What is the psychological and educational impact of being an emerging adult living with ME/CFS? A qualitative interpretative phenomenological analysis

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Contents

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List of abbreviations

Abbreviation	Meaning
ME/CFS	Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome
IPA	Interpretative phenomenological analysis
PEM	Post-exertional malaise
NICE	The National Institute for Health and Care Excellence
CDC	The Centers for Disease Control and Prevention
BPS	British Psychological Society
WHO	The World Health Organization
UN	The United Nations
ONS	Office for National Statistics (UK)
CBT	Cognitive behavioural therapy
GET	Graded exercise therapy
GET(s) (within context of IPA)	Group experiential theme(s)
Sub-GET	Sub-group experiential theme
PET(s)	Personal experiential theme(s)

List of tables

Abstract

Background: Emerging adulthood has been described as a life stage between adolescence and adulthood. Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (ME/CFS) is a highly intrusive condition with symptoms impacting psychological wellbeing and educational participation and enjoyment. **Aim**: Much of the qualitative research regarding ME/CFS has been conducted with children, adolescents or adults. The experiences of emerging adults has gone under-researched. This research aims to better understand and advocate for the psychological and educational wellbeing of emerging adults living with ME/CFS. **Methodology**: Through semi-structured interviews, five emerging adults shared their psychological and educational experiences of life with ME/CFS. Interpretative phenomenological analysis (IPA) was used to ideographically explore meaning and sense-making. **Findings**: Analysis found six group experiential themes (GETs): (1) others don't understand, (2) lacking control, (3) Pushing beyond energy capacity because of pressure, frustration or denial, (4) Feeling less-than and not enough, (5) grief and longing for lost identities, and (6) inconsistent educational support. **Conclusion**: Feeling misunderstood was at the heart of many psychological and educational experiences. Efforts to become better understood meant participants spent precious energy educating others. All participants reported ME/CFS has restricted their lives, bodies or future. A detrimental tendency to push beyond energy capacity was exacerbated by pressure, frustration and/or denial. Most participants grieved for lost hobbies, abilities and opportunities and most participants spoke about inconsistent, fluctuating educational support for their ME/CFS needs. **Implications**: Participants described a desire to feel less judged and better understood. It may be beneficial for family, friends and peers to identify unkind bias and suspend unevidenced judgement. The same actions made by education professionals can help reduce disability discrimination in schools, colleges and universities. Online teaching, deadline extensions, resources in additional formats, early access to lecture materials and personalised, well disseminated academic access plans may help students living with ME/CFS to feel better supported within the academic arena.

Declaration

No portion of the work referred to in this thesis has been submitted in support of an application for another degree of qualification of this or any other university or institute of learning.

Copyright statement

Chapter 1: Introduction

1.1 Chapter outline

This introductory chapter orients the reader to the current thesis. The chapter starts with a brief overview of chronic conditions and disability. I then outline ME/CFS, detailing its symptomology, prevalence, diagnostic process and recommended management. I shall go onto discuss past and present controversies and highlight what it is like to be an emerging adult living with ME/CFS, in both the United Kingdom (UK) and United States of America (USA). I focus on these two contexts since my participants reside within these two countries. I will then discuss the reflexive aspects of the study, including my personal history, presuppositions and positioning. An overview of key terms is provided, crucial given the fact that language ambiguities already exist within the field. Finally, the chapter closes with a brief structure of the upcoming study.

1.2 Background

1.2.1 Chronic conditions and disability

Chronic conditions are health problems that currently cannot be cured, but can be controlled with the use of medication and/or other therapies (NHS Data Model and Dictionary, 2023). They are persistent in their effects and require ongoing management for years or even decades. In this regard, ME/CFS is a chronic condition. Almost half of the UK population and six in ten Americans live with at least one chronic condition (CDC, 2022a). In the USA, chronic conditions are the leading causes of disability and death (Bauer, 2014). Worldwide, disability is on the rise (WHO, n.d).

Not all chronic conditions lead to disability. Around 24% of the UK population and 27% of the US population experience disability (CDC, 2023b; Kirk-Wade, 2023). This means approximately a quarter of people with chronic conditions don't experience disability. The WHO estimates that 16% of the global population currently experience significant disability (WHO, n.d).

Yet definitions and models of disability vary. The CDC defines disability as any condition of the body or mind that makes it more difficult to do certain activities and interact with the world (CDC, 2020). In the UK, under the Equality Act (2010), you are disabled if you have a physical or mental impairment that has a substantial and long-term negative impact on your ability to do normal daily activities. Both these definitions suggest that personal impairment is the sole cause of disability (Hogan, 2019). The WHO takes a slightly different approach, stating that disability results from interactions between individuals with a health condition, and personal and environmental factors. Such factors include negative attitudes, limited accessible transport, inaccessible buildings and limited social support. These differences in definition highlights changing societal thought, feelings and attitudes regarding disability. This will be discussed further in chapter two, literature review.

1.2.2 ME/CFS

Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (ME/CFS) is a complex, chronic, fluctuating condition that affects multiple body systems (NICE, 2021). Symptoms of ME/CFS include debilitating fatigue, unrefreshing and disturbed sleep, cognitive difficulties, flu-like sensations, dizziness, pain and post-exertion malaise (CDC, 2021). Post-exertion malaise, (PEM), the defining feature of ME/CFS, is an increase in severity of symptoms following physical and cognitive exertion (Hartle et al., 2021). This exertion may be minimal, and symptoms typically worsen twelve to forty-eight hours after activity (CDC, 2021). Increased symptoms can last for days or even weeks (CDC, 2021).

The impact of ME/CFS varies widely. Some people living with the condition are significantly incapacitated and either housebound or bedbound; others are able to carry out work and daily activities with adaptation and adjustment (NICE, 2021). In this sense ME/CFS is a spectral condition with an estimated 25% of people experiencing mild ME/CFS, and another 25% experiencing severe or very severe ME/CFS (Montoya et al., 2021). Pre-Covid global prevalence of ME/CFS ranges from 0.4% to 2.5% (Słomko et al., 2019). Its minimum adult pre-Covid UK prevalence is 0.2% (Nacul et al., 2011b) and its USA prevalence is between 0.2% and 0.4% (Słomko et al., 2019). Prevalence estimates for childhood ME/CFS vary from 0.06 to 0.75% (Jason et al., 2022; Bell et al., 2001; Nijhof et al., 2011; Rimes et al., 2007), with adolescents slightly more likely than younger children to experience the condition (Bell et al., 2001). ME/CFS has a peak age of onset between twenty and forty-five years and a female to male ratio of 3:1 (Cortes Rivera et al., 2019). Since the Covid pandemic, rates of ME/CFS have risen (Salari et al., 2022).

The term ‘ME’ can be dated back to 1955. It originally described an illness outbreak of undetermined cause at the Royal Free Hospital in London (Wojcik et al., 2011). Seventy years later the condition continues to have a complex and ununderstood aetiology. There are no definitive biological markers for ME/CFS and no diagnostic test (Dickson et al., 2008). Modern consensus is that the condition arises from a multifaceted relationship between immunological dysfunction, physical stress, genetics and psychosocial factors (Brurberg et al., 2014). Yet from almost the outset, some researchers and clinicians have labelled the condition functional, psychosomatic or non-neurological (McEvedy & Beard, 1970; Neu et al., 2014; Wojcik et al., 2011).

Diagnosis for ME/CFS is made using case definitions (criteria), but there is poor international agreement on a single set of diagnostic criteria (Deumer et al., 2021). Several established criteria exist, including The Canadian Consensus Criteria, Fukuda Criteria, Oxford Criteria, and The International Consensus Criteria (Deumer et al., 2021). However, clinical descriptions are variable, with each set of diagnostic criteria prioritising different characteristics as primary indicators of the condition (NICE, 2021). As a result, it is not uncommon for clinicians to use more than one case definition to diagnose (CDC, 2022b),

although the lack of international diagnostic consensus does increase the likelihood of delayed and/or misdiagnosis (NICE, 2021).

There has been some controversy over best management of ME/CFS (Sanal-Hayes et al., 2023). This controversy has mainly centred around the large scale randomised controlled PACE trial (White et al., 2007, 2011). The PACE trial advised both cognitive behavioural therapy (CBT) and graded exercise therapy (GET) for symptomatic treatment. In the UK, NICE included this trial in its 2007 best practice guidelines (Baker & Shaw, 2007). Yet, the PACE trial has come under considerable criticism from patient groups and clinicians both sides of the Atlantic (Sanal-Hayes et al., 2023). Both groups highlight methodological concerns and question the veracity of its conclusions. In 2021, NICE updated its ME/CFS management guidance. Currently NICE recommends pacing, an energy management technique, and CBT is included as an adjunctive, not curative, treatment (NICE, 2021; Vink & Vink-Niese, 2022). Pacing involves regulating activity to reduce the frequency and severity of PEM (Sanal-Hayes et al., 2023). Since ME/CFS is a spectral condition, appropriate regulatory activity levels vary from person to person (Goudsmit et al., 2012). In addition to pacing; pharmacological and non-pharmacological management of pain, mood, sleep, and orthostatic intolerance is recommended by NICE and the CDC, where appropriate (CDC, 2021a).

Several research trials have been undertaken investigating other pharmacological approaches to managing ME/CFS. However, many have poor external validity, and have proven to be inconsistent and inconclusive (Rivera et al., 2019). A systematic review into drug therapies for ME/CFS (Collatz et al., 2016) concluded that no universal pharmaceutical treatment could be recommended at the time.

1.2.3 Emerging adulthood

Emerging adulthood, a term coined by Jeffery Arnett, is thought to be “neither adolescence nor young adulthood but theoretically and empirically distinct from both” (Arnett, 2000, p.

469). This stage of development, experienced from (roughly) aged eighteen to the mid-twenties, is thought to be distinguished by five main features: identity exploration, a sense of instability, a tendency towards self-focus, feeling in-between, and an age of unparalleled opportunity and optimism (Arnett, 2004).

Wood et al. (2017) suggests that, as support structures begin to relax, emerging adults must learn to rely on their own resources. For those who go to college or university, the first year has been identified as a time of ruminative identity exploration and contemplation, especially regarding which direction to pursue in life (Luyckx et al., 2013). Over the course of college or university, emerging adults tend to become more assertive in their identity choices, ultimately engaging and committing to activities in line with identity preferences (Luyckx et al, 2008). As attachments shift from parents to peers, friendships can play a significant role (Fraley & Davis, 1997). Friends become confidants and companions, and they act as training models to prepare for intimate romantic relationships (Wrzus et al., 2017). Research shows that conflicts with friends can be negatively associated with trust, autonomy, and initiative (Jones et al., 2014).

Emerging adults in Western society tend to be within education or recently left it (Arnett, 2020). McDowell (2016) writes that, in the past, the change and transition that occurred during emerging adulthood was more sequential and linier than today. More recently transitions have become complex, in part owing to the 2007/8 financial crisis and subsequent recession (McDowell, 2016). Today's emerging adults may move in and out of the parental home, and meander from education to work and back again (Furlong, 2016). The last twenty years has seen the intensifying impact of technology on emerging adults. Technology has increased opportunities for learning, self-expression, social connection and income generation, yet with it come dangerous ramifications including cyber-bulling, sextortion, scamming and catfishing (Paat & Markham, 2021). Research suggests that climate change remains a significant worry for many emerging adults. Large scale surveys demonstrate that emerging adults experience eco-anxiety more than any other previous generation; feeling emotions such as powerlessness, helplessness and guilt (Hickman et al., 2021; Poortinga et al., 2023). In sum, it is argued that the modern-day path from dependency in childhood to independence in adulthood is now longer and more

complicated than any other point in history (Arnett, 2014 in Wood et al., 2017). In order for emerging adults to develop a stable sense of identity and wellbeing, they must navigate a complex modern world.

However, critics have challenged Arnett's concept of emerging adulthood as a developmental life stage. Clinicians, academics and researchers generally agree that adulthood is different now from what it was fifty years ago, but there is less agreement what this difference means (Paulsen et al., 2016). Many critics have methodologically challenged Arnett's studies, noting an overreliance on White-American, middle-class college samples (van Dulmen, 2013). Arnett himself notes that emerging adulthood only stands to reason in industrial and post-industrial societies. One notable critic, Côté, goes further, arguing that emerging adulthood barely stands to reason at all, since it has little regard for developmental and sociodemographic antecedents as well as cultural and social contexts. He writes that "those [individuals] facing oppressive and non-normative economic circumstances" may not have the same opportunity for optimism, identity exploration and unparalleled prospects as those living in less oppressive, more normative environments (Côté, 2014, p. 187). This calls into question whether emerging adulthood is applicably across the socioeconomic spectrum, or whether it applies only to Western middle-class individuals. This challenge is defended by Arnett who notes that variations in socioeconomic status and life circumstances may determine the extent that one experiences emerging adulthood, but not the existence of the developmental stage itself (Arnett, 2004).

This thesis explores the experiences of both US and UK emerging adults living with ME/CFS. Since emerging adults may be either within education or recently left it, this thesis focuses on the educational experiences as well as psychological experiences of emerging adults living with ME/CFS. This educational bi-national angle provides a unique insight into the similarities and differences in experiences, whilst limiting some transferability to education settings. This is elaborated upon in the methodology and discussion sections further below.

1.3 Links to counselling psychology

This thesis has been written so that I can fulfil the requirements for the qualification of Doctorate in Counselling Psychology. I am a trainee counselling psychologist, and as such, I cannot avoid bringing elements of my profession and training into this research. Counselling psychology within the UK is situated within a humanistic framework (Cooper, 2009). At its core are social justice values and a phenomenological positioning (Larsson et al., 2012). This means that counselling psychologists place great emphasis on the quality of the therapeutic relationship, empathic and non-pathologising engagement, in depth understanding of the subjective worlds of clients and participants, reflective awareness of power dynamics, difference and diversity, and anti-oppressive practice (Woolfe, 2016).

This thesis is infused with the above qualities. Research indicates that students living with ME/CFS generally lack empathic understanding and accommodation of need (Hamilton et al., 2023; Waite & Elliot, 2021). I have therefore sought to bring empathetic consideration to all aspects of this research, from implementing wellbeing check-ins during research interviews to deliberation of respectful and empowering language. Further research has shown that individuals living with invisible disabilities experience ableism in the form of microaggressions, the policing of their bodies and internalised self-judgement (Kattari et al., 2018). As a result of both this and my professional training, in this research I have consciously taken an anti-oppressive stance. I have reflexively considered my positioning, presuppositions and bias, and taken effort to bracket off bias, whilst also acknowledging that my positioning and presuppositions will inevitably affect interpretation and conclusions drawn from the study.

1.4 Reflexivity

Reflexivity can be described as a process of continual internal dialogue and critical reflection (Berger, 2015). It is an important aspect of all qualitative studies since it enables researchers to better identify the impact of tacit aspects of their own subjectivity on the research process (Donati, 2016; Parker, 2004).

Within the research environment, reflexivity places particular emphasis on the researchers' context, pre-conceptions and bias. Consideration is given to these three interconnected elements and the potential they have to influence the way a particular topic has been studied and construed (Donati, 2016; Etherington, 2007). This next section outlines my reflexive process of the past two years, pertinent to this research.

In considering my context, pre-conceptions and bias, I asked myself three questions:

- How has my personal history led to my interest in ME/CFS and emerging adulthood?
- What are my presuppositions about ME/CFS and emerging adulthood?
- How am I positioned in relation to what is known about ME/CFS and emerging adulthood? (Etherington, 2004)

Below is a discussion of each question. This section is formed, in part, from a research diary which I used to monitor and regulate the impact of my own subjectivity on the whole research process.

1.4.1 How has my personal history led me here?

My interest in myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (ME/CFS) originates in my professional background. I previously worked in an NHS service, providing psychological support to individuals living with acquired neurological conditions, as well as ME/CFS. As part of my role, I was asked to undertake a service evaluation regarding the ME/CFS branch of the service. This work involved speaking to clients experiencing ME/CFS and analysing data pertaining to their support needs. The evaluation concluded that clients living with ME/CFS were treated less favourably compared to other clients with a brain injury, stroke or neurodegenerative condition. I presented this finding to the multidisciplinary team but a few months later the ME/CFS branch stopped receiving referrals and was decommissioned.

Through this journey I developed a better understanding, deeper compassion, and greater respect for those living with ME/CFS. It seemed to me that such individuals tended to go unseen, invalidated and unfairly treated across many sectors of society. I developed a frustration, sadness, and felt a sense of injustice for these clients. Consquentially, I wished to better support and advocate for individuals living with ME/CFS.

Jung's concept of the wounded healer (1961) asserts that all people experience trauma and that therapists are empathically driven to help others in distress, because of their own experience of similar distress. At times, during my early adulthood, I felt unseen as I struggled emotionally but felt uncomfortable sharing my pain with others. In part, it is my past experience of being unseen that motivates me to help those experiencing the same. And this desire has led me to this research, so I can support emerging adults experiencing ME/CFS to feel more seen and better understood.

More recently, I have again worked with individuals experiencing ME/CFS. Last year I undertook a placement within another NHS service, this one exclusively supporting individuals living with ME/CFS. During this placement I facilitated 1:1 therapy with adults. All the individuals I worked with were either not in work or education, or were struggling to manage the demands of work or education. Psychometric scales indicated that most were experiencing at least mild to moderate depression and/or anxiety. Many shared feeling overwhelmed by their experience of ME/CFS and lacking a sense of agency. Some struggled with self-efficacy or reported low self-esteem. It became clear to me that my clients were experiencing varying degrees of loss, disability, and distress. It also became clear that this was rarely fully understood by others. A second reason for undertaking this research is because I wish to help those *without* ME/CFS better understand and support the struggles of those living with the condition.

A final consideration regarding my personal history and this research, is my adolescent experience of power and control. During adolescence I often witnessed acrimonious struggles for power between family members. Later, I unconsciously sought the familiar and found myself in other power struggles as an emerging adult. Growing self-awareness and

confidence has enabled me to better manage uncomfortable power dynamics. I now bring a sensitivity to power into my research and I seek to empower others, in line with my values of social justice, equity and empathy. In addition, I hold awareness, and still some fear, of systems, roles, positions and conditions that hold great authority and control. This may have influenced my decision to undertake this research in this population. I am researching a condition that drains energy (power), with individuals the same age as me when I felt most powerless.

1.4.2 What are my presuppositions about ME/CFS and emerging adulthood?

Etherington (2004) notes that it is important to reflect on one's presuppositions and their influence, since such consideration enhances the trustworthiness of research. As mentioned above, I have worked within two NHS services, psychologically supporting individuals living with ME/CFS. Clients are not referred to specialist psychological support without having meaningful need and being in some form of psychological distress. I have therefore often viewed ME/CFS as something that causes multiple unmet needs and ensuing distress. Over the years, I have listened to several clients speak about the disrupting effects of ME/CFS. The condition has therefore become shaped in my mind as something devastating, affecting almost all aspects of life including educational, relational and recreational. This viewpoint impacted my interview questions as I sought to understand how each sphere of my participants lives were affected, indisposed to believe any domain went untouched. On the other hand, my work has enabled me to see the positive effects of professional support and energy management. I have witnessed the reduction of ME/CFS symptoms in many NHS clients, and saw a simultaneous improvement in quality of life. I therefore, also, view ME/CFS as a chronic condition that can be improved over time, with appropriate support and strategies.

My experience of working clinically with ME/CFS affects this study's analysis, conclusions and implications. During analysis I was drawn to the more adverse and painful elements of

participants' narratives. Confirmation bias is the human tendency to favour information that confirms or supports one's prior beliefs and values. It may be that during this research, I was drawn to the more despairing side of ME/CFS because I was unconsciously seeking confirmation of my presuppositions, gained through working in specialist ME/CFS services.

I am aware of the sometimes-fierce debate regarding aetiology of ME/CFS, and I am aware of the harm and distress that some perspectives can cause to those living with the condition. This awareness led to careful consideration of my language and articulated judgement during research interviews. I am not a medical doctor, my knowledge of human biology is limited, and I do not seek to add to the debate around ME/CFS aetiology. However, it is important to note my opinion regarding the cause of ME/CFS. Through my clinical work and research activities, I have developed the personal belief that ME/CFS is a condition of complex multi-system biomedical origin, which can be exacerbated by environmental factors and life stressors such as such as family, work and financial disruptions (Balinas et al., 2021).

Regarding my assumptions of emerging adulthood, I view this period as a time of uncertainty and change because my own emerging adulthood was a time of uncertainty and change. I also view emerging adulthood as a time where emotions, playfulness and creativity can run free, before responsibility tempers each. Again, this is informed by my own experience. Within this research, I likely have a tendency towards complimentary projection. By this I mean I subconsciously assigned my past emerging adult experiences, beliefs, thoughts, emotions and behaviours to my participants. Ongoing reflexivity is necessary, to bring greater awareness to the projection and help me clearer see both similarities and differences between my participants' lives and my own.

1.4.3 How am I positioned in relation to ME/CFS and emerging adulthood?

Transparent, trustworthy research demands that researchers take a critical reflective stance towards their positions in relation to their research. After having discussed my personal history and presuppositions, here I will examine my various insider and outsider positions relative to ME/CFS and emerging adults. I will also consider the impact of this positionality on the research process.

Insider researchers belong to the groups they are researching and by definition share some group identity with their participants. Outsider researchers, on the other hand, are not members of the groups they research. They do not share group identity with their participants (Braun & Clarke, 2013). Within this research I have multiple insider and outsider positions, but I am mostly an outsider. I have never experienced ME/CFS, or any other chronic condition, and I do not identity as disabled (in the traditional medical-modelled sense of the word). To my knowledge, no one in my immediate family or friendship circle has experienced ME/CFS. Being in my mid-thirties, I am not an emerging adult, and I am over ten years older than my oldest participant. Conversely, I am an insider in the sense that I am a student and I currently belong to an educational institute, like four of my five participants. However, I am studying at a more advanced level, and this places me in a perceived position of greater knowledge and status.

My insider connection with my participant's educational identities mean that, at interview, I asked more prompting questions regarding their educational experiences. In addition, we shared a common educational language and I instinctively understood language and phrases that those outside education would not. On the other hand, my outsider status as a someone older than my participants meant I counter-transferred a sense of compassion and responsibility for several individuals. This was stronger with female identifying participants. I believe this felt sense would have lessened had participants been my own age.

The most noteworthy of my various positions is my outsider status as a person without experience of ME/CFS. As an outsider, I do not and cannot share the basic assumptions, taken-for-granted language, and life ways of those living with the condition. Schutz (1976) writes that every social group has its own private code and I am a stranger to the ME/CFS code. Within this research, two participants expressed the opinion that people living without ME/CFS will never fully understand what it is like to live with the condition. Yet I am someone who has worked with individuals living with ME/CFS. Consequentially I have professionally glimpsed the insider perspective. In this regard I do not possess absolute outsiderness (Gallais, 2008). And the more I study ME/CFS, the more I understand. I am therefore an ME/CFS "insider professionally, whilst being an outsider culturally" (Bukamal, 2022, p. 346).

In considering her professional outsider positioning, Green (2021) writes that role power in her research may have been used as an unwitting desire to rescue her clients. Elaborating, Green queries whether unconscious motivations place her within the position of the "white knight" (p. 148), elevating her own esteem and worth by championing those more unfortunate. In line with this argument, outside researchers could be seen as exploitative and disrespectful of their participants. Having outsider researchers articulate participants' views through the prism of their own experience may feel intrinsically disempowering to the inside (Bridges, 2001). Charton writes that there is an "innate inability of able-bodied people… to understand the disability experience (Charlton, 1998, p. 128). Applying these considerations to my research, I must ask myself if I am taking on the role of intrusive rescuer? By attempting to 'give voice' (Larkin et al, 2006) am I unintentionally disempowering and (as a sole researcher) controlling the narrative of my participants?

