university. I'm just like, okay, dad, yeah we get it. But you know, you ran the world we understand. So when I say, oh, I'm tired, and I'm getting out of bed at 11 o'clock on a Saturday, he's like, you're lazy, you know, you should be up by now. (278-283)

Appendix I: Master and Emergent Themes

Stage 6 of the analysis

Master theme	Emergent Theme	Sample Quotes
1: University as de(legitimising)	1a: Delegitimisation	Clara: …you're just put on the front of, you're just put on the front page it's very much kind of like, you have chronic fatigue so tell us what it's like and it's just like, I don't really want to do that every single time I need a week off, extension, so I kind of feel like you're getting a bit poked and a bit prodded, and it's like, you know, I don't know. It makes your life very difficult in a nutshell. I think it makes it extremely difficult simply because the institution isn't designed to support people with chronic fatigue, amongst other conditions. (399-404) Evelyn: …I had one tutor go oh so you're tired sometimes, and I was I was like on my file, I'm flagged as being someone with a chronic illness. But your reading of that was oh, you get a bit tired. And that was frustrating. So I then kind of went, oh, well, sometimes I'm really exhausted. Sometimes I'm not generally there's pain, and she was like there's pain, and I'm like, this isn't a new illness. (180-184) Kayleigh: I just sort of said to her, like, you know, I might have ME, and you know, I don't want to put too much strain on myself [laughs]. She just kind of said, oh, have you tried taking vitamin B12, and I was just like, um no I haven't, um yeah she was like my mum had ME, and it's just like, are you sure, you don't seem to know what it is? It's not just like you take a vitamin, and everything gets better… (173-177)
	1b: Legitimisation	Clara: At university, it's a bit more like, you know, it's kind of like school, you have to safeguard me, you have to do something about it, at least be seen to be doing something about it, whereas at work it can just get swept under the rug. (453-455) Lottie: Um and their um enabling team are amazing, amazing people. They um helped me, so the way that they work is that with new applicants because you disclose that you have some form of disability on your application, they get in contact with you even when you're an offer holder. And they start to put in, like support packages then. (160-163) Um so they were really supportive, um especially on one err period of fieldwork that I was really, really ill in [city]. Um my lecturer was absolutely amazing. Um so everybody from the department was incredibly, incredibly supportive. (171-173) Phoebe: I've found them as like an organisation to be like the most one of the most accepting and um useful, like helpful organisations of any social agency or anything that I've come into contact with which has been really like quite refreshing like I didn't expect that and one like there's no I've never had anything of a debate about whether or not it is an illness or not there was just like, never that issue. (172-175)

		Ramona: I mean, for my exams I have a small room or my own room wherever possible rest breaks I'm allowed to take in food and drink erm extra time and I can have a scribe if I want to but I don't like it because it makes me feel uncomfortable [laughs] so yeah they offer me a lot to make sure that I can get through exams. (140-143) **Sophie:** I think they do their best to trying to understand every student every student students needs, so I definitely think they've done their best. Um, and from what I could tell, it seemed like they had heard of it and they knew what it was, um which usually doesn't happen. Um because you say it and somebody's like, oh, no, what's that? But thankfully, they seem to be like right okay, so we understand you've got ME CFS, what do you need? (268-276)
2: Negotiating Disclosure	2a: Stigma	**Clara:** I feel it's basically like, what do you call it? Spotlights? So it's kind of like it was already there. But it's kind of like, now like it's centre stage [laughs] for everyone to see… Just kind of feel like, university isn't really the place where you say things like that. Because people will just kind of 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? I feel like that's what they're saying, I feel like they're judging me [laughs]. (334-340) **Evelyn:** And I've managed to figure out a uni routine where I can go and rest before I go in and do all of that. Um and I've managed to get to a point where I can walk every day for a reasonable period of time. Then I have my crutch for if I have to walk further than expected which I hate using because no 23-year-old wants, will ever want to be seen with a crutch, it's just there going literally a crutch. (144-148) **Kayleigh:** the osteopath I saw she she recommended that with day to day things, whatever I thought I could do, I should only do half of that so that I didn't push myself too much. And my flatmate used to, like, make these light-hearted jokes about like, oh, you could only do half like, I'd be eating a slice of cake and she's like, oh, you can only eat half kind of thing. So that sort of was like that sort of attitude is a bit difficult to deal with. (418-422) …probably I think as well there's there is a lot of like stigma around ME um a lot of people aren't quite sure what it is or they think that you just need to exercise more or yeah like do Pilates or something. So I think it's like also you just you want as little people to know as possible in a way (211-214)
	2b: Struggling to advocate	**Clara:** So um I feel like having to be an educator of what chronic fatigue syndrome, and people are just like isn't that just extreme tiredness, and I'm just like ah, now I have to be you know, the neurologist that explains it to you as well as the person that's suffering from it [laughs]. Um, so yeah it's it's tricky, it is a tricky one. (233-236) **Evelyn:** But I was just sat there going it doesn't matter if you give me an extra day when I can only work for two to three hours out of every day. And I was trying to explain that and they're like, oh, but we given you the extra and I was like, that doesn't change….So if someone is sitting in front of you going, I can only do three hours of work a

| | | day, and you turn around and go, Yeah, but you know, just this time, you're gonna have to do more. It's just that complete misunderstanding of no, I'm telling you I can only, like, I am only able to do that much I can't do more than that because that will put me at risk. (283-301)

Gabriel: Um, I think um err the disability service or the people who conduct the disability service do because I've talked a lot about and I've sent them you know, there's an action for ME brochure that I've sent them to it, but I'm not sure, well 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. (187-191)

Phoebe: Um or if they do I say like, yeah, I've been ill or I say like I've got a chronic condition but I don't really sort of educate um and I suppose that just comes from a) lack of energy and b) just this nervousness of like what to actually say in order for it to come across in the best way for everybody because I also feel quite conscious that you're speaking on behalf of like a community, which I know is a bit weird, but I think because 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 or even though your experience is valid, personally, it's kind of difficult. (370-376)

Ramona: One was a lecturer where I hadn't been sleeping very well at all. And it was our first lecture with him. And I slept through the entire thing… And then the lecturer came over and was like oh, she's sleeping through the lesson. He was all, he was a bit snarky about it. So I sent him an email explaining like, I'm not rude. I just need sleep. I'm really sorry, um and he just kind of went oh okay and that was about it. (151-156) |
| | 2c: Deciding to hide | Clara: I've just gotten used to struggling in silence because you don't really want to, you know, make yourself a bit vulnerable and, you know, tell people things if it's not going to be of use. (207-209)

Kayleigh: So I found myself just if I didn't need to go into university, I I just wouldn't I would do sort of do producing work from my bedroom, and just make phone calls and send emails and stuff but from the comfort of my own home (181-193)

Lottie: So, I didn't tell any of my friends that there was anything wrong with me um for the first two years of my undergrad degree. Erm and it was partly because um I was ashamed of that. And partly because in my head, I was sort of like, if I don't tell anybody, then it's not going to be a problem here. Like I'm moving away from home. And if I don't tell anybody that I have something wrong with me, then it's not going to be wrong. Um and I just had a massive desire for people to think that I was normal. (143-148)

Phoebe: I didn't really get the whole thing of a bed. Like I didn't really understand what people loved about being in bed so much. So now [laughs], it's like a complete 360. Um and so, yeah, I've really like understood the love of |

		the bed and how the sort of connotations of comfort and feeling secure and feeling I don't know safe, I suppose. And, so now I love my bed, which I didn't before. (163-167) I just don't think if you don't live with someone, I think it's a lot difficult. I don't think I'm very good at, I don't complain or I'm not very good at showing the realities of it, um I'm quite a people pleaser (324-326)
3: Loss and adaptation	3a: Academic persona	Clara: So it's got a little circle man with eyes um and then feet, err, kind of like a, I don't know what you call it. I suppose it's a frown. Beside, you've got the same man but he's smiling. Erm and then in between those two little men was the same person is like a scribble. It's a scribble and it says, it has the letters PhD on it, and the first image of him frowning is me. It says me underneath it. Um second image says Dr. me, so obviously, it's kind of like me kind of like sad and then I go through this, like scribble and then I come out and then I'm a doctor, and then I'm happy basically. (180-186) Evelyn: Um like I was, like really great at science and I was really great at erm the humanities subjects, I was really good at all of that. And if I hadn't got ill, I could have kind of explored one of those pathways to the extent that I would have wanted to like, erm I was always really interested in classics and love to go and do kind of the archaeological digs and doing all that. (538-542) Gabriel: So yeah, so things like err maladaptive perfectionism and imposter phenomenon and err CFS err is umm is real, is really err debilitating. And it makes it so that you err for fairly long periods, you're not really enjoying the course because you put yourself under so much pressure err when you should be… (385-388) Ramona: But when I was younger, I was always the best at everything. I was like, top of the class of everything, and it's really hard now to be like middle to bottom with grades because I just don't have the energy to make it any higher or revise four times a day. So that that's quite hard as well. And that makes you feel like, yeah, less of a worthy student. (255-258) Kayleigh: …in college, I was very much like that, um like I really wanted to get the top marks for everything and then first year of uni… but then after that, I think I was just like a bored of try to strive to be the best all the time um definitely yeah, I think since being diagnosed I remember my tutor saying to me like, Oh, I think if you really tried you can probably finish with like, a first class degree. Um but I was just like yeah, I don't want to push myself that hard. Um I'm happy to just get like a 2:1 that would be absolutely fine with me. (398-404) Phoebe: And so sometimes sitting and thinking, right look, you can't like not beating myself up about it, basically. And so, accepting that if you get a 2:1, it's not like the end of the world [laughs]. But it's difficult because when you like wired that way, it's kind of hard um, and it's almost as if you want to, I don't like saying that it's an excuse, like, I don't see it as an excuse, but then I have to remember that it is like a, I see it as like a disability.