Bridges, whilst not disregarding these concerns, states that they can be mitigated through the use of appropriate ethical constraints and proper human respect and care (Bridges, 2001). This involves, amongst other things, continuous reflexivity and conducting research in a way that it actively contributes to a more just society (Bridges, 2001). I intend to do this by involving an expert by experience in the research process, writing in clear accessible language, conversing in a power sensitive way with all stakeholders, maintaining openness to criticism, and publishing in an open access journal. These are five ways that I can use my

outsider position to create respectful research, whilst acknowledging that my lack of insider positioning means that I will never fully, properly, understand what it is like to live with ME/CFS.

1.5 Summary of reflexivity

The above section has considered my personal history, presuppositions, and positioning in relation to this research. I have outlined my status as a person with professional but not personal experience of ME/CFS. I have also discussed my experience of power and control and of feeling unseen during my own emerging adulthood. This reflexivity contributes towards transparency and trustworthiness of the study. I have located this section here, towards the beginning of the thesis, to allow the reader insight into my subjectivity before the research process is delineated over the next four chapters.

1.6 Defining key terminology

Earlier in this chapter I provided description and contextualisation to the condition ME/CFS and the developmental stage emerging adulthood. The latter term is arguably better defined in academic literature than the former, which is often beset with ambiguity. Other phrases in this research are also indistinct or not in common parlance. Therefore, in this section, I aim to provide definitions and some background of terminology relevant to the study.

1.6.1 ME/CFS

For decades there existed separate case definitions for ME and CFS, and both terms have been peppered with controversy throughout the years (Institute of Medicine, 2015). As mentioned previously, benign myalgic encephalomyelitis was first used in 1955 to describe an illness outbreak of undetermined (but suspected infectious) cause (Wojcik et al., 2011).

In 1960, the World Health Organisation (WHO) accepted myalgic encephalomyelitis (ME) as a pathophysiological disease entity (Speight, 2013) and the prefix 'benign' fell out of use (Institute of Medicine, 2015). However, a famous 1970 paper (McEvedy & Beard, 1970) refuted the claims of the WHO, concluding ME to be a psychosocial phenomenon resulting from an epidemic of hysteria. This angered patients and professionals alike who insisted that ME was an organic (rather than functional) condition characterised by measurable changes in how the brain functions (Compston et al., 1970; Ramsay et al., 1977). Rebuttals and debate ensue to this day.

In the USA, the term 'chronic fatigue syndrome' (CFS) was proposed and coined by Holmes et al. (1988) to refer to two large outbreaks of a fluctuating and fatiguing condition in Nevada and New York. From the outset CFS was acknowledged as not a new condition (Straus, 1991). CFS was initially linked to the Epstein-Barr virus, but this aetiology was later queried and currently the cause of CFS remains unknown (Institute of Medicine, 2015). From the 1990s the terms ME and CFS started to be used interchangeably and synonymously, especially in the UK. A 2002 UK report of the CFS/ME working group noted that CFS/ME is a "genuine illness" (p. 1) and "heterogeneous either in causative factors or in its clinical nature" (p. 21). Since 2021 the NHS has used the expression ME/CFS, acknowledging different terms and preferences around the world (North Bristol NHS Trust, n.d.).

Both terms, myalgic encephalomyelitis (or encephalopathy) (ME) and 'chronic fatigue syndrome' (CFS) have faced criticism from researchers and those with experience of the condition. Some report that the term CFS trivialises the seriousness of this condition, since fatigue is just one of many symptoms (Picariello et al., 2015). Others note that individuals with the diagnosis ME have a worse prognosis than those diagnosed with CFS (Hamilton et al., 2005), since, it is argued, ME excludes the psychosocial perspectives that can be useful in managing the condition (Wojcik et al., 2011).

Within this study I shall use the term myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (ME/CFS) to refer to a complex, chronic, multi-system fluctuating condition that causes many symptoms, including post-exertional malaise.

I adopt this encompassing term for several reasons: first, because the aetiology and symptomology of both conditions is not yet fully understood. Second, because the phrase ME/CFS acknowledges the varying international stances that researchers, clinicians and people with lived experience adopt. Third, because ME/CFS gives credence to the significant number of individuals living with the condition who assert that neither term separately captures the multifaceted nature of their experience. And lastly because the participants in this study varied in their terminology preferences. To respect the wishes of each participant I have used both terms consecutively. I have placed ME first since literature indicates that, out of the two, this is the preferred term amongst those living with the condition (Redshaw, 2020). I have included the adjunct '(or encephalopathy)' following the term myalgic encephalomyelitis. This is because 'itis' refers to inflammation, and brain inflammation was originally thought to be the cause of ME/CFS. However, it is currently believed that ME/CFS is not solely caused by inflammation and some people argue that encephalopathy is a more appropriate term, since 'opathy' refers to a disease or disorder, which many people believe ME/CFS to be (North Bristol NHS Trust, n.d.).

1.6.2 Post exertional malaise (PEM)

Post-exertional malaise (PEM) can be seen as the cardinal symptom of ME/CFS (Jason et al., 2015). It is described as the worsening of ME/CFS symptoms following physical or mental exertion (CDC, 2021). Symptoms typically worsening twelve to forty-eight hours after activity and can last for days or even weeks (CDC, 2021). For some, PEM can occur after simple everyday tasks such as walking, showering, or conversing (Spotila, 2010, as cited in Jason et al., 2015). Others living with ME/CFS can undertake more or less activity before PEM occurs. Unlike generalised fatigue, PEM is more profound and reduces daily functioning (Jason et al., 2015). It can be mitigated by activity management (also known as pacing), which is a self-management strategy aimed at avoiding symptom exacerbation by balancing activity with rest (CDC, 2021).

1.6.3 Emerging adulthood/emerging adults

Emerging adulthood, as a concept, has already been introduced and described. Critiques have been outlined and defences noted. This thesis asserts that emerging adulthood is a development stage, insofar as it describes a unique life stage in which individuals change over time. This thesis also asserts that emerging adults tend to experience greater identity exploration, a sense of instability, a tendency towards self-focus, a sense of feeling in-between, and unparalleled opportunity and optimism, as asserted by Arnett (2000, 2004).

It should be noted that emerging adulthood is a relatively new concept and much research on the topic has been conducted within the USA, with middle-class educated individuals. As acknowledged by Arnett, this thesis asserts that variations in socioeconomic status and life circumstances determine the extent that one may experience emerging adulthood, but not the existence of the developmental stage itself (Arnett, 2004).

Academic consensus notes that emerging adulthood begins around the age of eighteen (Arnett, 2000), however this thesis adopts a lower age bracket in consideration of the relative high degree of independence, identity exploration, educational experiences and new opportunities that sixteen to eighteen years olds experience in modern Western society (Becht et al., 2016; Klimstra et al., 2010; Verhoeven et al., 2019).

1.6.4 Psychological

The American Psychological Association (APA) broadly defines psychology as “the study of mind and behavior”. Psychology has many branches, and each branch asserts a different way of studying and defining mind and behaviour. Noting this, the APA elaborates that psychology can also refer to the “supposed collection of behaviors, traits, attitudes, and so forth that characterize an individual or a group” (APA, 2018a). The Collins Dictionary defines psychological as concerning “a person's mind and thoughts” (Collins, n.d). Here I use the word psychological to refer to the thoughts, beliefs, emotions, relationships and coping

behaviours of this study's participants. I'm especially interested in how living with ME/CFS impacts upon the thoughts, beliefs, emotions relationships and coping behaviours of emerging adults living with the condition.

1.6.5 Educational

Education is the process of teaching and learning (Cambridge dictionary, n.d). Education can be formal or informal, and this thesis focuses on formal education which occurs in schools or school-like environments (e.g., colleges, universities) (Britannica, 2023). Studies have shown that children and adolescents living with ME/CFS experience higher rates of school absenteeism, poorer school-related quality of life and reduced academic performance (Crawley & Sterne, 2009; Knight et al., 2018). However, less is known about the educational experiences of emerging adults living with ME/CFS. Within this thesis I raise the issue of the educational impact of living with ME/CFS. By this I mean the effect that ME/CFS has on teaching and learning within schools, colleges and universities. This includes, amongst others, the provision, enjoyment and success of teaching and learning in the presence of ME/CFS.

1.6.6 Disability

As mentioned previously, there are several definitions of disability. There are also several models. This thesis uniquely asserts an alignment with the World Health Organisation (WHO) definition of disability, which synthesises medical and social models, and asserts that disability is: "part of being human and integral to the human experience… and resulting from the interaction between health conditions… and a range of environmental and personal factors" (WHO, 2023).

By aligning this thesis with the WHO definition, I assert the belief that disability is a multidimensional continuum, relevant to all people at different degrees and at different times in their lives (Üstün et al., 2003). This thesis neither solely agrees with the medical

model of disability, that disability is exclusively located in the individual, nor does it agree with the social model of disability, that disability is exclusively located in society. In aligning with the WHO definition of disability I position myself between these medical and social models. I therefore distinguish myself from other studies on ME/CFS, which perhaps implicitly, subscribe to a medical modelled way of thinking and defining.

Regarding disability language, this thesis uses the terms 'disabling impairment' or 'individual/person/emerging adult with disability status' to refer to a person living with a physical or mental impairment, and that impairment has a substantial impact on their ability to carry out normal activities, including the ability to fully participate in a society designed for and benefiting those without disability status. These terms and definitions are consistent with my position, in-between the medical and social models of disability, neither wholly subscribing to nor shunning either.

1.7 Outline of thesis

This thesis aims to explore the psychological and educational experiences of emerging adults living with ME/CFS. Various elements of this exploration are presented across six chapters.

In this introductory chapter I have discussed the condition ME/CFS and the developmental epoch emerging adulthood. I considered aspects of my history, presuppositions and positionality in relation to ME/CFS and emerging adulthood. I then defined key terminology, providing some contextual understanding to the various terms that will be used throughout this thesis.

In the next chapter, literature review, I present a detailed review of existing literature relevant to the lived experience of ME/CFS. I begin by examining the disability landscape and go onto discuss the developmental theory of emerging adulthood. I then explore literature related to the psychological and educational impact of living with ME/CFS, noting

limitations and gaps in academic knowledge. The chapter ends with a statement regarding my rationale for the current study.

The third chapter, methodology, provides a detailed description of the research process, including the several steps involved in data collection and analysis. I describe my ontological, epistemological and methodological positioning and provide a brief summary of participant characteristics. This chapter ends with a discussion regarding trustworthiness and ethicality within the research.

In the fourth chapter, analysis, I present the study findings. I begin by summarising the six group experiential themes (GETs) and their associated sub-group experiential themes (sub-GETs), that arose from analysis. These are then discussed further using illustrative quotes from interviews.

In the final chapter, chapter five, I provide a critical discussion of the study's analysis and findings. This discussion is centred around the thesis' two research questions. I then discuss the study's limitations and implications. The thesis finishes with a summary conclusion and references and appendices are included at the close.

Chapter 2: Literature review

2.1 Chapter outline

This chapter provides a critical overview of academic literature and theory relevant to the current study. A literature search strategy was used to scour three databases (PsycInfo, Medline and Embase) for relevant research. Search terms were devised using the Population, Intervention, Comparison, Outcomes and Study (PICOS) tool (Methley et al., 2014). Over the course of several sections I will ground the study and simultaneously make the case for this research, based on gaps and inadequacies in the existing knowledge base. I shall start by examining two models of disability: the medical and the social. I shall discuss the impact of disability upon education and go onto explain how disability can affect educational participation and attainment in emerging adulthood. Later sections describe and appraise literature related to the specific psychological and educational experiences of those living with ME/CFS. I shall then explain why specifically this study is needed, making the case for an IPA study emphasising ideographic and reflexive analysis. I shall end with the presentation of my two research questions, which both guide and instruct the thesis from hereon.

2.2 Models of disability

ME/CFS is evidently a chronic condition and arguably a disability, depending upon the adjudging framework. When considering the various models of disability, it is worth deliberating two questions: who is responsible for the cause of disability? And who is responsible for the solution? (Smart & Smart, 2006). Different models claim different answers. Until exactly forty years ago, one single model of disability formally existed. This model, the medical model, asserts that disability is the result of impairment in bodily

function and structure, and can be caused by disease, injury or mental health conditions (Haegele & Hodge, 2016). In this sense disability, according to the medical model, is an individual experience and an individual problem.

In the UK, the medical model of disability has informed the development and structure of much legislation. It is also reflected in many people's beliefs and attitudes regarding disability. The Equality Act (2010) is informed by the medical model, since it focuses on what an individual may be unable to do (Parliamentary and Health Service Ombudsman, n.d).

For decades this model has faced criticism from several corners. Some argue the medical model unfairly labels disability as disordered, dysfunctional and/or a deficient (Smart, 2009). The degree to which a person is disordered, dysfunctional and/or deficient is determined by objective, quantifiable, standardised measurements from the norm. The further away from the 'norm', the greater the disability: the greater the disability, the greater the inevitable dependence on the medical and rehabilitation establishments. This arguably serves medical and rehabilitation establishments, but undermines and patronises those living with disability.

Some disability advocates, academics and clinicians disagree with the medical model of disability. They question the legitimacy of a model which views people living with disabilities as having something wrong with them (Oliver, 2004). They also question why such people are viewed as requiring fixing (Haegele & Hodge, 2016). They ask why the responsibility for any required 'solution' should rest with specialist 'expert professionals' (Olkin, 2002), for this only seems to create a cycle of dependence and exclusion (East Suffolk Disability Advice Service, n. d).

Oliver (2004) notes that the medical model exudes a sense of personal tragedy and engenders helplessness. It unnecessarily isolates and excludes disabled individuals at best (UPIAS 1976), oppresses them at worst. Furthermore, due to its allegiance with ontological reductionism, the medical model demands diminution in order to categorise (Patil & Giordano, 2010). Humans are either patients or clinicians; expert or inexpert. Experiences, sensations, thoughts and emotions are condensed to symptoms. A collection of symptoms is

a condition or a disorder or a diagnosis. This reductionist approach simplifies the complexities of existence. In doing so it creates abusive power dynamics by limiting language, depersonalising the individual, and silencing what is most significant (Dunn, 2015; Warshaw, 1989).

In 1976, a group of physically impaired individuals declared that that, for them, disability does not reside with the individual, rather, disability is a situation caused by social conditions. Furthermore, these individuals argued that it is society which disables, by preventing people with impairments the human right to full participation in social life (UPIAS 1976, p. 21). Seven years later, Oliver developed this idea further and coined the term 'social model of disability'. In the broadest sense this refers to:

> *Nothing more complicated than a clear focus [and removal] of the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment, whether physical, sensory or intellectual. [Such] barriers… include inaccessible education and working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport… and the devaluing of disabled people through negative images in the media* (Oliver, 2004).

The social model of disability distinguishes impairment from disability. The former is individual; the latter is public, structural and culturally and historically specific (Shakespeare, 2010). Applying this social model to ME/CFS, the condition becomes the impairment and society is the structure that is disabled. This societal structural disability occurs because, it is argued, society fails to provide universal inclusive education, compassionate working environments, unbiased healthcare and accessible buildings that help manage energy expenditure.

The social model of disability is not without criticism. One appraisal, pertinent to the ME/CFS experience, is that the model fails to properly consider individuals with chronic fluctuating conditions. Such individuals differ from those with physical impairments insofar as their needs vary. Societal elements may be significant barriers one day and less disabling

the next. Furthermore, in the case of severe ME/CFS, the severity of the condition means that those experiencing it have limited contact with the social world. As a result, external restrictions become irrelevant. Because the individual living with severe ME/CFS cannot go outside, impairment is significant, but disabling social barriers, which the social model suggests are ever present, are here non-existent (Owens, 2015). In short, the social model of disability can be described as indispensable in exposing faults with the medical model, and a helpful instrument to explain and combat the social exclusion that disabled individuals face, but its usefulness as a workable tool that captures the complex disability interplay between humans and the environment, may be limited (Owens, 2015).

The social model of disability can be thought of as a strand within the wider field of critical disability theory. Critical disability theory condemns traditional medical assumptions and discussions on disability, asserting that these only serve to oppress people with disabilities and violate their rights (Sztobryn-Giercuszkiewicz, 2017). Instead, critical disability theory views disability as a social construct, affected by issues of context (politics, culture, attitudes) and power (Devlin & Pothier, 2006; Reaume, 2014).

Hosking (2008) likens critical disability theory to a diverse family of critical theories, which includes, along with the social model, the rights model and the cultural model of disability. The former advocates for legal changes to address disability inequities, and the latter aims to understand disability as a cultural phenomenon that can be both positive and also discriminatory and harmful (Reaume, 2014). Critical disability studies, therefore, aim to reinterpret what it means to be disabled, "bringing people who live this experience to the process as the primary agents of change in word and deed" (Reaume, 2014, p. 1249).

2.3 Education and disability

15% of UK undergraduate students and 20% of US students report a disability at university (Hubble & Bolton, 2021; Irwin et al., 2023). Reported disabilities include specific learning difficulties, mental health difficulties, chronic health conditions, social communication

difficulties, autistic spectrum conditions, blindness, deafness and mobility issues (Hubble & Bolton, 2021).

In the UK, the Equality Act (2010) makes it illegal for an education provider to treat disabled students unfavourably. This includes direct and indirect discrimination, harassment and victimisation. In the US, a similar law, The Americans with Disabilities Act (ADA) prohibits discrimination against people with disabilities and guarantees equality of opportunity in many sectors of society, including public schools. In 2008, the UNESCO International Conference on Education confirmed their commitment to inclusive education, stating that education systems that benefit from diversity build a more just, equitable society (Bargerhuff et al., 2012). These laws and statements suggest that disability is a universally agreed upon concept, as is education inclusivity, and those who discriminate on the basis of disability are punished.

The reality is much more complex. The previous section of this literature review detailed how definitions of disability vary, and statistics suggest that education equality does not exist. In UK universities, 80% of graduates living without a disabling impairment achieve a first or upper second-class degree, but this drops to 77% for those living with a disabling impairment (OfS, 2021). Furthermore, students experiencing disabling impairments are more likely to drop-out of university compared to those living without. Following university, individuals experiencing a disabling impairment are less likely to be in highly skilled employment or higher-level study, and those who are employed tend to earn less (Hubble & Bolton, 2021).

A systematic review exploring conceptions of disability in Western education settings (Moriña & Carnerero, 2022), concluded that student and faculty conceptions were located mainly in the medical model. This meant that disability was considered an inherent problem and responsibility of the individual, not the educational institutes or their employees. Furthermore, this medical modelled view of disability prompted negative attitudes that hamper inclusive education.

Moriña and Carnerero's study indicates an ongoing and widespread acceptance of the medical model in academia, despite the availability of other models. Shume (2023) also concluded this in her critical discourse analysis of a teacher textbook. Her analysis showed the textbook's conceptualisation of disability was imbued with representations of disability as a "finite, knowable deficit that resides in individual learners" with students with disabilities were portrayed as "needy, passive and voiceless" (p. 260). Shume concluded that American school personnel need a richer, deeper, more sophisticated conceptualisation of disability than the medical model alone, in order to meet all students' needs.

However, research evidence to the contrary suggests disability attitudes aren't the problem, but resources. In disagreement with Shume, and in partial disagreement with Moriña and Carnerero, Pérez-Esteban et al.'s (2023) systematic review found that the majority of Western university teachers believe that working with students with disabling impairments is an opportunity for empowerment. Their study suggests that teachers tend to maintain both a positive attitude and an empathic climate of support towards students living with disabling impairment. Any lack of quality education to such students was attributed to the university institutions, who weren't prepared to provide an inclusive educational response. It should be noted that Pérez-Esteban et al. explored self-reported attitudes only. A likely bias occurred since, it could be argued, few professionals are willing to discuss problematic personal attitudes, even under guaranteed confidentiality. In a further suggestion that resources are the primary factor in education inequality, Nabors et al. (2008) compared the knowledge and confidence of US specialist disability teachers to regular teachers. They found that specialist teachers had greater disability training and knowledge but neither group were more confident than the other regarding meeting the academic needs of their students.

The studies discussed so far draw attention to several issues preventing quality understanding and support for students with a disabling impairment: the problematic and impeding discourse of disability, the lack of adequate training, resources and assistance for education professionals, and the under confidence of education professionals to meet the academic needs of students with disabling impairments. There appears to be a disconnect

between articulated inclusive positions of government and academic institutions, and the actual practices implemented at ground level (Bargerhuff et al., 2012).

For students living with a disabling impairment, this effect can be profound. Once such individuals reach the end of each academic year, they have no choice but to take part in a system of assessment arguably biased towards their non-impaired peers (McArthur, 2016). In the UK, university students living with a disabling impairment report staff ignorance regarding their impairment, an unwillingness to make reasonable adjustments, and a sense of feeling undervalued (Hamilton et al., 2023; Kendall, 2016). A 2023 thematic analysis of Reddit posts revealed university students living with disabling impairment report themes of distress and a sense of isolation, which in part reflected both avoidance and othering from non-impaired peers, exacerbated by their lack of understanding (Brewer et al., 2023).

Osbourne (2019) notes that the literature frequently distinguishes between 'invisible disabilities' and 'visible disabilities'. A person living with invisible disability is someone who might not be assumed to be impaired at first meeting (Kattari et al., 2018). A visible disability, on the other hand, usually presents itself in a physical or assistive form (e.g, a wheelchair) and is easily noticeable to others (Berry & Domene, 2015). Osbourne suggests that many students with invisible disabling impairment experience discomfort identifying as disabled, or disclosing a disability. Furthermore, students with invisible disability are more able to choose the extent to which their disability is known. In such cases, students may "struggle to find a balance between presenting themselves as disabled enough to receive support, but not so disabled that they are stigmatised for their disability" (Osbourne, 2019, p. 230). In agreement with this, other studies have noted that students may withhold disability disclosure due to concerns that their impairment will negatively impact a university application (Eccles et al., 2018), or for fear of judgement and associated stigma (Riddell & Weedon, 2014), or out of worry of being discredited and devalued (Burch, 2018; Grimes et al., 2019).

It could be argued that many studies exploring disabling impairment and education solely recruit students who disclose and identify as disabled, or teachers who identify their students as living with disability (Chase, 2024; Clery et al., 2022; Parie, 2023; Similä et al.,

2021a). However, as noted above, many individuals (including emerging adults) living with a disabling impairment do not disclose or identify as disabled, or possess a diagnosis. This potentially results in a self-reporting disability research bias, since the discourses, perceptions and experiences of those struggling to accept their disability, achieve diagnosis, or in disagreement with the disability label or medical model, never get heard.

2.4 Disability and emerging adulthood

Emerging adulthood is a developmental stage between adolescence and adulthood. During this life stage emerging adults tend towards self-focus and can feel a sense of instability and of being in-between. Support structures often relax, ruminative identity exploration can take place, opportunities tend to present themselves, and many individuals begin learning how to rely on their own resources (Arnett, 2000, 2004). As emerging adults transition to adult roles, they undoubtably encounter various challenges along the way. This is even greater for the emerging adult living with disabling impairment, who face additional challenges related to their disability status (Mannino, 2015).

Within developmental theory, a sense of belonging is central to healthy psychosocial development (Erikson, 1969). Among emerging adults, belonging has been linked with positive psychological and physical outcomes including greater self-efficacy and resilience (Begen & Turner-Cobb, 2015). Yet qualitative research has suggested that young adults living with disabling impairments face a myriad of barriers to belonging, such as inaccessible environments, rigidly held ableist beliefs and restricted choices that do not reflect their lifestyle or identities (Ingimarsdóttir et al., 2023).

In a study of self-reported belonging and empowerment, Raver et al. (2018) discovered two things: first that those who perceived greater social support were more likely to report a sense of belonging, and second, that positive disability identity predicted a greater sense of belonging. They concluded that emerging adults with greater perceived support and a more

positive disability identity, had a stronger sense of belonging and also a lower need to belong.

Tackling barriers to belonging is not the only challenge presented to the emerging adult living with disabling impairment. Ableism (defined as discrimination based on disability classifications) is a tangible experience for many (Christensen, 2023). Emerging adults with disability status can experience discrimination and prejudice in the workplace, which can then impact career opportunities, economic independence and stability (Lindstrom, Kahn, & Lindsey, 2013). In a case study of an emerging adult living with a chronic and fluctuating condition, Christensen (2023) notes how symptom flairs and internalised ableism led her participant to the belief she had been denied the full experience of emerging adulthood. This, combined with externalised ableism (including pity, discomfort and dismissal from others) meant Christensen's participant felt reduced to little more than her disability status. Caulk (2016) suggests that embracing one's disability status may protect against the stressful effects of such a marginalised identity, but acceptance and integration can be difficult, especially when individuals wish to maintain active engagement with their pre-disability status sense of self (Alder et al., 2021).

Although little research exists regarding disability identity and emerging adulthood, some studies suggest that positive disability identity in this life stage is associated with greater assertiveness, improved self-efficacy, and increased ability to be intimate with a partner (Elderton et al., 2014; Mejias et al., 2014). More recently, Caulk and others (Caulk, 2016; Caulk et al., 2020; Raver et al., 2018) have taken an interest in disability identity amongst emerging adults living with disabling impairments. Caulk et al. (2020) define positive disability identity as "the ability to accept one's disabling impairment realistically, and to retain a positive sense of self as a person, despite one's disability" (p. 307). In their survey of over two thousand emerging adults with disabling impairment, Caulk et al. (2020) discovered that holding a positive view of disability, in general, was associated with increased life satisfaction, regardless of whether participants self-identified as having a disability. In addition, there were differences in disability self-identification based on the type of disabling impairment. Those with physical and learning impairments were more likely to self-identify as having a disability, whereas those with sensory disabilities were less

likely. It was hypothesised that the greater the visibility of impairment, the more likely emerging adults are to self-identify with disability status.

Emerging adults living with disability status experience unique challenges. Developmental theories tend to separate the human lifespan into stages and assert that psychosocial crises occur at each stage. Crises can positively or negatively affect personality development, depending on the extent that each crisis is overcome. Arnett writes that the primary developmental task of emerging adulthood is to clarify an identity. This calls into question the long-term consequences if emerging adults living with disability status are confronted with so many challenges that their developmental trajectory is considerably interrupted. The impact on wellbeing, self-esteem and sense of power and control may be significant.

2.5 The educational impact of ME/CFS

School attendance is important for educational and psychosocial development (Clery et al., 2021; Gottfried, 2019; Freeman et al., 2019). Experiencing disabling impairment in childhood and adolescent can increase the risk of school absence, in turn leading to poorer educational, psychosocial and employment outcomes (Clery et al., 2021; Cortiella & Boundy, 2018). This is especially true for ME/CFS. ME/CFS is associated with significant functional impairment and has a proven considerable impact on emotional, physical and social functioning.

In a large sample of children and adolescents (five to nineteen years old) living with ME/CFS, Crawley and Sterne (2009) found that 62% attended 40% of school or less, with nearly a third attending no school at all. Reduced school attendance was associated with poorer physical function, and poorer physical function associated with higher levels of fatigue, pain and low mood. In a second study investigating the prevalence of unidentified ME/CFS in schools, Crawley et al. (2011) noted that 1% of children who has missed more than 20% of school over a six-week period could be said to have undiagnosed ME/CFS.

It should be noted that, in both of Crawley's studies, research was conducted in, and participants were from, the southwest of England. This is a largely affluent area with a well-established specialist paediatric ME/CFS service. Both studies acknowledge caution against generalising results to regions without a specialist service, or to regions with different socioeconomic factors.

Having said this, other quantitative studies with greater generalisability have demonstrated similar findings to both of Crawley's studies. Knight et al. (2018) discovered that adolescents living with ME/CFS who miss significant amounts of school, also report reduced school participation, poorer connectedness with school and reduced academic performance. And Bell et al. (2001) noted that amount of school missed correlated with both severity of ME/CFS and perceived social impact of the condition. However, disputing these findings Bould et al.'s multi-variate analysis (2013) found no evidence for an association between school attendance and depression, suggesting, in contrast, that children living with ME/CFS and not attending school experience no significant mood disruption.

In a systematic review, Tollit et al. (2018) note that most studies into ME/CFS and education have focused on the narrow construct of school attendance and performance. Tollit et al. acknowledge that school absenteeism and achievement is important in childhood and adolescent ME/CFS, but write that other aspects of education such as school experiences, educational enjoyment and socialisation deserve equal consideration. Currently there exists a gap in the knowledge base regarding these aspects of educational life. This study aims to fill this gap, albeit through qualitative methodology. In doing so, this study aims to build a more comprehensive understanding of the educational impact of ME/CFS and intends to further inform the management of ME/CFS in educational institutes.

Turning to qualitative studies of ME/CFS and education, a Norwegian thematic analysis of the school experiences of sixteen adolescents living with ME/CFS (Similä et al., 2021a) found that negative experiences were related to a lack of knowledge about ME/CFS among school staff. This lack of knowledge meant a lack of educational and social adaptations. A further British study (Clery et al., 2022) utilised three focus groups to understand the role of school in the management of ME/CFS. Focus groups included adolescents with ME/CFS, family

members, and medical professionals. Thematic analysis found varying levels of school support. Family members and adolescents who had described good support, spoke about the benefits of incremental steps and practical strategies when building confidence to return to the classroom. Furthermore, adolescents felt school support was particularly good when teachers had good knowledge of ME/ CFS. Poor support was described as a lack of three-way communication between schools, healthcare professionals and families. Some families had difficulties getting schools to recognise the ME/CFS diagnosis and implementing appropriate strategies. In corroboration with Knight et al. (2018), the adolescents in Clery et al.'s study worried about losing friends and not achieving their potential when out of school.

Taken together, both Similä et al. (2021a) and Clery et al. (2022) uncovered that the more knowledge schoolteachers have regarding ME/CFS, the greater the available educational and social support strategies. However, a major limitation of both studies is that neither investigated specific helpful or unhelpful strategies and adaptations, therefore they could not recommend practical educational solutions.

In two advisory pieces, Rowe and Fitzgerald (1999) and Rowe (2023) offered just this, practical solutions. Rowe and Fitzgerald (1999) assert that an appropriately supportive educational setting is one in which the social, emotional, developmental, and academic issues associated with ME/CFS are addressed and gradually resolved. Rowe and Fitzgerald developed a multidisciplinary program aimed at assisting students living with ME/CFS. Within this programme, advice was provided to students, caregivers and academic professionals. Guidelines for academic professionals included establishing one contact person at school, introducing a controlled return to study after absences, asking the student living with ME/CFS to list subjects in order of priority, negotiating subject attendance, and encouraging students to remain at school during breaks, since most socialising occurs at these times. In 2023 Rowe updated this guidance to include more recent opinions of young adults living with ME/CFS. In the updated guidance Rowe asserted that many young people living with ME/CFS reported a dislike of psychological assistance but welcomed the opportunity to work through social issues at schools.

Both of the above studies produce sound advice based on the opinions of children and adolescents living with ME/CFS, however, without an evidence-base to systematically assess these suggestions, the advice has limited benefit. Nevertheless, practical suggestions are often lacking in other studies and the suggestions of Rowe and Fitzgerald (1999) and Rowe (2023) could be used on an individual basis, and regularly assessed, in schools where support is needed but teachers have little prior knowledge to draw upon.

Research specifically focusing on the impact of ME/CFS at college and university is scant. Nevertheless, two qualitative studies have explored the broader impact of living with chronic conditions at university. Toller and Farrimond (2021) conducted a thematic analysis of the experiences of thirteen UK university students experiencing a chronic fluctuating condition. Participants spoke about their ill bodies as a frustrating barrier around which life has to be reshaped. Utilising disability support minimised the intrusion of their conditions on academic work, but the fluctuating nature of symptoms meant participants' conditions failed to fit into their universities' narrow definitions of disability. This resulted in inconsistent and sometimes irrelevant provision. Yet Toller and Farrimond also found that some students reported exemplary support and acceptance of their condition. This conclusion suggests that support on the ground was beneficial, but organisational structures did not allow for flexibility of changeable symptoms.

In contrast to this latter finding, Hamilton et al.'s (2023) thematic analysis of sixty-seven students with chronic conditions reveals poor understanding and acceptance amongst university staff. Participants spoke about a sense of inequality, of feeling undervalued and a felt sense that their invisible disabling impairments weren't classed as real enough. Misconceptions surrounding chronic conditions were not uncommon. Limited understanding regarding ME/CFS amongst professionals is a finding that reveals itself time and time again in the literature.

In a study specifically focusing on students living with ME/CFS, Waite and Elliot (2021) assert that universities are both delegitimising and legitimising. Delegitimizing in the sense that participants felt a lack of understanding and validation from authority figures. This resulted in lowered self-esteem and disempowerment. Legitimizing in the sense that, when

acceptance and validation occurred, participants felt surprise, relief, empowerment and increased confidence in their abilities.

The studies by Toller and Farrimond, Hamilton et al. and Waite and Elliot suggest that the university experience of students living with chronic conditions or ME/CFS could improve with several adjustments. These include mandatory staff training (Hamilton et al., 2023; Waite & Elliot, 2021), consistent, personalised support options based on need rather than diagnosis (Toller & Farrimond, 2021; Hamilton et al., 2023), and empathic accommodation of need rather than rigid policing of academic regulations (Hamilton et al., 2023). Many of these adjustments are included as recommendations within each study.

2.6 The psychological impact of ME/CFS

ME/CFS is a debilitating, difficult to diagnose condition with an elusive aetiology (Åsbring & Närvänen, 2002). The condition has been subject to controversy (Bakken et al., 2023) and experiences of delegitimation (Dickson et al., 2007; Travers & Lawler, 2008), stigma (Åsbring & Närvänen, 2002) and marginalization (Wilde et al., 2020) amongst those living with the condition are, unfortunately, not uncommon.

Several qualitative studies have investigated the psychological components to life with ME/CFS. Adults from both the UK and USA predominantly compose the participant demographic. From the research, it is clear that ME/CFS has a profound psychological effect on those living with the condition.

ME/CFS can have a significant impact on social dynamics with friends, family and partners. Regarding the latter, Catchpole and Garip (2021) write that dynamics can be strained when one individual in the partnership experiences ME/CFS. A high perceived caring burden, loss of intimacy, shifting roles within the household and a felt sense of duty resulted in frustration and overwhelm for their partner participants. Nevertheless, some couples continued to experience their relationships as rewarding and mutually supportive in the presence of ME/CFS. Accepting change was often a precursor to this. Dickson et al. (2007)

write that several of their adult participants felt their partners did not genuinely believe that they were ill. Defending their ME/CFS became a necessity, but this resulted in a loss of confidence, lack of trust and sense of rejection.

In a study exploring family dynamics, Crix et al., (2012) arrive at a similar conclusion, that is that family discourses regarding ME/CFS can be polarized around the issue of intentionality, with some family members doubting the genuineness of symptoms and suffering. Boulazreg and Rokach (2020) write that a family who receives a diagnosis of ME/CFS for one of its members, often experiences a ripple of changed relational dynamics. This can take the form of sibling jealousies and overwrought parent-child relationships.

When relational dynamics are disrupted, valued meaningful connection can be lost and loneliness can ensue. In a thematic analysis of isolation in ME/CFS, Wotherspoon (2023) differentiates between necessitated social isolation and compelled loneliness. The former concerns how ME/CFS symptoms can cause social lives to become increasingly restricted. The latter highlights how the dual experiences of stigma and delegitimisation can lead to social rejection and withdrawal (Wotherspoon, 2023). Wotherspoon perceives these two distinct yet overlapping concepts recursively producing one another. This conjures an image of the individual living with ME/CFS potentially trapped a spiral of limitation and disengagement.

Wotherspoon's concept of necessitated social isolation appears in other literature under the guise of invisibility. Pilkington et al. (2020) discuss the multifaceted nature of ME/CFS invisibility. They assert that ME/CFS is a condition with no visible signs whereby individuals can experience socially constituted invisibility. Places, situations and others can be avoided to minimise PEM. Williams et al. (2019) also note the invisibility of ME/CFS, writing that it can inducing feelings of shame and worthlessness, as others question the validity of symptoms. Others may not recognise that help is needed, and individuals living with ME/CFS may not feel comfortable asking for help when exhibiting a semblance of normality.

Several studies suggest that individuals living with invisible disabling impairments are more likely to experience indirect and internalised discrimination, are more likely to have their

bodies policed by others, and are more likely to feel a deep-rooted desire for justice around their impairments (Kattari et al., 2018; Olkin et al., 2019; Stone et al., 2013). Living with ME/CFS can bring about a sense of uncertainty and insecurity regarding the near and distant future (Fennell et al., 2021). Daily anxiety is not uncommon, with worry centred around the fear of not being able to manage daily activities or receive adequate help (Williams et al., 2019). Williams et al. writes that worries can be catastrophised into fears for the future and Dickson et al. (2008) assert that these worries are not baseless catastrophizations, but foundered upon a very real inability to plan for the future. This then results in subsequent feelings of failure, worthlessness and insignificance.

The studies mentioned thus far indicate ME/CFS to be a condition than can cause disruption, discrimination, loneliness, invisibility and fears for the future. Yet the psychological ramifications go further than this. Several researchers assert that ME/CFS causes a fundamental disruption in an individual's sense of self. Changes in self-identity have been identified in two qualitative systematic reviews (Anderson et al., 2012; Larun & Malterud, 2007) and several other qualitative studies. Larun and Malterud note that the identities of adults living with ME/CFS can be both lost and challenged. Lost in the sense that the bodily and social restrictions of ME/CFS force a more passive, marginalised life. Challenged in the sense that when others question the legitimacy of fluctuating ME/CFS symptoms, and this can lead to increased vulnerability. For these individuals, profound biographical disruption can ensue (Larun & Malterud, 2007).

Some researchers propose that this biographical disruption can led to a search for self-renewal (Anderson et al., 2012). In a narrative study, Travers and Lawler (2008) note that chaos, initially caused by ME/CFS, can become a catalyst for self-examination and reinterpretation. In this sense, biographical disruption can led to enrichment of the self. This has also been found in other research. Åsbring (2001) noted her adult participants described two separate identities, one belonging to before the onset of ME/CFS and the other to life after. Only after grieving the former could individuals embrace the newly arisen latter. Many of Dickson et al.'s (2008) adult participants spoke about an initial identity crisis (characterised by diminished control and agency), but this crisis was deemed to be time

limited. What occurred afterwards was a slow (re)emergence of agency, recovery, and acceptance.

However, the studies above have their limitations. Many studies investigating the psychological experience of ME/CFS possess a bias due to factors related to selection. Dickson et al. (2007, 2008) recruited participants from a local alternative therapy clinic. Williams et al. (2019) recruited from a ME/CFS support group. Åsbring's (2001) participants were from two Swedish hospitals. These individuals all had access to medical and healthcare systems. Furthermore, a gender bias can be observed too. Åsbring (2001) only interviewed women. Wotherspoon's (2023) study recruited thirty-six women and six men. Travers and Lawler (2008) interviewed fourteen women and five men. In many studies there exists a lack of community and male representation. Whilst qualitative studies do not seek to generalise findings to other settings, this selection skew will likely impact the transferability of many of the above studies to community settings and men living with ME/CFS.

Perhaps, to address this, two notable studies have explored the psychological impact of ME/CFS on men. Snell et al. (2023) conducted an IPA of the lived experience of five men with ME/CFS, and Wilde et al. (2020) used adapted photovoice and IPA to explore the experiences of ten men. Both studies note that ME/CFS compromises men's sense of masculinity. Men could no longer adhere to or identify with many typical 'normative' male behaviours. For Wilde et al.'s participants, this created a sense of marginalization from hegemonic society. In Snell et al.'s study, masculine norms inhibited the recognition of symptoms, delaying diagnosis and slowing participants' journeys to acceptance.

These studies demonstrate that ME/CFS can result in identity disruption (Åsbring, 2001; Dickson et al., 2008), identity loss (Larun & Malterud, 2007) and identity reformation (Anderson et al., 2012; Dickson et al., 2008). Identity is a developing, adapting, complex construct which, for many people, continues to develop during adult years (Fadjukoff et al., 2016). Nevertheless, it is widely agreed that the bulk of identity formation occurs during adolescence and emerging adulthood (Arnett, 2000; Erikson, 1968; Marcia, 1980). This calls into question how ME/CFS impacts identity when the condition is experienced in a life stage other than adulthood. If adolescents living with ME/CFS are still forming their identities, the

disruption, loss and reformation is surely not experienced in the same way. Few studies have explored how ME/CFS is psychologically experienced in childhood, adolescence and emerging adulthood. In fact, the bulk of studies investigating ME/CFS in these life stages have focused on the educational sphere. Education is a large part of early life, but it is not the whole.

2.7 The psychological impact of ME/CFS as a child, adolescent or emerging adult

Quantitative studies have demonstrated that children and adolescents living with ME/CFS experience greater anxiety and depression compared to those without ME/CFS, and compared to those with other chronic health conditions (Crawley et al., 2009; Loades et al., 2020; Rangel et al., 2003). This sheds concerning light on the quality of life of children and adolescents with ME/CFS. However, studies investigating this association have tended to use self-report questionnaires, which can be prone to bias. Items enquiring about restlessness and lack of energy may be confounded with ME/CFS symptoms, and participants may exaggerate or under-report symptoms, or misinterpret questions. These issues all compromise internal validity (Rangel et al., 2003). Quantitative methodologies are ideal for uncovering general patterns of behaviour, but they are limited in their ability to understand the unique complexity of human life (O'Reilly & Kiyimba, 2015). This is the advantage of qualitative methodologies.

A handful of studies have qualitatively explored the influence of ME/CFS on psychological wellbeing. Most of these studies have focused on the wellbeing of children and adolescents, with only two identified studies exploring the wellbeing of individuals living within the emerging adulthood life stage.

Taylor et al. (2017) conducted a thematic exploration of depression in nine adolescents living with ME/CFS. Analysis revealed that most participants thought that the condition caused their depression. This was due to the restrictions ME/CFS placed on activities and

their independence. Participants described loss of both enjoyable activities and the person they used to be. This led to sadness and a sense of being alone. Inflexible, unhelpful, unempathetic and invalidating education systems exacerbated this loneliness.

Other studies have concurred with this conclusion that ME/CFS restricts activity participation and enjoyment in younger people. A mixed-methods study (Smith et al., 2021) found that adolescent anhedonia (lowered interest and pleasure in activities) is common amongst those living with ME/CFS, with 42% of 164 adolescents reporting subclinical or clinical anhedonia. Qualitative interviews and thematic analysis suggest that ME/CFS is a barrier to engaging in activities which provides in-the-moment pleasure and enjoyment, and new activities felt like poor substitutes for previously enjoyed hobbies.

Fisher and Crawley (2013) wished to understand why children and adolescents living with ME/CFS felt so anxious. They conducted an IPA with eleven individuals, aged between twelve and eighteen. Similar to adults in other studies, the children and adolescents spoke about the distrust and disbelief they encountered, due to living with such a poorly understood, stigmatised and delegitimising condition. Unlike adults, this stigmatisation and delegitimising took the form of bullying from peers and conflicts with friends. Consequentially, separation anxiety from parents seemed not uncommon. Long absences from school, friends, and activities were regular and most participants worried they were missing out on a 'normal' life. This worry is understandable since research indicates that school absence negatively impacts psychosocial and identity development (John et al., 2022; Wood et al., 2012)

A similar study by Jelbert et al. (2010) noted analogous findings of loss, societal judgement and social disbelief, but Jelbert et al. also found that all five of their adolescent participants reported positive gains associated with ME/CFS. This most commonly manifested in a new appreciation for life and better self-awareness. Furthermore, all participants described a positive shift in their future hopes and expectations, but only after their symptoms had subsided. Positive gains have been mentioned in studies with adults living with ME/CFS, most notably in Åsbring's (2001) study, whose participants reported a new preferred identity emergent from ME/CFS. Jelbert et al.'s unique findings contradict several

developmental theorists who assert that disruptions to 'normal' adolescent development results in identity confusion (Erikson, 1968) and a lack of identity achievement (Marcia, 1980).

It must be noted that all five of Jelbert et al.'s participants were deemed to have recovered from ME/CFS at the time of interview. Limited evidence suggests that children and young people living with ME/CFS are more likely to recover than adults, with studies suggesting 60-80% partial or complete recovery (Royal College of Paediatrics and Child Health, 2004; Scottish Good Practice Statement on ME/CFS, 2023). Within Jelbert et al.'s research, it is possible that data was bias towards a recovery narrative, because participants were retrospectively recollecting from a position of relative health.

The above studies suggest that children and adolescents living with ME/CFS experience loss, sadness, depression, anhedonia, and also some positive gains manifesting in an appreciation for life and better self-awareness. This is not too dissimilar from the adult ME/CFS experience. Moving from experience to management, Hareide et al. (2011) investigated how nine adolescents (twelve to seventeen years old) cope with ME/CFS. Thematic analysis revealed that coping strategies of choice were dependent on symptom intensity. If high, participants preferred rest and avoidance of activity, since activity led to symptom exacerbation. If low, participants engaged in greater activity. This is different but not entirely contradictory to Smith et al.'s (2021) much larger study, that concluded that ME/CFS is a barrier to engaging in enjoyable activities. Combining the findings of these studies, it is suggested that adolescents experiencing moderate or severe ME/CFS are more likely to avoid activity, leading to greater loss and anhedonia, than adolescents experiencing milder ME/CFS.

Hareide et al.'s (2011) study reveals a shortcoming of many other studies into childhood and adolescent ME/CFS. ME/CFS is a spectral condition with an unpredictable course composed of relapses and remissions (Rowe, 2019). Yet Smith et al. (2021), Fisher and Crawley (2012) and Taylor et al. (2017) do not differentiate between different severities of ME/CFS in their participant recruitment. Smith et al. and Taylor et al. acknowledge the exclusion of individuals too severely affected by ME/CFS, but only Hareide et al. explicitly note the wide

spectrum of severity, and shape their conclusions accordingly. This limitation impacts the ease of extrapolation when it comes to applying the conclusions of the above studies to clinical, educational, home or other research settings.

The above qualitative studies all concern childhood and adolescent ME/CFS. Few studies explore the accounts and experiences of those within the emerging adulthood life stage. Furthermore, mostly use thematic analysis as a methodology. Thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data (Braun & Clarke, 2006). Whilst it is acknowledged that there are many forms of thematic analysis, ranging from systematic analyses to more reflexive analyses (Finlay, 2021), thematic analysis is not theoretically bounded to a phenomenological epistemology, like IPA is, and therefore does not commit firmly to understanding meanings derived from experience.