		(315-219)
	3b: Social life	Kayleigh: …you know my flatmate would want to go clubbing and I think a lot of the university scene is going to parties and gatherings and everything like that, like in my second year of uni I remember having um it was like from September to October, I was volunteering at the university like the sort of uh freshers events. (342-345) Phoebe: I used to seek a lot of self-validation and very, like, just very outgoing, very busy, sociable. Now I don't really have any friends [laughs] that many because it's just like, I can't do um the social life the socialising is just something I haven't managed to deal with yet. Like, I can't physically just don't have the energy or the inclination or anything to do that. And so that's been a massive thing. I've completely sort of retracted from people. (381-385) Sophie: …the way that I kind of think about ME just now is like, basically a puzzle piece. So I because I feel like I've missed out on so much so it's almost like an incomplete puzzle kind of thing would be the way I kind of picture it, just because certainly 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 kind of social side of things so I wasn't actually being able to go out and speak to friends as much… (187-192) Evelyn: Um so I think that's something you really struggle with when you first get quite sick is people who haven't got experience of that just going, well, why don't you come visit me and you're going, I would love to. But I can't do a three-hour journey on my own, it's not safe for me to do that. And that's that kind of real sticking point. And obviously, if you're gonna, if you've got good friend, you want to be able to give as much as you can into that friendship. But there's an understanding, there's a misunderstanding of how much is the right amount for you to put in, whereas the friends that I've got now it's understood that we would do, move, like, 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. (383-396)
	3c: Physical body	Clara: Um, because it's literally like you could wake up one day and be bed bound for a month. And I feel like university or not, that is a very worrying thing to have to live in fear of, I think. (421-423) Evelyn: … 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 do it like that sort of thing. Erm so that's, it more kind of unpredictable. And is based on the idea of something just not quite doing what it's supposed to. And that's what I think is an important one because it's even like, oh, well have you got enough rest? Well, I think so. But who knows what will happen now? (189-194)

		Kayleigh: Um the only thing I could think of comparing it to is being constantly hungover. Um that's usually what I think of a lot of the time, like, you know, when, and I don't drink a lot now, but when I did drink a lot, you know, in my student days, um then you know, waking up the next morning just feeling really groggy, and you're exhausted and just um yeah, you've got like a pounding headache and stuff. That's that's sort of how it feels to have ME, just every morning you wake up with a hangover even though you've not been drinking, so, yeah, that's the only thing I can really think of. (156-162) **Phoebe:** So, prior to this, I can't sleep, I never ever slept my whole life for very long. I could sleep for like, five or six hours and I'd be like, really awake. Like, that's just how my body works. I didn't really get the whole thing of a bed. Like I didn't really understand what people loved about being in bed so much. So now [laughs], it's like a complete 360. (161-164) **Ramona:** Um I'd say now, I [pause] I don't know I feel like I see myself as a person, but like a lesser one, if that makes sense. Because I don't I don't function properly. So I feel like I don't count as a full human. (240-241) <u>Sophie</u> …before my sport was my stress relief and when you don't have a stress relief, it's just like right, I need something…so um my go to became, adult paint by numbers, because it was just, it was getting you sitting not really thinking about anything, and it's really relaxing (394-396)

Appendix J: Ethical Approval

20th May 2020

Dear Frances,

School of Education Research Ethics Committee

Project Title:
The experiences of students who have a diagnosis of CFS/ME: An Interpretative Phenomenological Analysis

Application No: 402190253

The School of Education Research Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project, subject to the following conditions:

- Start date of ethical approval: 20/05/20
- Project end date: 31/12/21
- Any outstanding permissions needed from third parties in order to recruit research participants or to access facilities or venues for research purposes must be obtained in writing and submitted to the School of Education Research Ethics Administrator before research commences. Permissions you must provide are shown in the reviewer feedback form, titled *Notification of Ethics Application Outcome*, that has been sent to you.
- Data collected should be held securely for the period you indicated in the application and any personal data collected should be appropriately managed in accordance with the General Data Protection Regulation.
- The research should be carried out only on the sites, and/or with the groups and using the methods defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment as an amendment to the original application. The *Request for Amendments to an Approved Application* form should be used:
  https://www.gla.ac.uk/schools/education/research/ethics/forms/

Yours sincerely,

Barbara Read.

Dr Barbara Read
School of Education Ethics Officer