Few studies have utilised methodologies other than thematic analysis. One of these few is Krabbe et al.'s (2023) narrative analysis of retrospective accounts of severe ME/CFS. Krabbe et al. asked thirteen women aged sixteen to twenty-four, living with mild-moderate ME/CFS, to share their sense making stories of severe ME/CFS during their childhood and adolescence. Analysis yielded three shared storylines. The first describes the time before participants fell ill, when their healthy bodies were taken for granted and "often in the background of their attention" (p. 1168). The second storyline illuminates the simultaneous deterioration and increasing alienation from the body, and also from life as it was before. The third storyline "tells of participants' entrapment in severe illness and the shutting down of their lives" (p. 1168). Taken together, these storylines depict the brutal consequences of ME/CFS. Insecurity, worry and anxiety preside as the self becomes alien and ghost-like. This destructive depiction of ME/CFS is reminiscent of Larun and Malterud's (2007) finding that adults living with ME/CFS have their identities both lost and challenged. Here Krabbe et al.'s participants experience a loss of life as they knew it, and challenge in the form of bodily imprisonment and shut down.

Only one identified study has made a methodological commitment to understanding the ME/CFS psychological experiences of higher education students through a phenomenological epistemology. This IPA study, by Waite and Elliot (2021), again identified

loss as a central there. The study revealed that UK students living with ME/CFS experience multifaceted losses including their sense of self, academic achievement, a social life and control over their physical bodies. This latter loss left participants feeling detachment from their bodies. And yet Waite and Elliot's participants adapted to this loss by taking up new creative hobbies, adopting a kinder attitude, and surrounding themselves with understanding people. These changes allowed participants to remove, from themselves, excessively high expectations. This finding contradicts Smith et al.'s conclusions that, for children and adolescents living with ME/CFS, new activities can feel like poor substitutes for previously enjoyed hobbies. It may be that as individuals get older, their ability to adapt and enjoy new hobbies increases.

The sense of loss uncovered in Waite and Elliot's study is woven throughout many qualitative explorations of child and adolescent ME/CFS, from loss of the self (Taylor et al., 2017), to loss of enjoyed and valued activities (Jelbert et al., 2010; Smith et al., 2021; Taylor et al., 2017), to loss of school attendance and enjoyment (Fisher & Crawley, 2012). Loss is also found in studies of adult ME/CFS. Catchpole and Garip (2021) noted loss of partner intimacy, Dickson et al.'s (2007) participants expressed a loss of confidence and identity loss was captured in Larun and Malterud's (2007) qualitative synthesis.

2.8 Study rationale and research questions

ME/CFS has a demonstrable psychological impact on those living with the condition. While the literature reveals this impact to be both positive and negative, the condition is predominantly experienced as negative. ME/CFS also has a demonstrable adverse educational impact. A review of literature has found that quality educational support for students living with ME/CFS is generally lacking, with teachers and staff lacking sufficient understanding and confidence in supporting students living with ME/CFS.

Much of the qualitative research regarding educational and psychological elements of ME/CFS has been conducted with children, adolescents, or adults. The experiences of

emerging adults has gone under researched. One identified study has explored, through IPA, the ME/CFS lived experiences of UK university students: Waite and Elliot (2021), yet this study has limitations. Waite and Elliot (2021) had only one male participant and only interviewed individuals well enough to remain on their university course, thereby impacting transferability. The current study addresses some of these limitations by recruiting exclusively through social media and not excluding participants on the basis of geographical location or ability to stay in education.

As mentioned previously, a bias can occur in disability research, as many studies only recruit those who disclose and identify as disabled, or possess a diagnosis. To overcome this bias, this study did not require participants to identify as disabled or even possess a diagnosis of ME/CFS. Instead, this study requested that participants have experience of ME/CFS for at least six months. This is unique amongst ME/CFS studies and enabled greater inclusivity, ensuring that no eligible participant was excluded on the basis of a difficulty identifying with the disability or ME/CFS label.

This research is thought to be the first of its kind to specifically explore the psychological and educational impact of ME/CFS within the life stage of emerging adulthood. The aim of this study is to understand how emerging adults psychologically and educationally experience ME/CFS. This study has two research questions. In developing these questions, I sought inspiration from available relevant literature, conversations with ME/CFS NHS professionals and clients, interactions on social media and discussions with my supervisors. These research questions are:

1. What is the psychological impact of being an emerging adult living with ME/CFS?
2. What is the educational impact of being an emerging adult living with ME/CFS?

Chapter 3: Methodology

3.1 Chapter outline

In the previous chapter I discussed some of the existing literature relevant to this thesis. I also outlined my research rationale and questions. Here I turn to the methodology of this study. Methodology, in a broad sense, is defined as a system of methods, principles and rules of procedure (APA, 2018b). More specifically to research, the term describes the practice of identifying, selecting, processing, and analysing information regarding a particular topic (University of the Witwatersrand, 2023). In this chapter, I shall outline the steps I took to identify, select, process, and analyse information regarding this study's topic, that is the psychological and educational experiences of emerging adults living with myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (ME/CFS).

The chapter begins with an introduction and explanation of my chosen research design, including methodological changes that occurred as the research evolved. Following this I shall discuss interpretative phenomenological analysis (IPA), my selected method of data examination. I shall outline my rationale for choosing IPA, before reviewing its philosophical underpinnings, including epistemological and ontological influences. The focus will then shift from theory to practice as I discuss participant recruitment and briefly introduce the five participants who kindly volunteered to take part in this study. Middle sections of this chapter focus on data generation, trustworthiness and reflexivity. Lastly, ethical considerations are detailed and deliberated.

3.2 A note on methodological changes

3.2.1 Emerging adulthood

During the initial stages of this research, I consulted academic literature regarding age parameters for the nomenclature of child, adolescent, youth, young person, young adult and adult. I wished to ground this research in an age group in which individuals develop a sense of identity and transition to new, more independent roles. I specifically wished to investigate the process of navigating this change in the presence of ME/CFS.

I was surprised to find that global definitions and age ranges differ for almost all age groups. For example, the NHS refers to 'young people' as individuals aged sixteen to twenty-four, and 'adults' as anyone eighteen and upwards (NHS, 2021). The World Health Organisation (WHO) defines 'adolescents' as those aged ten to nineteen and 'youths' as individuals aged fifteen to twenty-four (WHO, n.d; UN, n.d). Moving from healthcare to UK government, The Children Act (1989) has two binary classifications, a 'child' is under eighteen and an 'adult' is over eighteen (Department for Education, 2021). Yet the Mental Capacity Act (2005) defines a 'young person' as aged sixteen or seventeen and a 'child' as under the age of sixteen (SCIE, 2022). The UN agrees with the WHO regarding their definition of 'youth' as fifteen to twenty-four years old, but this statistically orientates children as any person fourteen or under (UN, n.d). With so much difference of opinion I became easily confused. I eventually resolved to research the sixteen to twenty-four age group. Furlong (2016) writes that this phrase in the life course involves significant change as new statuses are negotiated and old ones abandoned. Moreover, as an NHS scientist-practitioner (Jones & Mehr, 2007) I wanted my research to correspond with its pre-existing age parameters for 'young people'. Yet felt the phrase 'young people' sounded patronising so I settled on 'young adult' and recruited young adults aged sixteen to twenty-four into the current study.

Mid-way through data analysis I discovered a new proposed stage of development named 'emerging adulthood' (Arnett, 2000). The description of this developmental stage matched what I wished to research, that of psychological change, identity development and the

transition to new roles. Furthermore, Arnett's description of emerging adulthood corresponded with many of the themes my participants had spoken about. I therefore decided to reorientate this research towards the developmental stage of emerging adulthood.

3.2.2 From discourse analysis to interpretative phenomenological analysis (IPA)

This study was initially designed to be a discourse analysis of fatigue. Discourse analysis is the close study of language in use (Taylor, 2001). For the discourse analyst, language is a pattern of activity, performed by individuals, to achieve purpose, action and goals (Gee & Handford, 2012). Such analysts aim to explore how and when we use language patterns and for what ends (Parker, 2004).

There are two major versions of discourse analysis, discursive psychology and Foucauldian discourse analysis. This study was originally planned as a discursive psychological analysis of the performative qualities of fatigue discourses. While discursive analysis makes no strong ontological or epistemological claims (Wiggins, 2017), it is generally grounded in relativism and social constructionism. This grounding means that discourse analysis emphasises language over the people producing the language (Clarke, 2010), and experience for the discursive analysist is just another discursive construction, to be deployed as and when required (Willig, 2021). As this research progressed, I developed a sense that this deconstruction of experience and emphasis on language, to me, seemed to disempower and trivialise human life. I worried that by focusing on the performative qualities of my participants' fatigue discourses, I was dismissing the essence of their phenomenological experiences.

I began to realise the ontological and epistemological positioning of discursive psychology did not sit comfortably with me. O'Reilly and Kiyimba (2015) stress the necessity of congruence between ontology, epistemology and methodology when undertaking research. After some consideration, I opted to change my methodology to IPA, to align better with my

personal ontological and epistemological positioning. This positioning is detailed in earlier sections of this chapter. I made the decision to change methodology after I had interviewed all participants and before transcription had been completed. My recruitment letter, poster and consent form (appendices A, B and C) therefore refer to discourse analysis as my methodology, which is now incorrect.

3.3 Design

This study is qualitative. The landscape to qualitative research is rich and complex (Lawthom & Tindall, 2011; Madill & Gough, 2008), perhaps because, initially, qualitative research was defined not in terms of what it is, but what it is not.

The qualitative approach emerged from a growing dissatisfaction with traditional quantitative methods, with their firm belief in objective reality, universal truth and empirical measurement. Qualitative researchers wished to give voice to the tangled, messy, and multi-faceted aspects of personhood (Eatough, 2012). However, it became apparent that these elements of a human being could not be captured using empirical measurement and mathematical precision (Eatough, 2012). Instead, a new perspective was sought. This new qualitative perspective asserts that there is no objective reality or universal truth, but rather 'reality' and 'truth' are context specific (Lyons, 2007).

Within this research I chose a qualitative design for several reasons. First, because qualitative research aligns with my personal philosophical orientation. This orientation asserts that human experiences (including those of participants and researchers) are not fixed, rather contexts and perspectives are constantly changing (Sandelowski, 1993) and in Polkinghorne's words, "people use self-stories to interpret and account for their lives" (Polkinghorne, 1988, p. 119)

I also chose a qualitative design because I wished to explore the tangled, messy, and multi-faceted aspects of personhood, and I wanted to understand how my participants interpret

these aspects. I wanted to understand my participants feelings related to ME/CFS, and I wished to discover their reflections on their experiences of the condition (Biggerstaff & Thompson, 2008). A qualitative design, with its interpretivist emphasis on sense-making through language, rather than numbers, seemed ideal for this.

Lastly, I chose qualitative research because I wanted to 'give voice' to my participants. Larkin et al. (2006) writes that the concept of 'giving voice' means capturing and reflecting the concerns of participants. Yet the concept has been criticised, especially within disability studies. Ashby asserts that "the hierarchies of power and privilege are re-inscribed when the researcher presumes to give voice to someone else… and [too often] giving voice falsely assumes the person or group being researched has no voice" (2011, para 12). She suggests that researchers instead facilitate the empowerment of participants through 'voice agency'. In this research, I merge these two concepts together and wish to give voice by facilitating voice agency. This means recognising that my participants' voices are not mine to give or uncover; they belong to the participants themselves. Instead, I simply make space for my participants' voices. I allow them to be heard whilst also continually acknowledging and owning my own role in their interpretation.

3.4 Ontology

Ontology is the study of being, existence and the fundamental nature of reality. In social research, ontology refers to beliefs about the nature of social reality (University of Warwick, 2017). Reflexive consideration of my personal ontological positioning is crucial if I want my research to have integrity and credibility (O'Reilly & Kiyimba, 2015). To ensure this, I spent some time deliberating my perceptions and interpretations of the world.

I considered the ontological position of realism, the belief that there is a single observable, knowable reality which exists entirely separate from human understanding and perspective. Realists believe this world can be directly and accurately observed through research (Braun & Clarke, 2013), and many quantitative studies are positioned within a realist ontology. I

also considered the position of relativism, the opposing belief that reality is not something external, but subjective and entirely dependent on human knowledge and interpretation. For relativists there exists multiple constructed realities, rather than a single knowable one (Braun & Clarke, 2013). Realism and relativism sit on opposite ends of an ontological continuum. Several positions sit in-between including critical realism, subtle realism and materialism (Braun & Clarke, 2013).

Realism has been the dominant ontological position throughout my life. My culture, education and social experiences have been permeated with realist thought and discourse. Olsen (2007) writes that many qualitative researchers are implicitly realist, even when asserting other ontological positions, and they may be unaware of the deep impact this has on their work. My experience working within and researching chronic fatigue has taught me that fatigue is real, given, measurable and objective. There is an observable, assessable biological process to it. By holding this belief, I lean towards a realist perspective. Furthermore, I believe that to label the concept of fatigue as relativist, (subjective and dependent on human knowledge and interpretation) could arguably undermine and patronise those who experience it.

Yet, my work as a psychologist has taught me that several other concepts *are* subjective and open to interpretation. Emotions such love, grief, anger and anxiety are experienced differently by different people at different times. In this sense, such concepts are socially constructed, since we each hold our own subjective reality and interpretation, and this can be shaped by context and perception, and can change across time (Nightingale & Cromby, 1999).

Holding these two ontological beliefs in tandem means I subscribe to the position of critical realism (Bhaskar, 1975/2008). Critical realism sits between the two opposing perspectives of realism and relativism. From this position I can believe in the existence of an external reality that existed before my birth and will continue to exist after my death. And I can also believe in a socially constructed world, where mind-dependent knowledge changes over time and varies from place to place (Pilgrim, 2020). Critical realists acknowledge that the world is real, and that knowledge production is fallible and mind-dependent, but not mind determined

(Fryer, 2022). Critical realism can underpin several qualitative approaches including IPA (O'Reilly & Kiyimba, 2015), which commonly rejects the objective real, focusing instead on interpretation and meaning-making derived from experience.

3.5 Epistemology

If ontology is concerned with what there is to know, epistemology focuses on how it can be known (Green, 2021). The term refers to theories of knowledge as well as means of knowledge production (O'Reilly & Kiyimba, 2015). Within this research my epistemological position determines how I communicate with, and interpret my participants, and also how I impart that interpretation to readers.

There are several epistemological branches and several positions within each branch. These range from rationalism (rational intuition is the best source of knowledge) to empiricism (experiences and observations are the best source of knowledge). Objectivism (meanings of phenomena exist within the phenomena themselves) to subjectivism (meanings are derived from individual interpretation). And positivism (a researcher can only be an observer of an independent existing universe) to interpretivism (a researcher can only understand and interpret how other people perceive, feel and experience their social world) (O'Reilly & Kiyimba, 2015).

In my journey to understanding my personal epistemology, I was guided by my ontological positioning. By positioning myself within critical realism I take an epistemological anti-positivist and anti-objectivist attitude, yet I neither fully lean into the subjectivist, interpretivist view of reality either. I therefore affirm my epistemological orientation towards contextualism. Contextualism does not assume a single reality, but it does retain an interest in understanding truth (Braun & Clarke, 2013).

Contextualism asserts that truth claims vary within the context in which those claims are made (Pynn, 2016), and while no single method can get to the truth (Tebes, 2005),

knowledge will be true in its own particular context. Applying contextual epistemology to the current research, I am asserting the truth of my participant's lived ME/CFS whilst also stressing that my participants' knowledge will be contextual and will vary accordingly. My participants' different contexts will generate different insights into the phenomena of ME/CFS, and each of those insights is equally as true as the others.

3.6 Methodology

All methodologies are constrained by the ontological and epistemological assumptions they stem from (O'Reilly & Kiyimba, 2015) and all methods can only make sense if they are anchored to their methodological, epistemological and ontological frameworks (Staller, 2013). My ontological positioning is critical realism and my epistemological stance is contextualism. The aim of this research is to better understand the psychological and educational experiences of emerging adults living with ME/CFS. Given these positions and aims, interpretative phenomenological analysis (IPA) - with its emphasis on socially constructed realities, idiographic understanding and the detailed examination of major life experiences - seems an apt choice of methodology. Interviews seem an appropriate method since they elicit rich data, crucial for such detailed examination of experience. Together, these ontological, epistemological, and methodological positions and choices represent my research paradigm. This paradigm (see figure 2) is the underpinning interpretative foundation which guides my actions as a researcher throughout this project (O'Reilly & Kiyimba, 2015).

Figure 2

Research paradigm of interconnected ontological, epistemological and methodological positions.

3.7 Interpretative phenomenological analysis (IPA)

Developed by Jonathan Smith and colleagues (Smith, 1996; Smith et al., 1997; Smith et al., 2022; Smith & Osborn, 2003), interpretative phenomenological analysis (IPA) is a relatively new addition to a family of phenomenological methodologies. It is an accessible and flexible approach that allows rigorous exploration of idiographic subjective experiences. In particular, IPA explores how people ascribe meaning to their experiences (Biggerstaff & Thompson, 2008). IPA is methodology for researchers who wish to understand the experiential claims and concerns of their participants. Yet IPA upholds the belief that obtaining a genuine first-person account is impossible, since researchers all come to research with their own experiential claims and concerns. My epistemological commitment to contextualism, combined with my wish to better understand the experiences of emerging adults with ME/CFS, means IPA is a suitable choice of methodology for this research. Moreover, Smith and Osborn (2015) write that IPA is a particularly useful methodology for examining topics which are complex, ambiguous and emotionally laden. ME/CFS is such a phenomenon: physically and emotionally draining with an indistinct aetiology and too often misunderstood.

IPA is underpinned by three theoretical and philosophical attitudes: phenomenology, hermeneutics and idiography (Smith et al., 2022). Below I shall outline each and note how each approach informs the present study.

3.7.1 Phenomenology

Phenomenology is the study of experience in all its richness and texture (Lawthom & Tindall, 2011). Phenomenological methodological approaches explicitly focus on sense making and personal meanings. They aim to explore how the world is humanly experienced by gaining first-person accounts of a particular phenomenon under investigation (Lawthom & Tindall, 2011; Moran, 2000). Phenological investigations within IPA rest on the ontological assumption that there is no fixed objective reality. Research findings therefore relate not to the phenomenon itself, but to participants' experiences and understanding of that phenomenon. In this sense phenomenological approaches are generally concerned with 'persons-in-context' or 'being in the world' (Larkin et al., 2006). That is to say, the individual and their context are inextricably linked; one cannot study one without the other.

Academics in the field of phenomenology assert that experiences exist in a hierarchy, ranging from the everyday unselfconscious, to comprehensive life events that take on a particular significance (Smith et al., 2022). It is this latter type of experience that IPA is concerned with. In this research, the epoch-making experience under investigation is ME/CFS and the persons-in-context are emerging adults living with the condition. The aim of this study is to investigate how emerging adults experience and understand ME/CFS.

3.7.2 Hermeneutics

For the interpretative phenomenological analyst, all humans, including researchers and participants, are self-reflective, self-interpretative beings insofar as we have unique personal, individual experiences which we reflect on, interpret and make sense of (Braun & Clarke, 2013). Martin Heidegger, a 20th century German philosopher whose work significantly influenced the development of IPA, wrote about the elusive and hidden elements of personal experience. These elements may be consciously disguised or

unconsciously buried. It is the job of the IPA researcher to uncover what is hidden, whilst maintaining an ethical stance which prioritises the wellbeing and empowerment of participants at all times (Spiers & Smith, 2019).

For researchers, it is impossible to access participants' worlds directly. We can only make sense of such worlds by using our own interpretative resources (Braun & Clarke, 2013). In IPA research, a cycle, therefore, is created where participants are making sense of their worlds, and researchers are making sense of participants, making sense of their worlds (Smith & Osborn, 2003). This is the interpretative element of IPA, where a dual interpretive process takes place. This is named the double hermeneutic and links IPA to the discipline of hermeneutics and theories of interpretation (Smith & Osborn, 2003).

This double hermeneutical process means it is essential that researchers acknowledge the unavoidability of their own biases, preoccupations and assumptions (Eatough & Smith, 2017). Once acknowledged, researchers must question how these beliefs impact the whole research process. This demands a high degree of reflexivity. In this thesis, such reflexivity is woven into almost all chapters, with an in-depth reflexive exploration contained in the introduction and discussion chapters.

3.7.3 Idiography

Idiography concerns itself with how to understand the concrete, the particular and the unique (Eatough & Smith, 2017). Idiographic research views participants as individual, unique and complex, and commits time and effort to studying this uniqueness. This type of research is often contrasted to nomothetic research which emphasises the uncovering of general patterns of behaviour to predict and explain phenomena (O'Reilly & Kiyimba, 2015).

IPA has an idiographic commitment insofar as it asserts a commitment to the detailed examination of each 'case' whilst also maintaining the integrity of the person (Spiers & Smith, 2019). In this research, this was achieved by close line-by-line analysis of each

transcript in turn, before moving to the next. This idiographic commitment meant I could make specific claims about each participant, highlighting their unique concerns, emotions and wishes.

3.8 Recruitment

Regarding sample sizes in IPA studies, Smith and Eatough (2007) write of the importance of doing justice to each participant's account, whilst at the same time acknowledging the time-consuming nature of line-by-line, case-by-case analysis. They note the benefits of assessing participant convergence, as well as divergence, and also advise depth before breadth. They therefore advise a sample size of six to eight participants, to adequately investigate detail and nuance in all participant's accounts. Smith et al. (2022) suggests higher numbers for doctoral work, advising an optimal sample size of ten, however, their guidance was not published at the time this project began. Due to the nebulous nature of data saturation (Nelson, 2017), I did not recruit until data saturation, instead I recruited according to time and resource constraints and guidance set by Smith et al. (2022), who note the intensity of IPA's idiographic commitments and analytic depth. Ultimately, I intended to recruit and interview six participants, but struggled slightly with recruitment, in part due to the Covid-19 pandemic. I consequentially recruited and interviewed five emerging adults with lived experience of ME/CFS.

Participant recruitment occurred between July and November 2022. An introductory letter (appendix A), research poster (appendix B) and participant information sheet (appendix C) aided recruitment. I initially advertised on Facebook ME/CFS groups, Twitter (recently renamed to X) and through email contact with ME Association support group leaders. Any individual who expressed an interest in participation, and provided an email address, was emailed a copy of the participant information sheet and consent form (appendix D).

Participant recruitment was based on self-selection and no individual was followed-up if they failed to respond to my initial email. Whilst I had informative and engaging discussions

with several individuals across all platforms, all five participants were recruited through Twitter (X).

3.8.1 Inclusion and exclusion criteria

Table 1

Participant inclusion and exclusion criteria for taking part in the study

Inclusion criteria	Exclusion criteria
• To have experience of ME/CFS lasting six months or more	• Current experience of severe depression or anxiety
• The ability to speak and read fluent English • To be between the ages of sixteen and twenty-four inclusive	• Current experience of severe ME/CFS

Pre-determined inclusion and exclusion criteria (table 1 above) facilitated the recruitment of a purposive homogenous sample. Purposive sampling helped me to find a closely defined group for whom the research questions were significant (Smith & Osborn, 2015). Participants were required to be emerging adults between sixteen and twenty-four years old, inclusive, with the ability to speak and read fluent English. All participants were also required to have personal experience of ME/CFS for at least six months, in accordance with the Fukuda diagnostic criteria for ME/CFS (Fukuda et al., 1994). Most ME/CFS research operationalises the Fukuda criteria for participant selection, which is why I used the timeframe element of it in this research. In addition, since participants were not required to have a diagnosis of ME/CFS, I needed a condition timeframe to ensure homogeneity.

There were two main reasons why this research had no diagnostic requirements. Firstly, I was aware of several barriers to diagnosis including long NHS waiting list and a lack of healthcare professional knowledge and medical legitimacy (NICE, 2021). I did not wish to constrain my research and exclude individuals because of such barriers. And secondly, I was aware that a majority of emerging adults living with a disabling impairment do not self-identify as disabled, and therefore are often excluded from disability research (Chalk, 2016). I sought to address this by recruiting individuals who had experience of ME/CFS only, without priming the concept of disability (Chalk, 2016).

The lack of national inclusion criteria meant participants were geographically spilt between two countries, the UK and the USA. This heterogeneity provided unique insight into the similarities and divergencies of ME/CFS experienced in different countries, but also impacted transferability of some findings. This is further considered in the discussion chapter of this thesis.

3.8.2 Pre-interview screening

Before each research interview I conducted an online screening. A screening template was used to guide discussion (appendix E). The screening was used to inform participants of the purpose and procedure of the research. We also discussed participants' rights to complain about the research, withdraw from the research, or stop their research interview. The screening provided an opportunity to check that participants met all inclusion and exclusion criteria. Regarding this, I asked all participants three or four questions before interview:

1. Do you feel emotionally well to take part in this research?
2. Some people find talking about their ME/CFS helpful. Others find it more difficult and distressing. How do you think you'd feel talking to me about your ME/CFS?
3. Do you think that taking part in an online interview of around sixty minutes would result in a significant exacerbation of your ME/CFS symptoms?
4. If so, how do you think this would this impact you?

All participants were also asked to complete two psychometric measures of depression and anxiety, the PHQ-9 and the GAD-7 (appendix F). Any participant who scored within the severe range on either measure (20 or above on the PHQ-9, 15 or above on the GAD-7), were asked to withdraw from the research. This qualitative and quantitative assessment of fatigue and emotional wellbeing was conducted to ensure that no participant would experience undue psychological distress or PEM from taking part in the research. As it stood, all participants who consented to the research, met all inclusion criteria and fulfilled no exclusion criteria. One participant requested that we conduct the research interview in two halves, so they could better manage their ME/CFS symptoms. We therefore co-ordinated two interviews of approximately twenty minutes, one week apart.

3.9 Participants

Five participants gave full informed consent to part in the research. Two participants identified as female, two as male and one participant expressed a preference for gender neutrality. Three participants were of British nationality and two were American. To avoid compromising anonymity by deductive disclosure (Saunders et al., 2015) I did not specifically enquire regarding participant's heritage, ethnicity, racial identity or religion. This action may have affected quality of analysis, since deeper, richer understandings regarding any interplay between these demographic characteristics and ME/CFS were forfeited.

All participants reported experience of ME/CFS that had lasted six months or more. All participants were asked if they wished to choose their own pseudonym. Three participants chose their own, one participant requested I choose for them, and one did not respond to my request, so I chose for them. Pseudonyms are commonly used in research to conceal participants' identities and ensure confidentiality (Itzik & Walsh, 2023). There is growing recognition of the connection between names, naming and self-identity (Dion, 1983), and pseudonyms, whether chosen by participant or researcher, are affected by issues of power and voice (Allen & Wiles, 2016). Renaming has psychological meaning to participant, researcher, and the content and process of research (Allen & Wiles, 2016). When

considering the pseudonyms of the latter two participants, I engaged in a process of thoughtful naming, as advised by Allen and Wiles. This involved choosing names in accordance with participant's age, geographical location and gender identity, and with respect and awareness of my own power and voice.

ME/CFS is a condition with many names. Some terms used to describe the condition include myalgic encephalomyelitis (or encephalopathy) (ME)**,** chronic fatigue syndrome (CFS), post-viral fatigue syndrome (PVFS), systemic exertion intolerance disease (SEID), energy limiting chronic illness (ELCI) and, more recently, long-Covid. Before each interview I asked each participant what term they preferred. Participant's answers varied and throughout each interview I endeavoured to use each individual's preferred term. One individual, James, stated a preference for the term long-Covid, since a Covid infection preceded the onset of his now chronic condition. Throughout our interview, and within his data analysis I have used the term long-Covid, in line with IPA's ideographic commitment and Ashby's (2011) suggestion that qualitative researchers facilitate voice agency.

Brief participant details can be found in table 2, below. More detailed portraits can be found in the following chapter. Some potentially identifiable information has been altered or omitted to ensure anonymity.

Table 2

Brief participant details

Morgan
Morgan is their early twenties and lives in the UK. Morgan's preferred term to describe their condition is ME. Morgan has been experiencing symptoms of ME for seven to eight years, since their early teens. This means Morgan underwent secondary and higher education with the condition. At the time of our meeting Morgan was completing an undergraduate degree at a university close to their home.
Samantha
Samantha is in her early twenties and lives in America. Her preferred term to describe her condition is chronic fatigue syndrome (CFS). Samantha was diagnosed with CFS at the age of sixteen. Following high school Samantha attended a local university college. She is currently in work having recently graduated.
Olivia
Olivia is in her early twenties and lives in the UK. Her preferred term to describe her condition is chronic fatigue syndrome (CFS). At the time of interview Olivia had a nine-month history of CFS. She was training to become a health professional and was balancing placement, university lectures and assignments in the presence of CFS symptoms.
Peter
Peter is a teenager living in the UK. His ME/CFS started when he was nine and his symptoms have worsened with age. Peter is in higher education and has been educated at home for the past few years.
James
James is in his early twenties and lives in America. At the time of interview, he was completing a university degree from home. James had been experiencing symptoms for

almost two years, following a Covid-19 infection early in the pandemic. Due to this, James preferred to call his condition long-Covid.

3.10 Use of expert by experience

In the early stages of this research, I consulted a single expert by experience who had both lived and research experience of ME/CFS. There is growing recognition that the involvement of experts by experience in health and social care research improves the quality, relevance and outcomes of studies (Jones et al., 2021). Through a single phone conversation, the expert by experience was involved in the process of recruitment, in refining the interview schedule and in developing ethical ways of interviewing. Involving an expert by experience this way was very effective and influenced important aspects of the study. Due to time and workload constrains the expert by experience could not contribute further, however I hope this form of collaborative research went some way towards fostering empowerment and equality.

3.11 Data collection

In qualitative research, the aim of data collection is to create a valid and comprehensive record of participant's words and actions in as naturalistic a way as possible (Willig, 2021). In order to create such a valid record, analysis (and the research as a whole) must be legitimate, trustworthy and of worth to others (Yardley, 2008). In order words, it must describe, measure or explain what it aims to describe measure and explain (Willig, 2021).

I used an interview schedule to facilitate comfortable discussion during each research interview (appendix G). The schedule was developed using guidance by Smith and Osborne (2004). My experiences and knowledge gained through clinical practice fed into the development of the schedule, as well as my reading of the existing ME/CFS IPA literature. I discussed the interview schedule with my primary and secondary research supervisors, as

well as the expert by experience who contributed their knowledge to the study. The final schedule consisted of nine open questions, with prompts, that were designed to facilitate comfortable discussion. I had planned to pilot the schedule but this was ultimately not possible due to time constraints.

Participants were asked to attend an interview with myself, undertaken and recorded over Zoom. Interviews were conducted in a semi-structured in-depth style. Smith et al. (2009) advise that research interviewing is about learning in practice with the researcher, "like a naïve but curious listener, trying to get to know the person in front of them" (p. 64). I adopted this advice and my interviewing confidence and skill increased with each interview. I engaged much more with participants in my early interviews, summarising and checking for clarity often. In later interviews I became more adept at listening, allowing my participants to explore their experiences with little interruption. This ultimately resulted in richer, fuller answers.

All interview audio recordings were stored on the University of Manchester Research Data Storage (RDS) in .m4a format. Audio recordings were later transcribed by myself. Once transcription was complete, audio files were deleted. All transcriptions were stored on the University of Manchester RDS.

3.12 Transcription

IPA requires a verbatim record of the data collection event (Smith et al., 2022). Once all interviews were conducted and recorded, I set out to transcribe. I recorded all words spoken by everyone present. Being a semantic method of enquiry, IPA does not require detailed translation of non-verbal communication, however where there were noticeable laughs or pauses, these were represented by italicised text in brackets. Each transcript had wide margins for coding exploratory notes on the right hard side of the page and experiential statements on the left hand side of the page.

3.13 Method of analysis

Well executed IPA data analyses are inductive and iterative (Smith, 2007), dialogical and subjective (Smith et al., 2022), and demonstrative of strong empathic engagement and high attunement (Smith & Osborn, 2015). The primary concern of IPA is the lived experience of each participant and the ways in which each participant interprets their experience. However, as detailed above, free access to another individual's interpretations is an impossible task. Therefore within IPA data analysis, the researcher must make sense of how the participant makes sense of their experience (Smith et al., 2022). This process, known as the hermeneutic circle, is unique to IPA.

The analysis conducted in this study is heavily guided by Smith et al.'s (2022) seven step process. I have also drawn upon the guidance of Smith and Osborn (2015) and Eatough and Smith (2017). Below is a description of the steps I undertook, and an outline of how I used each step during my analysis. In brief, these steps are:

- Step one: Reading and re-reading each individual transcript.
- Step two: Exploratory noting.
- Step three: Construction of experiential statements.
- Step four: Searching for connections across experiential statements.
- Step five: Naming, consolidating and organising experiential statements into personal experiential themes (PETs).
- Step six: Continuing the analysis for other participants.
- Step seven: Forming group experiential themes (GETs) and sub- group experiential themes (sub-GETs) from individual PETs.

Steps one to five were followed, in a linier order, for each individual transcript before moving onto the next. Step seven was completed once all transcripts were analysed.

3.13.1 Step one: Reading and re-reading

An initial immersion in the transcribed interview data is advised as the first step of IPA analysis. This involves reading and re-reading transcripts, ideally aided by interview audio. This active engagement with the verbatim data ensured my participants became the focus of analysis. During immersion I gained an awareness of the overall structure of each interview, including the location of richer detailed sections, contradictions, paradoxes, mood shifts and complex or confusing sections.

During this step I read each transcript four times, first accompanied by audio, and later on my own without audio. Alongside this reading, I recorded my own thoughts, emotional reactions and observations in a separate document. This assisted focus and allowed me a sense distinction between mine and my participants' sense-making, aiding reflexive awareness in later steps. The document heavily contributed towards development of the reflexive sections of this thesis.

3.13.2 Step two: Exploratory noting

Exploratory noting tentatively examines semantic content and language with a curious, probing attitude. The aim is to create an open-minded, comprehensive and detailed set of notes and comments that accompany each transcript. This process is interpretative, however notes stay close participants' explicit meanings. Smith et al. (2022) detail three types of exploratory noting: descriptive, linguistic and conceptual. Descriptive comments focused on summarising the content of the transcript. Linguistic notes explore the specific use of language, and conceptual comments move the analysis beyond the superficial to the interrogative. These latter comments explicitly ask questions of the data and allow for trial-and-error reflection (Smith et al., 2022).

Regarding my exploratory noting, I separated my transcripts into three columns. The middle column contained the interview transcript itself, the right column allowed space for exploratory noting, and the left column left room for experimental statements (detailed

below). Starting at the beginning of each transcript, I underlined any text which felt important, then wrote exploratory notes alongside. When writing, I aimed to achieve what Eatough and Smith (2017) name the 'both/and approach'. This immersive technique involves empathically imagining what it is like to be the participant, whilst also being critical of what appears to be the case. The purpose is to probe for meanings that participants may have felt unsafe to do themselves. This analytic method allows for a more textured, multi-layered narrative of possible meanings (Eatough & Smith, 2017). The righthand column of Appendix I contains an example of exploratory noting for one of my research participants, Samantha.

This stage of analysis was both cognitively and emotionally intense. I felt several strong emotions whilst noting, including sadness, anger and anxiety. The strength of emotion varied from transcript to transcript with some participant's evoking much more of one emotion that another. Throughout this process I sought the opinion and guidance of my research supervisor, who helped me achieve a greater level of interpretative depth and reflexivity.

3.13.3 Step three: Constructing experiential statements

Experiential statements are described as "concise and pithy summaries… usually expressed as phrases, which speak to the experiential core of the [data] and contain enough particularity to be grounded and enough abstraction to be conceptual" (Smith et al., 2022, p. 86). Following comprehensive exploratory noting, I used the data from each interview, and my exploratory notes, to create a series of experiential statements. I wrote these in the left-hand column of each interview transcript.

Although experiential statements included an unavoidable element of myself, my interpretation and my sense making, I endeavoured to ensure each statement directly related to my participant's experiences and *their* process of making sense of *their* experiences. An example of my experiential statements can be found in the lefthand column of Appendix I

3.13.4 Step four: Searching for connections across experiential statements

Following the creation of experimental statements, I grouped the statements to create coherent connection and a structure of interesting and important aspects of participants' accounts. To achieve this, I scanned and printed each transcript, now containing written exploratory comments and experiential statements. The page number on which each experiential statement was found was written next to all experimental statements. I then cut and separated out all experiential statements for each participant, randomly distributing all statements on the floor. This scattering disrupted the initial order to facilitate a search for a different, more conceptual order. Smith et al. (2022) note that the way participants understand their world is unlikely to be reflected in the exact order in which it was recounted. I then grouped the experiential statements by theme or connection, treating each one as equal to the others. As thematic clusters emerged, I cross-checked clusters against each participant's transcript. This was to ensure connections reflected the actual words and meanings of each participant (Smith & Osborn, 2015).

During this stage, not all experiential statements were included in a cluster. Some statements were irrelevant to the research questions and consequentially discarded. When I came across two or more statements that were very similar, I placed them one behind the other. This kept them both within the analysis, but also enabled better visual organisation of the copious data.

3.13.5 Step five: Naming, consolidating and organising Personal Experiential Themes (PETs)

Once all experiential statements were clustered according to connection, I named each cluster to describe its characteristics. These names then became that participant's personal experiential themes (PETs). Smith et al. (2022) write that PETs are rooted at the level of the individual. The photo in appendix J shows clusters of experiential statements and their

engendered draft PETs for Samantha. These PETs relate directly to Samantha's experience and sense-making. PETs for all participants were reworded several times, as I checked and grounded each within the interview data. PET clusters were later transferred from paper hardcopies to an electronic document in the form of a table. The final electronic version of Samantha's PETs, along with their associated experimental statements, can be found in appendix K.

3.13.6 Step six: Continuing the analysis for other participants

This step involved moving to the next participant's transcript and repeating steps one to five. During this stage I consciously bracketed off one participant from the other, so I could do justice to each participant. This is in keeping with IPA's idiographic commitment. Of course, I was inevitably influenced by PETs found in previous transcripts, however, by attempting to bracket off each participant, I allowed space for new analytic entities to emerge with each new transcript analysis (Smith et al., 2022).

3.13.7 Step seven: Forming group experiential themes (GETs) from individual PETs

Once all transcripts were analysed with exploratory notes and experiential statements, and once all transcripts were cut, experiential statements disrupted, and PETs formed, only then did I start the process of generating group experiential themes (GETs). The aim of this step is to identify patterns of convergence and divergence across PETs. I began by scanning and re-sequencing each participant's table of PETs in turn, thinking about similarities and differences. PETs that were similar across participants were reordered, so they consistently appeared in the same order across each table of PETs. PET tables were coloured coded, with each participant receiving a different colour. Morgan was green, Samantha blue, Olivia red, Peter was yellow, and James was grey. This colour coding aided my next step when I printed out and cut up each PET table. At the end of this process I was left with a series of cut and colour-coded PETs.

Similar to my process in step four, I randomly distributing all PETs onto a table, ordering them in ways that identified convergence and divergence. This ordering created embryonic draft GETs. Smith et al. (2022) write that this is a dynamic process and I often found myself fitting and re-fitting GETs. Appendix L contains a photo showing this stage in process. GET composition and names changed several times as I engaged in individual and supervisory reflection. Throughout, I wanted to ensure all GETs were grounded in the data and yet were faithful to my own analytic work. I also wanted to ensure that all GET names reflected accurately and appropriately the composition of PETs within that GET. It was important that the GETs created answered my research questions, therefore I discarded any emergent GETs that did not do this. Finally, once satisfied with GET composition and labels, I created an electronic table of GETs, sub-GETs, PETs and engendered quotes. This can be found in appendix M. The final analytic corpus composed of six GETs. One GET has three sub-GETs and another has two. I later created a colour coded flow chart of GETs, sub-GETs and PETs and this can be found in appendix N.

3.14 Trustworthiness

Trustworthiness within qualitative research is analogous to the concept of validity in quantitative research (Green, 2021). Assessing validity in quantitative research involves judging against a predefined set of quality criteria, however, within the qualitative sphere there is little consensus regarding what constitutes quality markers and academic debate, therefore, has been rife (O'Reilly & Kiyimba, 2015). It is necessary that I, and other qualitative researchers, critically apprise the quality of our work, yet how to do this continues to be an ongoing dialogue.

Drawing upon the works of Guba and Lincoln (2005), Lincoln (2010), and Spencer et al. (2003); O'Reilly & Kiyimba (2015) propose five guiding principles for designing and evaluating the quality of qualitative work. These principles are: transparency, reflexivity, transferability, ethicality and integrity. Below I shall use these guiding principles to explicate how my research can be considered good quality and, consequentially, trustworthy.

3.14.1 Transparency

The transparency of my research refers to the extent that it is honest, clear and can be easily audited. To achieve transparency, I have been explicit in how my research was carried out and I have justified all research decisions. Many of these explanations and justifications can be found in this chapter, including explanations of my participant recruitment, method of interviewing and ethical considerations. I have unambiguously described my ontological and epistemological positioning and have detailed the congruence between these stances, my methodology, and my methods.

Another way transparency has been achieved is by including, in my appendices, copies or examples of my participant information sheet, interview schedule and all stages of data analysis. The journey from raw data to six eventual GETs regarding the psychological and educational impact of ME/CFS is clear and auditable. A further, final, way I have been transparent is by including a significant amount of participant verbatim quotes in the analysis section of this thesis. This acts as a way of clearly grounding analysis in participants' words and meanings.

3.14.2 Reflexivity

Reflexivity, written down, creates rigour in qualitative research by providing readers with information about the researcher's context in which the analysis is located (Etherington, 2004). Furthermore, it goes someway to addressing issues of power between researchers and participants (Etherington, 2004). Good reflexive awareness is a key marker of quality in any qualitative research, but especially within IPA because of the dual interpretative process of double hermeneutics. It is crucial that I have an awareness of my biases, preoccupations and assumptions, since these inevitably affect my interpretation of my participants' interpretations of their experience.

In this thesis I have dedicated a section of the introductory chapter to reflexivity. Within this section I present an in-depth and critical exploration of myself, in relation to this research. I discuss my personal interest in ME/CFS, my presuppositions about ME/CFS, fatigue and productivity, and my positioning in relation to ME/CFS and emerging adults in general. Further reflexive considerations are found within the discussion chapter of this thesis, where I outline how my ability, social class, gender, ethnicity and culture all impact my positioning, specifically in relation to my participants. Throughout other chapters, reflexivity is interwoven, the end result being a thesis imbued with honest, reflexive consideration.

3.14.3 Transferability

Transferability in the qualitative domain is debatably synonymous with generalisability in the quantitative domain (Treharne & Riggs, 2014). Transferability, within this research, refers to the study's degree of relatedness and the extent to which my conclusions can be transferred to other settings. In considering this, I pondered how my analysis, discussion and conclusions could resonate with other emerging adults living with ME/CFS, and how I could make this thesis helpful and accessible for friends, family, peers and professionals of emerging adults living with ME/CFS.

In my analysis section I have provided a rich description of my participants' experiences, together with interpretations, which has made the assessment and practice of transferability easier (Treharne & Riggs, 2014). All participants who took part in this research were emerging adults with experience of ME/CFS. This homogeneity of health condition allows findings pertaining to the psychological experiences of participants, to be applicable to other emerging adults living with ME/CFS. These findings can also be used to inform the understanding of friends, family, peers and professionals living, working and socialising with emerging adults living with ME/CFS.

Unfortunately, the transferability of this research to education contexts is somewhat reduced. Three of my participants live in the UK and two in the USA. The UK and USA has different systems of education governed by different legislation and funded in different

ways. This national non- homogeneity should be considered when applying findings and implications to educational settings.

3.14.4 Ethicality

Ethically refers to the risks and benefits of conducting research, the worthiness of the topic under investigation, and the degree that the research will contribute towards a knowledge base (O'Reilly & Kiyimba, 2015). A consideration of ethical risks, benefits and other issues can be found in the next section of this chapter and will not be discussed here. Here I will touch upon the worthiness of the current research, and what it can contribute towards the current knowledge base.

Existing research has demonstrated that ME/CFS is more disabling than several other chronic conditions (Kingdon et al., 2018; Nacul et al., 2011a). There is a body of qualitative research exploring adult's psychological experiences of living with ME/CFS (Åsbring & Närvänen, 2002; Dancey & Friend, 2008; Dickson et al., 2007; Dickson et al., 2008; Cheshire et al., 2021; Hunt, 2020; Murray, 2016; Snell et al., 2023; Tuck & Wallace, 2000; Wilde et al. 2020; Williams et al., 2019), and a slightly smaller body of qualitative research exploring child and adolescent psychological experiences of the condition (Crix et al., 2012; Fisher & Crawley, 2013; Hareide et al., 2011; Jelbert et al., 2010; Smith et al., 2021; Taylor et al., 2017; Williams-Wilson, 2009; Winger et al., 2014). Several studies have reviewed the educational impact of ME/CFS in school aged children (Clery et al., 2022; Crawley et al., 2011; Crawley & Sterne, 2009; Knight et al., 2016; Similä et al., 2021). Two studies have been found investigating the educational experiences of adolescents and young adults with chronic illness (Hamilton et al., 2021; Toller & Farrimond, 2021), and only one study has been identified that explores, through IPA, the lived experiences of university students with ME/CFS (Waite & Elliot, 2021). Whilst these students in this study could be said to be in the developmental stage of early adulthood, Waite and Elliot did not view their analysis through a developmental lens. This study, therefore, aims to provide a unique contribution to the evidence base by being the first to qualitatively explore the psychological and educational

impact of ME/CFS on those in emerging adulthood, and explore what this means to the emerging adult.

In an effort to enhance the worthiness of this research, I present, towards the end of this thesis, in-depth and considered recommendations for future research, education professionals, friends, family and peers. It is hoped that these recommendations will increase and enable champions of ME/CFS, whilst minimising opponents and sceptics.

3.14.5 Integrity

Integrity in qualitative research refers to the epistemological congruence, authenticity and sampling adequacy of the study (O'Reilly & Kiyimba, 2015). It is about honesty and probity within the conduct of the research and is characterised by openness and wholeness on the part of the researcher (Watts, 2008). I have maintained epistemological integrity by carefully and openly considering my ontology and epistemology, and choosing a methodology that is congruent with both.

Authenticity has been achieved in several ways. First, I have explicitly detailed the whole research process, from conception to recommendations and implications. Second, I have engaged with reflexivity throughout, and have dedicated several sections to honest reflexive discussion. Third, I have been clear regarding the limitations of the research and transferability of findings.

Regarding sampling adequacy, in this study participants were recruited through purposive sampling. This sampling method helped me to find a closely defined group for whom the research questions were significant (Smith & Osborn, 2015). I intended to recruit six participants, however, recruitment was harder than anticipated and I eventually recruited five. I have been open regarding this. On a final note regarding integrity, two chapters of this thesis contain brief and more detailed participant portraits. These honest summaries bring a sense of wholeness to the study. This research is as much theirs as it is mine.

3.15 Ethical considerations

Researchers hold responsibility for the safety and wellbeing of participants during the time they are engaged with the research. Ethical challenges threaten this safety and wellbeing and can be present at all stages of a study. Such challenges include protecting anonymity, ensuring confidentiality, establishing informed consent and managing potential distress.

This research was guided by, and sits in compliance with, the British Psychological Society's Code of Human Research Ethics (BPS, 2021) and the Health and Care Professions Council's Standards of Conduct, Performance and Ethics (HCPC, 2016). Ethical approval for the research was granted by the University of Manchester Research Ethics committee (UREC) in May 2022 (project ID: 12811, review reference number: 2022-12811-22909).

All participants were requested to read the research information sheet and consent form at least twenty-four hours prior to interview. The information sheet detailed the purpose of the study, requirements of participation, ethical procedures, principles of confidentiality, data handling procedures, my contact information, my supervisors contact information and information regarding the complaints process, should participants wish to raise a concern. Written consent was obtained and then reconfirmed verbally before interview.

I informed all participants, in writing via the information sheet and again verbally at the beginning of our interview, that they were free to withdraw at any time, without stating a reason, up until the point of data analysis. During analysis participants' data would be pooled and it would be difficult to distinguish one individual's data from another, therefore making withdrawal problematic.

Safeguarding my participant's wellbeing was of paramount importance throughout the research process. The study exclusion criteria stated that any individual who wished to take part in the research, but were deemed to be experiencing severe ME/CFS, severe anxiety or severe depression, would be disallowed. This was to protect their physical and psychological

wellbeing. I asked all participants for their GP details, should any issues regarding risk of harm to self or others emerge during the research interview.

During all interviews I informed participants when we reached the approximate mid-way point, so they were aware and could regulate energy levels, if required. A debrief sheet (appendix H) was sent to all participant's following interview. This sheet thanked participants for their time and detailed several organisations they could go to, should they wish for professional support following interview. These organisations included the ME Association and NHS primary care talking therapies.

Confidentiality was of paramount importance throughout the research. All interview consent forms were encrypted and stored on my personal storage space on the University of Manchester's P drive. Also encrypted and stored on the P drive was a log of participant names, their email addresses, GP details and corresponding pseudonyms. Zoom audio recordings were encrypted and transferred to a VPN accessed research data storage (RDS) facility immediately following interview. This is separate to the P drive and requires different access codes. Only the research team has access to the RDS. Files on the RDS are kept for five years following the conclusion of the research, as per The University of Manchester Policy for Research Data Storage. Zoom automatically creates a video when recording on the platform. I deleted all videos immediately following interview. All participant data was anonymised. Pseudonyms were chosen or given to all participants. Geographical locations, job titles and names were erased or broadened in efforts to safeguard participant anonymity.

3.16 Chapter summary

I began this chapter by stating my research aims, that is to explore the psychological and educational impact of being an emerging adult living with ME/CFS. Coming from an ontological position of critical realism and an epistemological position of contextualism, I have employed an interpretative phenomenological analysis (IPA) methodology and semi-structured interviewing to explore the experiences of five emerging adults living with

ME/CFS. I noted the methodological changes that occurred partway through this research, namely the orientation towards emerging adulthood and the change from discourse analysis to IPA. This latter change was made because IPA sits in better congruence with my ontological and epistemological positioning. Middle sections of this chapter included a thorough presentation of all stages of the research process, from recruitment to data collection, to transcription and analysis. I discussed the trustworthiness of this study using O'Reilly and Kiyimba's (2015) five guiding principles for designing and evaluating the quality of qualitative work. Lastly, I discussed how this research has been conducted in an ethical way, adhering to standards of informed consent, confidentiality, data protection and safeguarding.

Chapter 4: Analysis

4.1 Chapter outline

This chapter presents the analysis of interview data from five emerging adults regarding their psychological and educational experiences of living with ME/CFS.
This study has two research questions:

1. What is the psychological impact of being an emerging adult living with ME/CFS?
2. What is the educational impact of being an emerging adult living with ME/CFS?

Analysis focused on answering these two questions. Guidance provided by Smith et al. (2022) was instrumental in the analytic process. This chapter begins with individual participant biographies, introducing each individual in turn. I then present a tabulated overview of the analysis, including group experiential themes (GETs) and sub-group experiential themes (sub-GETs). A more in-depth table of analysis, including personal experiential themes (PETs) and participant representation, can be found in appendix M. Additionally, Appendix N includes a flow chart of GETs, sub-GETs and PETs. The bulk of this chapter illustrates and examines, in turn, each GET and sub-GET (where applicable). Verbatim extracts from participant transcripts and person reflexive comments aid illustration.

4.2 Participant biographies

Below is a summary biography for each participant. Participants varied in their preferred term to describe their condition. In this sub-section I have used participant's preferred terms, out of respect, and also to illustrate the numerous ways ME/CFS has and can be described. The main analytic body applies the term ME/CFS to all participants. All

participant names have been pseudonymised and some potentially identifiable information has been altered or omitted to aid anonymity.

4.2.1 Morgan

Morgan, currently in their early twenties, lives in the UK. Morgan has been living with symptoms of ME for seven to eight years. This includes periods of time when they experienced milder symptoms, and periods when they experienced more severe symptoms. Morgan had a relapse of their symptoms after contracting Covid during the pandemic.

Morgan was still in school when their symptoms first started. Morgan spoke about being off school for months at a time and this, coupled with subsequent part-time education, impacted their ability to sustain friendships. Morgan received a diagnosis of ME/CFS four years prior to our meeting and identifies as autistic.

Morgan described their ME as something that limits everything they do. They spoke about the necessity of organising and planning both activity and rest, which they described as "ironically, quite exhausting" (Morgan, p. 3). When we spoke, Morgan was completing their undergraduate degree at a university close to their home. Morgan spoke about the sacrifices they have had to make in pursuit of their degree. They described their degree as something which has taken over their whole life, because they have no energy for anything else.

4.2.2 Samantha

Samantha is in her early twenties and lives in the USA. Samantha's preferred term to describe her condition is chronic fatigue syndrome (CFS). Samantha was diagnosed with CFS in her mid-teens. Samantha described the difficulty of being unable to go to her first-choice college, due to CFS, opting to go to a local one instead.

Samantha often compared her pre-CFS self to her current self. She described feeling like she is not reaching her full potential and spoke about sacrificing one aspect of life for another, because she could no longer have both. She forwent good grades and honours for her health and social life. Samantha later graduated and is now currently working.

The support Samantha receives from family, friends and education professionals is mixed. Samantha's old school friends had difficulty understanding and accommodating her CFS needs but her college friends, who had not seen the 'old' Samantha, were understanding and helpful. Future financial security, her health, and the ability to raise children were all things that worried Samantha. She manages these worries by focusing on joy in the present.

4.2.3 Olivia

Olivia is a healthcare student in her early twenties from the UK. Olivia's preferred term to describe her condition is chronic fatigue syndrome (CFS). At the time of interview, Olivia had a nine-month history of CFS. Her CFS started abruptly and Oliva was able to pinpoint the day of onset and describe it in detail.

Before her CFS, Olivia described herself as "the busiest person you would ever meet" (Olivia, p. 3), She spoke about having very high standards and had come to realise that "I can't do that anymore" (Olivia, p. 18). Achievements now come at a cost. Olivia described a strong work ethic, with perseverance valued by her and her family. Olivia had recently given up work to focus on her studies and health. She also spoke of other sacrifices, for the sake of her health, including social activities, a full-time work placement and university attendance. Olivia had been on a journey with her CFS and she reported now celebrating small achievements, such as one hundred percent university attendance over the previous four weeks.

Olivia often described feeling misunderstood. It took Olivia's family several months to better understand her condition and its limitations. Even Olivia's CFS support group, which was

formed of out-of-work individuals older than her, did not fully understand. For Olivia, what was particularly important was feeling validated and understood.

4.2.4 Peter

Peter is a teenage male living in the UK. He was the youngest participant in this study and stated no preferred term regarding his condition, although he later referred to his condition as 'it' or 'chronic fatigue'. Peter has been living with chronic fatigue since the age of nine and his symptoms have worsened with age. Peter attended school, at least part-time, until he was approximately thirteen years old. For the past several years he has been educated at home. He was continuing his education through home-schooling when we met.

When we spoke about the effects of chronic fatigue Peter reported, "for me, because I was so young, it doesn't really affect me as much as someone who was, like, my age when they got it" (Peter, p. 17). Post-exertional malaise (PEM), a hallmark of chronic fatigue, means Peter's ability to learn and focus deteriorates after around twenty minutes of sustained activity.

Regarding the future, Peter was aware he would need accommodations for any further education or work. He spoke about the usefulness of the internet, both in terms of socialising and keeping up with current events.

4.2.5 James

James is in his early twenties and lives in the USA. James' symptoms began almost two years prior to our meeting, following a Covid-19 infection. Because of this, James preferred to use the term long-Covid to describe his condition.

James had caught Covid while in his first semester of his first year at university. He took a Covid test, which came back positive. Over time, several symptoms remained including fatigue, PEM and heart palpitations. These symptoms continue to be problematic. James described his long-Covid as severe and he reported "I don't really get out much, because not doing much of anything at all can trigger my symptoms to get worse" (James, p. 8).

James spoke about several losses including the loss of time, understanding friends, the ability to exercise, the ability to take part in in-person student events, and the loss of his preferred degree. James spoke about the politicisation of Covid in the US. He also spoke about his struggles with the unknown, in particular not knowing his own body or his own future. James reported difficulty accepting his long-Covid. Long-Covid, for him, had resulted in a sense of dismissal and disconnect, but also a great appreciation for those who do understand and are willing to accommodate him.

4.3 Group experiential themes (GETs) and sub-group experiential themes (sub-GETs)

This study explored the psychological and educational experiences of emerging adults living with ME/CFS using interpretative phenomenological analysis (IPA). IPA involves a close analysis of the experiential claims, concerns and understandings of each participant (Smith et al., 2022). Within this study I engaged in interpretative exploratory noting on each participant's transcribed data. I then developed experiential statements from my exploratory notes, with these experiential statements forming the basis of personal experiential themes (PETs). Examples of exploratory noting, experiential statements and PET development for Samantha can be found in appendices I, J and K. After engaging with this process for all five participants, I generated initial group clusters and thematically developed six group experiential themes (GETs). Two of the six GETs have sub-group experiential themes (sub-GETs), and four exist as standalone GETs with no associated sub-GETs. Table 3, below, presents an overview of these group themes and sub themes. In line with IPA's

idiographic commitment, the focus of analysis has been grounded within participants' experiences and their unique nuanced process of sense making, whilst also acknowledging my own.

Table 3

Overview of group experiential themes (GETs) and sub-group experiential themes (sub-GETs)

	Group experiential themes (GETs)	**Sub-group experiential themes (sub-GETs)**
1	"*They're not seeing all of me*": Others don't understand.	"*Invisible disabilities*": Feeling unseen, forgotten and dismissed.
		"*They didn't understand*": Relationships become complicated, fragile and lost.
		"*I wanted them to know*": Educating others in the face of disbelief and misunderstanding.
2	"*It literally does disable you*": Lacking control.	"*I can't do that anymore*": Lacking control over life and body.
		"*Your future's in the air*": Uncertain, limited future.
3	"*You'll be fine*": Pushing beyond energy capacity because of pressure, frustration or denial.	N/A
4	"*Not good enough*": Feeling less-than and not enough.	N/A
5	"*Giving that up is really difficult*": Grief and longing for lost identities.	N/A
6	"*It's very mixed*": Inconsistent educational support.	N/A

Below is a theme-by-theme analysis of each GET and sub-GET. Illustrative quotes are included to amplify meaning. At times I reflect on my own emotions and processes pertinent to the data.

4.3 Group Experiential Theme (GET) 1 – "They're not seeing all of me": Others don't understand

Table 4

Sub-GETs and participant representation for GET 1: "They're not seeing all of me": Others don't understand

Group Experiential Theme (GET) 1 – "T*hey're not seeing all of me*": Others don't understand					
Sub-GET	**Morgan**	**Samantha**	**Olivia**	**Peter**	**James**
"*Invisible disabilities*": Feeling unseen, forgotten and dismissed.	☒	☐	☒	☒	☒
"*They didn't understand'*: Relationships become complicated, fragile and lost.	☒	☒	☒	☐	☒
"*I wanted them to know*": Educating others in the face of disbelief and misunderstanding.	☒	☒	☒	☐	☒

All participants spoke about not feeling understood by family, friends, professionals and even themselves. Phrases such as "*they won't understand*" (Morgan, p. 17), "*he never really understands*" (Samantha, p. 17), "*people don't understand*" (Olivia, p. 5), "*they've not been as understood*" (Peter, p. 34), and, "*I didn't understand*" (James, p. 17) were present across all transcripts. Lack of understanding was at the heart of many psychological and educational issues. It acted like a thread, connecting one theme to another, one participant to another. In this respect, feeling not understood was like a global group experiential theme (GET), underpinning every other group and sub-group experiential theme (sub-GET). "*They're not seeing all of me*": Others don't understand' is presented as the first GET. Three sub-GETs emerge from this. I shall elaborate on each below.

4.3.1 Sub-GET 1 – "Invisible disabilities": Feeling unseen, forgotten and dismissed.

Almost all individuals who took part in this study spoke about feeling unseen, forgotten or dismissed. These feeling arose from not being listening to or understood. During interviews, when participants spoke about these issues, I became conscious of my professional responsibility to listen and understand. Olivia, who had a nine-month history of ME/CFS, spoke about the lack of understanding displayed by her housemates. Olivia's housemates seemed unable to grasp the seriousness of a PEM flare, leaving Olivia alone in a time of need:

> *All of my housemates did not understand, they didn't get it, they didn't think it was real, and then, I think it was the first day back at university… I had a major flare up, um, when I got home. I was. I was in bed, I could not move, I couldn't open my eyes, I couldn't even lift a finger, I couldn't talk, all I could do was breathe. That was it. And, I was in and out of consciousness for four hours, and nobody was there to help me. I was, I was on my own* (Olivia, p. 5).

Olivia explains that she was suffering and immobile. Her housemates "*didn't think to come and check*" (p. 6). Her condition went dismissed, her needs forgotten and her distress unseen. Olivia's words "*they didn't get it, they didn't think it was real*" indicates scepticism and trivialisation towards Olivia's ME/CFS, something that was found across all participants' accounts. This ultimately results in a powerful sense of loneliness, "*I was, I was on my own*". This felt loneliness is accentuated by Olivia's reported tendency to hide her condition from everyone around her:

> *People don't understand until they've seen it, like I hide my condition, I do, I hide it from my own family, I hide it from everyone around me, I hide it from my partner. The only person that knows the true extent of my condition is me* (Olivia, p. 5).

It seems that no one truly sees Olivia's condition, so no one can truly understand. The only person who fully sees and understands it is herself. Hiding can be indicative of shame, and shame is maintained by negative judgement, from others and ourselves. Perhaps for Olivia, ME/CFS is something shameful, a flaw within herself, so she hides it. Hiding, perhaps, maintains further misunderstanding and a cycle manifests. It should be noted that shame is a familiar emotion to myself. It is possible that here I am projecting my experience of shame onto Olivia, therefore erroneously attributing the emotion to her.

Morgan, Peter and James echo these feelings of invisibility, but their sense of invisibility was noted more frequently in educational settings. Morgan said:

> *But I kind of just kept feeling like they're not seeing all of me. They're seeing, like, we need to get this person back into school because that's what people like… that's what a quote unquote, normal teenager would be doing with their day (Morgan, p. 33).*

Morgan describes a period when they were younger, unwell and off school. At the time, several professionals seemed eager to get Morgan back into school. Whilst Morgan could see the value of this, they also just "*wanted to be with my cadet friends*" which "*felt more important to me*" (p. 32). With a power differential between Morgan and the education

professionals, and a limited amount of energy for self-advocacy, Morgan's preferences went unseen and/or dismissed.

Peter spoke about the lack of accommodation afforded to people with ME/CFS. He compares individuals with ME/CFS to individuals with learning difficulties, stating that learning difficulties are more common, better understood, and better accommodated for:

> *I think it should be more like, you know… learning difficulties… they, they just accommodate you… because I think like, learning difficulties are probably more, a lot more common (*Peter, pp. 30-31).

For Peter, because learning difficulties are more common, they are better seen and accommodated, in comparison to ME/CFS. During interview and analysis I was reminded of my perception of my brother's experience of a specific learning difficulty, dyslexia. His dyslexia was diagnosed in childhood and the support he received afforded him greater educational opportunity. This comparison resulted in me feeling great compassion and also sadness for Peter. James echoes this lack of accommodation within the education system when he says: "*When it comes to the school itself, they provide no support whatsoever to to people with, er invisible disabilities, you know, mainly like chronic fatigue syndrome* (James, pp. 7-8). James' use of the term "*invisible disabilities*" highlights his sense of being unseen and forgotten. ME/CFS generally has no visible markers, and because of this, James' support needs go unnoticed. His use of the third person and hesitancy before speaking the phrase "*invisible disabilities*" suggests an uncertainty, discomfort or reluctance using or identifying with the term.

When participants did feel seen, understood and supported, they considered themselves lucky. Olivia reported, "*I was very lucky with my experience with my GP, that she, believed me*" (p. 29). Having met so much scepticism and dismissal in the past, Olivia explained that she felt fortunate just to have her health condition believed by a professional.

4.3.2 Sub-GET 2 – "They didn't understand": Relationships become complicated, fragile and lost.

Four of the five participants who took part in this study spoke about fragile relationships, complicated family dynamics and lost friendships. Some relationships made it through a period of flux to arrive at a steady state of respectful understanding. Others were severed or lost completely.

When discussing the period immediately following the onset of their ME/CFS symptoms, Morgan spoke about their school friendships:

> *When I was first very poorly, I didn't go to school for like four or five months… And then I was doing school part time, so then it was like when I wasn't there, they didn't really care, when I was there, they weren't, didn't really care either* (Morgan, p. 20).

Morgan learnt that their presence at school did not matter, whether they were there or not. This evokes a sense of sadness, since Morgan felt both unnoticed and uncared for. Morgan's friendships were lost not of their own volition, but due to the restricting and excluding condition that would later be diagnosed as ME/CFS.

Similar to Morgan, Samantha's ME/CFS also affected the friendships she had around the time of onset and diagnosis. Regarding her friends, Samantha said:

> *They didn't understand why couldn't I, just get like a pill or something, that would make me back to who I was or, you know, and I think I also drew away a little bit because of that. But I know that those relationships were always, that was kind of a severed relationship after that, because I always got frustrated that they didn't understand* (Samantha, p. 14).

Samantha's friends struggled to understand and adjust to her new limitations. Being teenagers themselves, Samantha described how they seemed not to understand why there

was no quick fix. This suggests they held the narrative of ME/CFS as a defect to be rectified as soon as possible. When no immediate remedy became apparent, and Samantha's friends continued to lack understanding. Samantha then "*drew away*", motivated by frustration, leaving relationships "*severed"*. Samantha later made new "*very understanding*" (p. 15) friends at college. For both Morgan and Samantha, the onset of ME/CFS meant school friendships became difficult, if not impossible. However, whereas Samantha chose to draw away from her friends, Morgan's friendships were lost without her choosing, leaving her feeling uncared for.

James also spoke about the twin concepts of care and understanding. He had noticed that with the onset of his ME/CFS "*some friends I've grown closer to*", and others "*I've since, you know, distanced myself from*" (p. 22). For James, ME/CFS helped distinguish between people who care and understand and those who "*are less supportive because they don't really understand*" (p. 22). In conclusion James said, "*I feel like it's helped weed out, who, who really cares about me and who doesn't*" (p. 22). Understanding precedes care and support. For Morgan, Samantha and James, persistent misunderstanding seems associated with lost, severed, and distanced friendships.

Three participants spoke about the impact of ME/CFS on family relationships. For all three individuals, family dynamics became fragile and complicated as one or more members of their immediate family didn't understand.

> *My relationship with my family was difficult… I got my perfectionism and my busy nonstop from my family… A rest day in my family does not exist. It's that simple. It doesn't exist, and it's always been pushing to do more. And I think that… served me well… up until I got chronic fatigue syndrome because they didn't understand that if I hover the house that day, I couldn't go on a dog walk with them, or I couldn't go and do the family food shop* (Olivia, p. 25).

Olivia's family were "*always… pushing to do more*". They knew the pre-ME/CFS "*perfectionism*" version of Olivia; the woman who was "*busy nonstop".* They could not understand her new reduced energy levels. Olivia's ME/CFS seemed to challenge the family

status quo. Dynamics improved after Olivia's family took opportunity to "*try and understand me and my condition… because what we were doing wasn't working*" (p. 26). Coming from a family where productivity is highly regarded and dynamics are also fragile, I felt great understanding and empathy for Olivia during these moments of the interview and analysis.

Morgan also spoke about the struggles of their family to understand their ME/CFS, and the consequential limitations. In contrast to Olivia, Morgan's family didn't appear to make any significant efforts to better understand:

> *My dad's side of the family just don't really get it at all. They're very much in the camp of, oh, well, if you tried a bit harder, I'm sure it would be fine. But they don't get to see the massive PM crashes that come from the half an hour that I might spend with them* (Morgan, p. 24).

Half of Morgan's family not only seem to misunderstand ME/CFS, but they appear to be proponents of a false and dangerous narrative. If only Morgan tried harder, they would be ok. Because Morgan's dad's side of the family don't see their crashes, they come across as lacking understanding. This is similar to Olivia's experience outlined in the previous sub-GET, not seeing is correlated with not understanding.

For Samantha, family appears to be important. In contrast to some of her school friends, Samantha spoke about having a small close family who understand and accommodate her ME/CFS.

> *Any time we'll do a family thing… they often always ask me… do you think you can do this?... Are you okay? Do we need to go home? Do you think? … kind of like really always checking in with me to see if I can do it* (Samantha, p. 16).

But when Samantha's brother-in-law was welcomed into the family, Like Olivia, another status quo was questioned and disrupted, creating tension.

> *I have one sister, so she's grown up with me. We're very close. And she married, recently, and erm my brother-in-law really struggles with it… he kind of thought, you know, like, um, everyone's catering to you, everyone's only caring about you, no one is caring about your sister… so, I think he never really understands. And I think he's still learning* (Samantha, pp. 16-17).

With so much scepticism, trivialisation and dismissal, family understanding seems incredibly important. Supportive families provide compassion and validation to a condition shrouded in misunderstanding. Olivia sums this up when she says, *"feeling validated is, probably the best feeling, for someone with chronic fatigue syndrome"* (p .27).

4.3.3 Sub-GET 3 – "I wanted them to know": Educating others in the face of disbelief and misunderstanding.

The five participants who took part in this study all spoke about a public lack of understanding about ME/CFS. This, as detailed above, was noted as frustrating and isolating. Four participants spoke about their efforts to educate others in the face of such disbelief and misunderstanding. James spoke about a need to make others understand. For him, educating was an exhausting necessity:

> *I have to go out of my way to talk to people about it and make people understand. And… one it's exhausting to always, you know, explain this to every new person I meet and two it's just, well, it's frustrating to me also because… I don't fully understand the disease myself* (James, p. 12).

Despite exhaustion, frustration and his own lack of full understanding, James persists in the education of others. The recompense being validation and compassion: "*if I say to someone long-Covid is a disability, it helps them understand that people with long-Covid, yeah, they have limitations, they need to work around their condition*" (James, pp. 31-32).

Like James, Olivia described a need to educate others. Olivia, who had previously experienced dismissal of her condition, needed others to understand that her ME/CFS was real: "f*or everyone, I just need them to know that I'm not making this up. It is real. And, I have to live with this every single day*" (Olivia, p. 36). Olivia previously spoke about hiding her ME/CFS and consequentially it went unseen. Here Olivia speaks about the essential need for others to, if not see, then understand her experience of ME/CFS. Samantha also spoke about making a concerted effort to "*make sure*" others "*really understood*" (p. 12). Regarding her professors at college, Samantha said:

> *I really tried to make sure that they knew and really understood, like what chronic fatigue was, why I would not be, if I was missing class, like because it was, I had a crash or something. I wanted them to know, like, it wasn't like, no, I'm not just like tired* (Samantha, p 12).

In a reversal of roles and displacement of power, the onus was on Samantha to educate her professors regarding ME/CFS. For Samantha, this was surprisingly successful. She reported: "*I never had a professor who gave me, you know, was mad at me for anything. And that was surprisingly yeah, I mean, it was pretty good in that sense*" (p. 12). These words suggest Samantha's baseline for successful understanding is never being at the receiving end of an angry professor.

In an echo of James' experience, Morgan described the exhausting effects of relentlessly educating university peers about their wheelchair:

> *Sometimes I will use a wheelchair, just to conserve energy. And it's like the whole, whoa, what happened to you? And I'm like, well, it's the same me that you saw yesterday, but just pacing themselves a bit more for later on. And they're like, well, ME's just the one where you get a bit tired. Why are you in a wheelchair for? And it just gets exhausting constantly having to like advocate* (Morgan, p. 16).

ME/CFS can be considered to be an invisible disabling impairment in the sense that it has no physical markers. Morgan was only identifiable as disabled when they used a mobility aid.

Others did not seem to understand that Morgan's ME/CFS is a fluctuating condition that existed before they sat in a wheelchair, and in fact the wheelchair was a sign of beneficial pacing, rather than debilitating decline. Because of this Morgan was required to spend some of her limited energy educating others at university, rather than herself.

4.4 Group Experiential Theme (GET) 2 – "It literally does disable you": Lacking control

Table 5

Sub-GETs and participant representation for GET 2: "It literally does disable you": Lacking control

Group Experiential Theme (GET) 2 - "It literally does disable you": Lacking control					
Sub-GET	**Morgan**	**Samantha**	**Olivia**	**Peter**	**James**
"*I can't do that anymore*": Lacking control over life and body.	☒	☒	☒	☒	☒
"*Your future's in the air*": uncertain, limited future.	☒	☒	☒	☐	☒

In this study, all participants spoke about a reduced sense of control and authority, which extended to their lives, bodies and futures. Other people, systems and ME/CFS itself held the reins, leaving participants feeling sad, frustrated and overwhelmed. The second GET in this analysis details this. This GET has two sub-GETs, which are elaborated upon below.

4.4.1 Sub-GET 1: "I can't do that anymore": Lacking control over body and life.

All participants spoke about the way ME/CFS has limited their lives and bodies, and most spoke about the way ME/CFS has limited their future. In discussing the controlling impact of ME/CFS on their lives, two participants, Olivia and Samantha, spoke about the contrast between their pre-ME/CFS existence and the present. Prior to the onset of her ME/CFS, nine months previously, Olivia was able to go out, socialise and have a good time:

> *But I love, used to love going out for a meal or going out for a couple of drinks at the pub, you know? And I can't do that anymore. I can't.* (Olivia, p. 18).

Olivia's mixture of the present and past tense, "*but I love, used to love*" indicates an ongoing process of adjustment to the abrupt unwanted loss of something she enjoyed. Presently, for Olivia, socialising involves careful planning and restrictions, "*I need to make sure I rest up the day before, and I rest up the day after*" (p. 18). Going out now seems to involve making an active choice and sacrificing adjoining days. Olivia concluded "*I have too many deadlines to… balance the workload with the things that I enjoy*" (p. 18). Academic work was prioritised and going out was forwent as ME/CFS took control of Olivia's social life.

Samantha's "*old me*" would "*stay up super late and try to finish everything*" (p. 10) but her present life with ME/CFS meant, contrary to Olivia, she "*made a choice to socialise*" (pp. 9-10). Again, life involves planning, restrictions and sacrifice. The sacrifice for Samantha was handing in work "*not fully completed and I'll take the grade*" (p. 10). ME/CFS's power over both Olivia and Samantha meant they were unable to both socialise and get good grades. As Olivia' managed the loss of a social life, Samantha managed the loss of good grades, reconciling with herself, "*you know, it's okay if I don't get amazing grades, because I'm spending energy with people that I love*" (p. 10).

A third participant, Morgan, also spoke about the demanding nature of ME/CFS on their life and studies:

> *My degree has been my whole life for the past two years, because I have no energy for anything else. So to do my degree, which isn't, it's like pretty much a part time degree, to be able to do that, I do nothing else* (Morgan, p. 14).

All of Morgan's restricted energy is spent on their "*pretty much a part time degree*". Their life is subsumed by their degree and this leaves no room for anything else. Morgan also spoke about the *"predictably unpredictable"* (p. 29) demanding nature of ME/CFS. When their symptoms flare, they have no choice but to cancel plans:

> *If like you wake up one day and you're just feeling completely awful, then everything in that day goes out the window for the sake of trying to not feel this awful for as long* (Morgan, p. 5).

ME/CFS seems to demand Morgan's time and attention by making them feel "*completely awful*". In appeasing the condition, with the hope of feeling not so awful tomorrow, their freedom is sacrificed. This limiting nature of ME/CFS is echoed in Peter when he says:

> *I can go out for, like, ten minutes if I'm, if it's a good day, but that's not really much to go anywhere. Enough to go anywhere* (Peter, p. 11).

The nature and severity of Peter's ME/CFS means he can go outside for only ten minutes, and that's on a good day. His words "*that's not really much to go anywhere. Enough to go anywhere*" indicate isolation and restriction. There's not much that can be done in ten minutes. Similar to Olivia and Samantha, Peter verbalises time and the passage of time, which emphasises the boundaries and increasing power of his condition:

> *I got it when I was nine, so for like a few years after that, I would still be able to go out for the day and do stuff… but then… I could do it less and less, and it progressed* (Peter, p. 11).

Peter's words, "I could do it less and less, and it progressed" evoke a sense of sadness regarding his diminishing abilities.

ME/CFS also took control of participant's bodies, as well as their lives. In describing her PEM, Olivia details how she lost control of her body at the start of a family holiday:

> *I, lost control of my body, I couldn't hold my head up. I couldn't do anything. I. It was it was really difficult, and it was very much just trying to get out of the airport... And I couldn't walk on my own for two weeks, anywhere* (Olivia, pp. 21-22).

Olivia's body shut down and she was trapped in a public place, focused on "*just trying to get out*". Ruminating on this experience Olivia later reported, "*I lost my independence entirely*" (p. 22). ME/CFS took control of her body for two weeks, at a time when, on holiday, she likely wanted to relax and have fun.

In concluding this sub-GET, James' words describe how ME/CFS affects not only his life but also his interactions with medical professionals:

> *I feel like doctors… shouldn't get frustrated when patients have these questions, especially when the condition, you know, is determining their future, and, it it derails their life, right… I don't think they should make patients feel like, everything's under control when it isn't* (James, p. 37).

The hypocrisy and impatience of medical professional's grates James. The falsity of their words suggests a felt absence of control, over both James' present life and his future.

4.4.2 Sub-GET 2 – "Your future's in the air": lacking control over future.

Felt lack of control over the future is the second and last sub-GET within the overarching group experiential theme of "It literally does disable you": Lacking control. All but one participant spoke about uncertainty and worry regarding their future. Continuing the focus on James, he describes the frightening consequence of living with such an uncertain condition.

> *It's extremely scary, and it should be scary because people need to know that this is something that's not only real, but debilitating. And it's something you really need to actively try to avoid, because as of now, if you get it, you're kind of screwed, there's nothing that you can do. Your health is completely up in the air, your future's in the air, and no amount of money or, um, resources can really help you with this* (James, pp. 40-41).

James' health and future seem completely out of his control. Attempts to gain leverage, by spending money and resources, result in hopelessness, fear and a degree of anger. This realisation comes with a warning to others: avoid this debilitating condition at all costs.

Future uncertainty and worry go hand in hand. For Olivia, who values work and prioritises her vocational degree, worry seems centred on her workplace abilities and feeds into anticipated attitudes of any future employer.

> *I don't know how long I'm going to be able to be a [job title]… I think I'm going to have to work part time. I don't know whether I'm going [to]… not be able to work in specific areas because it's going to be too physically demanding for me. I don't know if I'm going to be discriminated against by my employer* (Olivia, p. 35).

Because Olivia lacks control over her ME/CFS, she also lacks control over the future. She doesn't know how often or how long she will be able to work. Workplace discrimination is a concern. She will need an empathic, flexible employer in order to manage both workload and ME/CFS symptoms.

Two participants spoke about their future wish to have children, but also concerns regarding their ability to raise them. Samantha said:

> *If I want to have a kid someday… I don't know how I could do that. How could I have a kid if I can't even, you know, make it through a lot of the days that I'm living out? Like that would be unfair to like, even my child, you know? And finding someone who, would want to have that co-parenting relationship where, you know, I would be, not able to do a lot. And, you know, is that even possible?* (Samantha, p. 24).

Children can require energy, but with ME/CFS energy is in short supply. Along with worries about the ability to have children, Samantha questions the ethicality of having children. She wonders if having children is fair, both on her envisioned children and envisioned partner. Samantha feels she could not equally contribute towards raising and supporting her

children, leaving her questioning her future worth as a mother and partner: "*who, would want to have that co-parenting relationship*"? As someone who has also considered the ethicality of having children, of bringing children into a world where climate change

Morgan also speaks about their desire to have children, but this is quickly followed by worry and doubt: "*My sister… had a baby. I'd quite like to have a baby when I'm older, but I spend half an hour with [the baby] and I'm literally dead on my feet"* (Morgan, p. 28). Half an hour with their sister's baby is enough to make Morgan feel "*dead*". This strong choice of word enhances Morgan's sense of complete exhaustion. Morgan is then led into a cycle of uncertainty, fear and avoidance regarding the future: "*It's like rethinking, but also just not thinking about it at all. It's too, sometimes too tricky to be like, well actually I've got to reassess my entire life"* (Morgan, p. 28).

Morgan oscillates between considering and reconsidering their future, with ME/CFS in mind, and avoidance of the same. For James, Olivia, Samantha and Morgan, the future is uncertain, worrying and limited by their ME/CFS symptoms.

In contrast to these four participants, Peter seems to adopt a different conception of the future. He notes that because he experienced his ME/CFS from such a young age, he had no chance to conceptualise a realistic future without ME/CFS: "*Since I was pretty young when I got it… all I wanted to do in my future was be like an astronaut or something*". (Peter, p. 20). The sense uncertainty and worry that was present in James', Olivia's, Samantha's and Morgan's interviews, is lacking in Peter's. Instead, Peter talks about the future in a practical, sensible, almost stoic way.

> *Any job I would get would probably be like, part time if I'd have to get a bit better first… and with education… I'd just have to do it in more, more slowly, over like, if I wanted to do a specific subject I'd, um, I'd have to do that, and that one, one at a time* (Peter, p. 21).

Peter has had longer than any other participant to adapt to his condition. This, coupled with the fact that he was just nine when his ME/CFS began, means fear seems lacking, replaced by considered realism, tolerance and acceptance.

4.5 Group Experiential Theme (GET) 3 – "You'll be fine": Pushing beyond energy capacity because of pressure, frustration or denial.

Table 6

Participant representation for GET 3: "You'll be fine": Pushing beyond energy capacity because of pressure, frustration or denial.

	Morgan	Samantha	Olivia	Peter	James
GET 3 – "*You'll be fine*": Pushing beyond energy capacity because of pressure, frustration or denial.	☐	☒	☒	☐	☒

Participants in this study could be divided into two groups, those who had experienced ME/CFS since childhood (Morgan and Peter), and those who developed it in their late teenage years or early twenties (Samantha, Olivia and James). All individuals in the latter group spoke about a detrimental tendency to push beyond their energy capacity, often due to felt pressure, frustration or denial. This was more pronounced towards the beginning of their ME/CFS journey and always resulted in a worsening of symptoms. This worsening has many names including PEM, a flare, a crash, sickness, or a relapse. Preferred terminology varied from participant to participant with some participants tending to describe the worsening of symptoms rather than ascribe a name.

> *So, towards the beginning of my, you know, bout with long Covid, I, um, I tried to still go on runs, right. And I thought to myself that I could exercise my way out of my condition, and, yeah, it made me much, much worse* (James, p. 33).

Here James speaks about exercise, a large part of his identity and self-care. Reluctant to let go of this, James continued to exercise in the presence of ME/CFS, hoping his could escape it by literally running his way out. This misbelief only resulted in James feeling "*much, much worse*".

Both James and Samantha use adverbs to emphasise the effects of over-exertion. For Samantha, feeling "so sick" was the result of peer pressure and a discomfort asserting herself:

> *They, weren't ever mean about it, but it was just, you know, like, why not? What? Like, why can't you walk? Like, can't you just walk the three miles down the beach? And I was like, that's really far, no (laughs). It's, you know, and they would be like, why? It's not that far. You'll be fine. And, you know, then I was so sick* (Samantha, p. 15).

It was these school friends who didn't understand why Samantha couldn't be the person she was, "*everyone didn't understand, because they had known me as being this really energetic, outgoing person who was able to do everything*" (p. 14). Their lack of understanding meant empathic consideration was in short supply and Samantha relented to the wants and expectations of others. Here, Samantha's overstressed language ("*everyone didn't understand",* "*really energetic*", "*able to do everything"*) emphasises her felt sense of being misunderstood, as well as the acute loss of energy and abilities.

Friends weren't the only individuals who seemed to pressure Samantha into pushing beyond her energy capacity. Staff at college appeared to contribute also: "*if they're like, hey, could you bring like a couple boxes of some equipment or something, you know, like I would do it. But it was also like, that was really hard*" (p. 13). Hierarchical systems of power present at college meant Samantha did not feel comfortable challenging those with greater role

power. Samantha again conceded to the expectations of others who did not fully understand.

Olivia, on the other hand, pushed beyond her energy capacity out of frustration. A self-described “major perfectionist” (p. 9) who “did not stop” (p. 3), Olivia described immense difficulty adapting to a slower pace of life with ME/CFS:

> *And I have, almost had to force myself to press pause, and I don't do that very well. That is, that is part of my problem. I go in a vicious cycle where I am fed up with doing nothing, and I'm fed up of feeling like I'm going nowhere. So I will do everything and then I'll flare up again* (Olivia, p. 4).

Professionals often advise the energy management technique, pacing, to individuals with ME/CFS. Pacing aims to balance activity with rest, to avoid over-exertion and flare-ups. For Olivia, pacing presents a significant challenge to her “*busy nonstop*” (p. 25) default. Resting is almost synonymous with “doing nothing”. Feeling frustrated, unproductive and immobile, Olivia will “do everything” and then get caught in an unhelpful cycle of over-exertion, flaring and frustration.

It wasn’t just frustration that caused Olivia to push beyond her energy capacity. Similar to Samantha, Olivia felt a pressure from others. In describing the decision to attend a placement interview, Olivia said:

I remember my dad saying to me, just do it. Just fake it, through the whole interview. You don't need to tell them. You've just got to last an hour… so I did that. And I never told them. I never disclosed my chronic fatigue syndrome (Olivia, p. 20).

Olivia was encouraged, by her dad, to hide her ME/CFS from potential employers and push on through. The projected values of hard work and success seemed to supersede honesty and self-care. In hiding her condition, it arguably becomes something secretive, shameful and an inconvenient defect. Olivia later attended the two-week placement, supervisors unaware of her ME/CFS. She consequentially experienced a severe flare of symptoms

following the end of the placement. Again, during this point in the interview and analysis I felt a wave of compassion for Olivia.

4.6 Group Experiential Theme (GET) 4 – "Not good enough": Feeling less-than and not enough.

Table 7

Participant representation for GET 4: "Not good enough": Feeling less-than and not enough.

	Morgan	Samantha	Olivia	Peter	James
GET 4 – "*Not good enough*": Feeling less-than and not enough.	☐	☒	☒	☒	☐

Three of the five participants spoke about feeling less-than, less worthy and not enough. Participants described themselves as "*terrible*" (Peter, p. 7), "*stupid*" (Samantha, p. 11) and a "*fraud*" (Olivia, p. 3). In describing themselves this way, participants either compared themselves to more-able others, or they compared their current "*not well enough*" (Olivia, p. 3) selves to their pre-ME/CFS better selves. I was often filled with sadness while I listened, transcribed, analysed, and wrote these portions of interview. It was not easy learning how and why such thoughtful, articulate, brave individuals could also be so self-critical.

Peter, the youngest participant in the study, had experienced ME/CFS since childhood. He described annoyance when tiredness overwhelms, and he can no longer be "*the best*" but only "*a quarter as good*" instead.

> *There's a point where you can't be the best that you can be when you're tired. Because even if you're, even if somebody who's the best in the world at something, as soon as they get tired, they're like a quarter as good* (Peter, p. 6).

Here Peter compares himself to someone who is "*the best in the world*". Later in our interview, when talking about people without ME/CFS, Peter says, "*I want to get better [at hobbies] and be as good as them*". But, in contrast to these others, Peter's tolerance for concentration is around twenty minutes, then brain fog sets in: "*It's annoying when I'm getting tired, because you can't really enjoy doing it if you're just terrible at it, when you know you're a lot better than that*" (Peter, p. 7). Peter negatively appraises and devalues himself due to his ME/CFS symptom of brain fog, believing himself to be less than the more-able 'others', and also not as good as his previous self of twenty minutes earlier. Yet, at the same time, he strives to be one of these better others, hoping and trying to, one day, be "*as good as them*".

Like Peter, Samantha also negatively appraises her current self compared to her previous self. In speaking about her pre-ME/CFS pride in academic achievement and hard work, Samantha reported: "*I was like an A student*" (Samantha, p. 10). Samantha was an "*A student*" because of the effort she put into her work: "*I worked as hard as I could at anything*" (p. 4). However, this was all before ME/CFS. With ME/CFS Samantha felt lacking because she could not achieve the A grades, "*to me, like getting a C or a B wasn't, you know*…" (p. 10). Samantha trails off, her self-criticism for currently getting Bs and Cs unsaid but not unheard. Later she speaks about how underachievement made her feel: "*it made me feel stupid because I was like, man, I should be able to be reading all this. I know I can, but I can't. Um. I felt like it made me look like I wasn't as smart as I was"* (Samantha, p. 11). Samantha, who valued big achievement and hard work, could neither achieve big nor work hard. As a result, she felt stupid and not as smart as her previous self. These feelings were ignited when Samantha graduated:

> *Even graduating, I didn't make honours. And if, when we graduate, if you make honours, you get these tassels that you know, you wear with your, and everyone, you*

> *know, you get them. And some people have like, you know a lot, and like all my friends had the tassels, but I didn't* (Samantha, p. 11).

Graduation tassels are a symbol of success. The more tassels a graduand wears, the more distinguished their achievements. Samantha's friends all had the honours tassels, some people had lots, but Samantha had none. Samantha compares herself to her more achieving friends, feeling not clever enough. Her lack of tassels an outward indicator of these inner feelings.

Olivia, on the other hand, felt not enough because she was not productive enough, due to not being well enough. Like Samantha, Olivia illustrates this by comparing her pre ME/CFS busy self to her current not-enough self.

> *I was the busiest person you would ever meet, before, before this. Like, I did not stop. Rest was not in my dictionary… I would manage numerous jobs… I am a student now… and I have actually had to give up work entirely, because I'm not well enough to work, and do the course… I'm not well enough and it's it's heart-breaking because I've dreamed of being a [job title] for years, and this is a big obstacle* (Olivia, p. 3).

Reminiscing and overstressing previous accomplishments sustains a sense of not being enough. ME/CFS took away Olivia's ability to work and this is heart-breaking for her. Being not well and not productive enough is an obstacle in Olivia's way, impeding her path towards occupational, and perhaps other forms of success.

All three participants who contributed towards this group experiential theme spoke about feeling in the 'not enough' minority, compared to the 'enough' majority. People without ME/CFS were better, smarter, busier, more productive, and able to work. Olivia sums this up when she says:

> *We will never be normal, but it's a level of normal that you can hide. Chronic fatigue syndrome, and myself included, I do feel like a fraud sometimes… so you go and do*

more and then you flare up. You realise, oh, I'm not a fraud. I am still ill. (Olivia, p. 28).

Olivia seems to be caught in a no-win situation. She feels not normal and feels she will never be normal. But she hides her not-normalness, impressing to others a sense of normality, which results in thoughts of fraudulence. Fraudulence motivates Olivia to do more and try harder. But this ultimately only serves to increase Olivia's ME/CFS symptoms, emphasising the fact that she continues to be less than and not enough.

Olivia's use of the plural 'we' is noteworthy. This quote is taken from a discussion regarding ME/CFS support groups. Despite others in the support group being older than her, Olivia's 'we' suggestions a sense of solidarity. In being othered from the able-bodied majority, Olivia finds solidarity with others living with ME/CFS. If she is to be 'not normal' she wishes to be part of the 'not normal' collective. This elicits a sense of Olivia searching for a new group identity, one which incorporates and better accepts her ME/CFS.

4.7 Group Experiential Theme (GET) 5 – "Giving that up is really difficult": Grief and longing for lost identities.

Table 8

Participant representation for GET 5: "giving that up is really difficult": Grief and longing for lost identities.

	Morgan	Samantha	Olivia	Peter	James
GET 5 – "*Giving that up is really difficult*": Grief and longing for lost identities.	☒	☒	☒	☐	☒

All participants except one described grief for lost hobbies, abilities and opportunities. When describing this loss, participants seemed to display a range of emotions, from anger and frustration to sadness and hopelessness. During interviews I found myself also feeling the same or a similar emotion. For example, I felt sadness when speaking with James about his loss and frustration when speaking to Amber about theirs. Peter, the only participant who did not indicate grief, had had ME/CFS since childhood and did not feel so acutely the loss of pre-ME/CFS identities. His ME/CFS seemed integrated into his sense of self: "*for me, because I was so young, it didn't really affect me as much as someone who was, like my age [now] when they got it*" (p. 18).

James, by contrast, spoke with sadness about the difficulties accepting the loss of a previously enjoyed sport, hobby and identity.

> *I was a powerlifter, right. So I lifted weights…and so losing the ability to do that, was the, the prospect of me losing the ability to do that was, something I wasn't ready to accept for a long time... finally stopping exercising was, me accepting the fact that this is something I'm not going to be able to do for a while, and it was tough, it was extremely, um, depressing* (James, pp. 32-33).

James seems to go through a journey of grief, from denial ("*I wasn't ready to accept"*), to depression ("*it was tough*"), to acceptance ("*this is something I'm not going to be able to do for a while*"). The very nature of powerlifting sits in direct contrast with ME/CFS. Power is associated with strength, energy and control. ME/CFS, by definition, is experienced as chronic exhaustion and reduced energy. For James, losing the identity of being "*a powerlifter*" and becoming someone who gets "*tired from, you know, doing not much of anything*" (p. 30) is a hard-hitting ordeal.

Morgan also spoke about reluctantly giving up a large part of their identity. Anger and sadness saturate their words when they say:

> *I was a… cadet who was going into the [armed forces], I'm never going to be able to do that anymore because chronic fatigue/ME is on the list of things that you can't go into the [armed forces] with* (Morgan, p. 9).

For Morgan, ME/CFS has not just taken away their cadet identity but also their desired career. Their words "never" and "can't" suggest an irrevocability. Morgan's identity and career has been forever removed. They have no choice but to mourn the loss. But for Morgan this loss can be hard to bear:

> *I played the clarinet before I was a cadet, but then I played the clarinet in a military band, and now I don't want to play the clarinet because it makes me think of that. And that's something I'm not doing, like, anymore* (Morgan, p. 9).

Morgan played the clarinet in a military band. The band provided a purpose, community, friends and enjoyment. Now, with ME/CFS Morgan has not only lost their position within the band but also that purpose, community and enjoyment. Playing the clarinet now triggers a sense of loss and frustration, and the associated feelings are too much to bear. Avoidance of the clarinet seems the only answer to managing the ensuing emotional pain.

Olivia also spoke about giving up part of her identity: *"work has been one of the biggest parts of my identity since I was fourteen. And giving that up is really difficult"* (Olivia, p. 14). Giving up such a valued part of her identity is incredibly tough.

All four participants in this GET spoke about losing, giving up or forever leaving large parts of themselves. For James it was exercise, for Morgan it was cadets, the clarinet and a career, for Olivia it was work. None of the participants spoke anything that had replaced these absent pieces of identity. An empty space remained with only grief in its place.

Samantha's loss was slightly different, not something discernible, but rather a loss of an intended future. She explained:

> *Before I was sick… I just knew that if I worked as hard as I could at anything… I knew that I could achieve what I wanted. And so, I was, I did really well in school… but I was diagnosed [in mid-teens], which was right before we were all kind of leaving for college* (Samantha, p. 5).

The pre-ME/CFS Samantha knew that if she worked hard, she could achieve. Her overstated "*anything*" amplifies the strong sense of opportunity loss that accompanies her ME/CFS.

> *I didn't go to the college that I wanted… I went to a college that's… a local one near me… I think there's always a part of me that feels like I'm, which isn't good, this isn't a good thing to think about, but incomplete* (Samantha, p. 5).

Samantha didn't go to her first-choice college, she attended a less prestigious local one instead. Because of this she feels incomplete, and she judges herself for feeling incomplete. There's a sense of Samantha believing herself to imperfect or lacking. And yet Samantha longs for her lost envisioned future. She holds onto the hope of treatment, that could restore her life to what it was:

> *There's like two paths. There's a path where I think about, how I'll have to live with this for the rest of my life… and then there's this path where, you know, hopefully treatment could come. And then I'm thinking, well, then it will just be like I've always planned (Samantha, p. 23).*

4.8 Group Experiential Theme (GET) 6 – "It's very mixed": Inconsistent educational support.

Table 9

Participant representation for GET 6: "It's very mixed": Inconsistent educational support.

	Morgan	Samantha	Olivia	Peter	James
GET 6 – "*It's very mixed*": Inconsistent educational support.	☒	☒	☒	☐	☒

All participants in the study had experienced formal education, but their mode of education was different. Samantha had been educated to degree level in the USA and James was currently at university in the USA. Olivia and Morgan were studying at British universities and Peter was being home-schooled in the UK, having previously attended mainstream school.

Four of the five participants spoke about inconsistent, fluctuating educational support for their ME/CFS needs. Equity of education was important, but for some participants this equity was easier to achieve than others. Samantha had the most positive experience regarding disability support provided by her college. She described the disability service and professors as good or very good, and was allowed extensions when required:

> *They have a really good disability service centre, and I think all the professors were really good with me there. We had good professors. It's not a huge school so they knew me. Um, and so I, was able to really get the grace when I needed it, but I would say it was really hard. I never took full credits (Samantha, pp. 7-8).*

Despite a good experience of college disability support, Samantha found education tough and she sacrificed full credits to maintain pace with everyone else. Later Samantha said:

"*people [at college] were sympathetic and empathetic… and I think they understood that I was tired a lot… but I don't think they fully understood*" (p. 13). This links back to the first group experimental theme, others don't understand. In Samantha's case, there was partial understanding but not full understanding. Educational professionals understood that Samantha was tired a lot of the time, but they did not comprehend the nuances and unique difficulties of living with ME/CFS.

Olivia, like Samantha, spoke about the partial understanding of education professionals. Unlike Samantha, Olivia found support for her ME/CFS to be more mixed:

> *If I am unable to attend lectures… they understand why I'm leaving but they will not give me extra tuition. They will not give me any form of resources apart from just the PowerPoint they've used… but, they have been supportive… with trying to sort a part-time placement (Olivia, pp. 16-17).*

Olivia cannot attend all university lectures due to ME/CFS symptoms. Lecturers therefore provide passive support, by understanding her absence, but according to Olivia, they fail to provide active help in the form of additional resources. Placement organisers are more helpful, providing extra support in the pursuit of a part-time placement, something that is not the normal course. This emphasises and evidences Olivia's previous remark, that people with ME/CFS fall outside the boundaries of convention and "*will never be normal*" (p. 28). With Olivia outside these margins, educational professionals seem to help her to a point, but there is potential for much greater support:

> *It's very mixed. Very mixed. they haven't completely not supported me, but there are big gaps where they should have supported me, where they haven't* (Olivia, p. 17).

James echoes this experience of mixed educational support. For him, professors seem to be either very understanding and helpful, or not at all.

> *I have had a good experience with some professors when it comes to, you know, my condition. Some of them… have been extremely understanding. Others have, have*

> *haven't been understanding whatsoever. And they flat out said, if you can't attend, you just drop the class* (James, p. 7)

James' words "*when it comes to, you know, my condition*" suggests a sense of awkwardness, confusion, or perhaps guilt or shame regarding his ME/CFS. The refusal by some professors to provide accessible support only serves to maintain or enhance these emotions. This dismissal and lack of support also limits James' learning opportunities. With a smaller pool of classes to choose from, James is discriminated against because of his ME/CFS.

Discrimination seems to permeate Morgan's educational experiences, from school through to university. During their school years, Morgan repeatedly asked their school if they could attend lessons online. The school refused. A few years later, the Covid pandemic hit and all schools moved their teaching online within days. Online teaching then remained the norm for months.

> *I spent two years literally like every meeting I had with a consultant was them going, well, we could try and get you on like a Zoom link in your classroom and my school going, well, that wouldn't work. That would be too difficult for the teacher. Well, suddenly they were all able to* (p. 35).

The refusal, by the school, to provide online learning, could be said to be an ableist practice. When Morgan transitioned to university, practices such as these continued as Morgan was excluded from impromptu class trips, because of their ME/CFS. This further limited educational and social experiences:

> *We'd have a module that had like random trips in the seminar time and nobody would tell me… and I'd get there and like we're off on a bus into town and I'm going, well, I won't be because I haven't factored in the sensory input of a bus journey into town (*pp. 17-18).

Accessibility problems were also present at placement, as Morgan tried to get their needs heard and accommodated, but was met with false assurances:

> *I spent about three weeks continuously being like, these are my access requirements. I need to do half days on this day. I need to have a school where I don't have to go up any stairs etc etc etc. And they were like, oh yeah, we sorted it… they said they were wheelchair accessible. Yes, but now I've got to have somebody follow me around the whole school opening every door, which makes me look like a child, not another professional (Morgan, p. 18).*

Here there seems to be a misunderstanding of Morgan's needs, and a trivialisation or dismissal of their independence and dignity. Placement organisers did not seem to understand the belittling impact of having an able-bodied person open and close doors, in an environment where Morgan wished to appear professional, competent and sufficient. Like Samantha, Olivia and James, at the heart of Morgan's educational experiences seemed to be a lack of considered, meaningful understanding.

4.9 Chapter summary

This chapter illustrated and examined six group experiential themes (GETs) and five sub-group experiential themes (sub-GETs). These GETs and sub-GETs are:

GET 1 - "*They're not seeing all of me*": Others don't understand. With three sub-GETs:

- "Invisible disabilities": Feeling unseen, forgotten and dismissed.
- "They didn't understand": Relationships become complicated, fragile and lost.
- "I wanted them to know": Educating others in the face of disbelief and misunderstanding.

GET 2 - "*It literally does disable you*": Lacking control. With two sub-GETs:

- "I can't do that anymore": Lacking control over body and life
- "Your future's in the air": lacking control over future.

GET 3 - "*You'll be fine*": Pushing beyond energy capacity because of pressure, frustration or denial.

GET 4 - "*Not good enough*": Feeling less-than and not enough

GET 5 - "*Giving that up is really difficult*": Grief and longing for lost identities.

GET 6 - "*It's very mixed*": Inconsistent educational support.

The GETs and sub-GETs were identified from an IPA of the psychological and educational experiences of five emerging adults living with ME/CFS.

In sum, all participants experienced misunderstanding from others, which, for most, fuelled a sense of being unseen, forgotten and dismissed. Relationships suffered and participants felt that the onus to educate was on them. All participants experienced a lack of control over their body and life and most participants worried about the uncertainty of their future. Several participants spoke about pushing beyond their energy limits due to pressure from others, frustration or denial. Self-esteem was impacted and several participants spoke about not feeling good enough compared to healthy others and their previous selves. All but one participant grieved and longed for absent pieces of their identity and most participants spoke about inconsistent educational support, fuelled by misunderstanding and sometimes exclusionary or ableist attitudes and practices.

Chapter 5: Discussion

5.1 Chapter overview

The previous chapter presented the analysis of interview data. This final chapter aims to consider this analysis within the context of existing literature. First, I bring the discussion back to my two research questions, exploring these with reference to my findings, psychological theory and existing research. Following that, I consider strengths and limitations of this research, outlining shortcomings and how these could have been addressed. Middle sections of this chapter include a return to reflexivity and I also outline the impact of the Covid-19 pandemic. A sizable section is devoted to implications and recommendations. This is divided into four sub-sections: implications for future research, implications for health professionals, implications for education professionals, and implications for friends, family and peers. The chapter, and thesis, ends with concluding remarks and a tentative hopeful look towards the future of ME/CFS understanding and support.

5.2 Key findings with reference to existing literature

This thesis has detailed how an IPA of data pertaining to the experiences of emerging adults living with ME/CFS led to six group experiential themes (GETs) and five accompanying sub-group experiential themes (sub-GETs). In this section I return to my two research questions, applying findings from this research, as well as theory and knowledge from other studies, to answer them. My two research questions are:

1. What is the psychological impact of being an emerging adult living with ME/CFS?
2. What is the educational impact of being an emerging adult living with ME/CFS?

5.2.1 The psychological impact of being an emerging adult living with ME/CFS

Of the six GETs that developed from data analysis, five helped answer this thesis' first research question, regarding the psychological dimensions to life with ME/CFS as an emerging adult. Here, I examine these five GETs in turn, exploring how each relates to existing research findings and theory regarding emerging adulthood.

5.2.1.1 GET 1 - "They're not seeing all of me": Others don't understand.

This research uncovered that a felt lack of understanding underpinned many psychological issues for emerging adults living with ME/CFS. This lack of understanding varied, from fundamental erroneous beliefs, to mistaken assumptions, to partial but not full understanding. Not being listening to or empathically understood resulted in a sense of being unseen, forgotten, dismissed and/or belittled.

Scepticism and trivialisation was found across all participants' accounts. Morgan's family felt that if they tried harder, they would be ok. Samantha expressed worry that her brother-in-law viewed her ME/CFS as selfish. James reported feeling that some friends did not care. Olivia explained that her dad urged her to push past her energy limits, for vocational achievement. Peter felt ME/CFS was granted less accommodations than more acceptable recognisable difficulties, like dyslexia.

Within existing research, this scepticism and trivialisation is often named delegitimisation. Delegitimisation refers to the various ways in which individuals living with a disabling impairment experience their definitions and perceptions of their condition disconfirmed (Kleinman, 1992). People living with ME/CFS have experienced delegitimisation within medical settings (Dickson et al., 2007; McManimen et al., 2019; Snell et al., 2023), in family units (Crix et al., 2012) in interactions with partners (Dickson et al., 2007), with friends (Dickson et al., 2007), with educational tutors (Waite & Elliot, 2021) and within disability

services (Waite & Elliot, 2021). Delegitimisation seems on par with invalidation, and arguably only serves to uphold and preserve structural power inequalities.

Morgan and Samantha specially spoke about delegitimising experiences within their families. For both, delegitimisation caused a tension and divide resulting in feelings of being left out (Morgan) and a worry about being seen as selfish (Samantha). Tensions and divides in families where an individual has been diagnosed with ME/CFS has been identified in Boulazreg and Rokach's (2020) and Crix et al.'s (2012) research. Boulazreg and Rokach concluded that disruptions of the family dynamic result in sibling rivalries and strained parent-child relationships. In particular, feelings of envy, abandonment and guilt were found to be common. This can be seen in Samantha's account of her brother-in-law's attitude, "*everyone's catering to you, everyone's only caring about you, no one is caring about your sister*" (Samantha, p. 17). Crix et al.'s (2012) discursive investigation of a single family system note that discourses around ME/CFS were polarized around the issue of intentionality. Family members, in their study, were divided as to the representation of ME/CFS as a genuine illness or intentionally used for advantage. In this study, within both Morgan and Samantha's accounts, there is an implicit sense of family members questioning intentionality, in doing so members overlook Morgan and Samantha's actual experiences, leaving them feeling misunderstood and delegitimised.

Delegitimisation experiences within friendships is under researched, however Dickson et al. (2007) found that individuals living with ME/CFS interpret friendship delegitimisation as a questioning of their integrity and honesty. In their IPA study, participants felt let down, rejected and isolated. This then led to a revaluation of friendship, trust and love. In this study James described exactly this when he spoke about ME/CFS helping "*weed out, who, who really cares about me and who doesn't*" (p. 22). Here, James alludes to the process of re-evaluating attachments. Olivia also described friendship delegitimisation when she spoke about feeling ill and alone at university, with none of her friends thinking to come and check on her for hours.

Arnett (2000, 2004) asserts that many emerging adults experience increased autonomy as they transition from living with parents to independent living. During this life stage, support

structures relax as emerging adults become increasingly self-sufficient. Yet for emerging adults living with disability status, the transition to independence and adulthood can be interrupted. Families continue to provide support and resource throughout emerging adulthood, as in seen in this study. At the time of interview Morgan was living with their mum, and during his interview James expressed gratitude for the high level of support provided by his parents and sister. Rasalingam et al. (2023) write that parents of emerging adults' with long-term health challenges can act as 'safety nets' to aid successful transition to adulthood (Swartz et al., 2011). This may be more so when other relationships are strained due to misunderstanding and delegitimisation. Families with greater socioeconomic status and education may be likely to provide more resources than those with less (Lareau & Conley, 2008).

Embedded in participant's accounts was a sense of loneliness, accentuated by the invisibility of ME/CFS, and also by hiding ME/CFS symptomology and need. The relationship between (in)visibility and (non)disclosure within ME/CFS has been noted in several studies. For Waite & Elliot's participants, hiding was motivated by a desire to fit in, be seen as normal, and protect the self from feeling vulnerable (Waite & Elliot, 2021). This can be seen in Olivia's tendency to hide her 'not-normalness', which seemed to create a cycle of hiding, feelings of fraudulence, over-exertion and further hiding.

This study suggests that shame encourages hiding. In agreement with this DeBeer et al. (2022) propose that hiding be an attempt to avoid social stigma. DeBeer et al. write that if a university student does not disclose their invisible disability status, they face feelings of neglect or exclusion, and if they do disclose, they face the possibility of stigma. In an exploration of men's experiences, Wilde et al. (2020) noted that the invisibility of ME/CFS, along with its limits, ensues a sense of marginalization from hegemonic masculinity and society. To cope with this marginalization, men attempt to protect their male credentials through upholding activities they still could participate in. This is reminiscent of James' account of continuing to run in the presence of ME/CFS.

Within this study, and the above-mentioned studies, ME/CFS is explicitly or implicitly viewed as not normal, something to be hidden and something that is stigmatised or shameful. This

narrative is contested by critical disability theorists and proponents of the social model of disability, who challenge the medicalised, discriminatory assumptions underpinning such thinking. The social model of disability asserts that disability is not the result of impairment, but a societal failure to respond adequately to the diversity presented by impairment (Hoskins, 2008). Viewed through this lens, Olivia's sense of not being normal, and her hypothesised shame, could be seen as the result of society's failure to accept, respond, protect and respect her difference. The impairment belongs to Olivia, but the disability belongs to the systems in which she lives and works. It could therefore be argued, drawing upon the social model of disability, that the felt loneliness and invisibility imbued in participants' accounts exists because their voices, impairments and skills have been disregarding by a society which fails to welcome difference and diversity.

Hoskins (2008) writes that identifying and being identified as a disabled person is central to understanding the self, one's social position and one's knowledge of the world. Within this study participants were hesitant to identify and be identified as disabled. Taylor (2005) uncovered the same finding in their qualitative analysis of adults living with ME/CFS, noting that themes of disability pride, disability culture, and positive disability identity did not resonate with their participants' perspectives. It could be theorised that the medical model is so dominant in disability discourse, and that shame is such a strong emotion, that even when alternative, more empowering models and narratives are available, individuals living with ME/CFS continue to position themselves as defective and not enough.

5.2.1.2 GET 2 - "It literally does disable you": Lacking control.

In this study, all participants spoke about lacking control over their lives, bodies or future. Choice and freedom were reluctantly forgone as ME/CFS asserted its demands. Williams et al. (2019) note that many chronic conditions can impact the ability to predict, manage and enjoy life. This dramatically alters one's sense of personal control (Williams & Koocher, 1998 in Williams et al., 2019). A felt lack of personal control is named in the literature as 'illness intrusiveness' and can be defined as the extent to which the symptoms and treatment of a condition intrude on valued aspects of an individual's life (Devins et al., 1996). Dancey and Friend (2008) note that ME/CFS intrudes into more life domains and to a greater extent than

other chronic conditions such as multiple sclerosis, laryngeal cancer, end-stage renal disease and irritable bowel syndrome.

In this study, participants described the means and impact of ME/CFS intrusiveness. Samantha and Olivia were unable to both socialise and get good grades. Samantha chose friends over grades and Olivia prioritised study but acutely felt the loss of socialising. Peter could go outside for only ten minutes at a time. Morgan's life was predictably unpredictable leaving them scared for the future, and James forwent his preferred in-person degree for one that he could do online. He too spoke about fears for his future.

These findings support existing research, which has revealed that illness intrusiveness negatively impacts psychological wellbeing. When individuals living with ME/CFS are forced to sacrifice activities; leisure and social events are the first to go (Bartlett et al., 2022; Drachler et al., 2009; Kingdon et al., 2018). With illness intrusiveness comes a greater likelihood of clinical depression (Dancey & Friend, 2008; Goudsmit et al., 2009) as well as unpredictability, unreliability and dependency, ultimately leading to a sense of inadequacy (Williams et al., 2019). This self-evaluation can be seen in Samantha when she denigrates herself as "*dumb*" and "*stupid*" (p.11). In the literature, it is not just individuals living with ME/CFS that make sacrifices, but also their partners and family members. These individuals may spend considerable time caring for their relatives, and consequentially sacrificing work, finances and social activities (Nacul et al., 2011a). This can result in higher levels of felt anxiety (Boulazreg & Rokach, 2020).

In this research Olivia and Morgan explicitly spoke about PEM, the worsening of symptoms following even minor physical or mental exertion. During PEM, their bodies felt out of control, resulting in a sense of imprisonment in body and environment. In the literature, children, adolescents and adult men living with ME/CFS have been known to use words and phrases such as 'locked in', 'trapped', 'death-trap' and 'dictator' to describe life with ME/CFS (Dickson et al., 2017; Similä et al., 2021a). This latter phrase, 'dictator' implies a kind of power struggle between mind and body. This has been noted by Lombaard and Mouton (2005) who found that ME/CFS provokes the body and self into a frontline battle where conflict prevails. For a while, the body and self exist in discordant opposition, then the self

learns to responsibly listen to the body, responding in a way that sensibly balances activity and rest (Lombaard & Mouton, 2005). Applying Lombaard and Mouton's battle analogy to this study's findings, participants in this research seem to be at different stages in this battle of will. Peter, who has experienced ME/CFS since childhood seems to have better acceptance of his limits compared to other participants. Morgan similarly knew how to listen to their body, although disliked the unpredictability of it. Olivia, who had only had the condition for nine months, contained an ongoing battle between body and self.

In this research, two participants (Morgan and Samantha) expressed a desire for children, yet both spoke about concerns regarding their ability to raise children. Samantha went further to express hopelessness regarding her ability to find a partner who would be willing to take on the bulk of childcare. To my surprise I found no other qualitative study with a similar finding in the existing ME/CFS literature. This is perhaps because no other study has specifically explored ME/CFS experiences and emerging adulthood, and it is this emerging adulthood life stage where individuals may start to contemplate pregnancy (Gómez et al., 2021). In an exploration of emerging adulthood and pregnancy, Gómez et al. (2021) found that emerging adults overwhelmingly reference achievement of educational or professional goals, before that of pregnancy. This was in the belief that education and work would facilitate financial stability, which was seen to increase the ability to parent. Perhaps, for Morgan and Samantha, because ideal education and work goals are compromised by ME/CFS, traditional notions of pregnancy planning go abandoned, and thoughts more easily turn to the challenges of raising children in the presence of such a debilitating condition. In Gómez et al.'s study, socially disadvantaged participants expressed the notion that they would never have what they needed to be prepared for pregnancy. In this study both Morgan and Samantha communicated worry regarding child raising. Perhaps their disability-based disadvantage means they feel they will never be ready for pregnancy and child raising.

In this study, concerns about the future were also present in Olivia's narrative, although her worries centred around work rather than raising children. Olivia worried about her ability to fulfil occupational duties and responsibilities, and the potential for workplace discrimination. This concern is not unfounded. Of the 207 adult participants living with

ME/CFS in Assefi et al.'s (2003) study, 39% were unemployed. Of those in work, 44% had decreased their hours, 25% had taken a job requiring fewer skills, and 29% had lost a job due to ME/CFS. Further research has indicated that working individuals living with ME/CFS report unsupportive workplaces which are poorly adapted to fluctuating and fatiguing conditions (Pilkington et al., 2020; Snell et al. 2023). For many the workplace is a source of friendship and a place of belonging, but if people living with ME/CFS experience a job or career loss, loss of community can also occur (Dancey & Friend, 2008).

Emerging adulthood is a time of uncertainty and instability for all, regardless of disability status. Emerging adults change jobs, relationships, and residences more frequently than any other age group (Beyer & Lazzara, 2020). Wilson et al. (2021) note that, because of this, emerging adults may try to gain a greater sense of control over their body and life course. It can therefore be especially distressing when a chronic condition impacts that sense of control. In this study, distress can be seen in several participants' accounts as they grapple for control over a condition that disempowers, during a life stage that destabilises.

5.2.1.3 GET 3 - "You'll be fine": Pushing beyond energy capacity because of pressure, frustration or denial.

In this study, three of the five participants spoke about a tendency to push beyond their energy capacity, due to felt pressure, frustration or denial. Many health professionals encourage those living with ME/CFS to keep their level of exertion consistently within the limits of their available energy. This concept of attempting to live within the confines of a set amount of energy is often termed the energy envelope theory. For individuals living with ME/CFS, the theory postulates that those who expended energy at a level consistent with their available energy will have better health outcomes and quality of life, compared to those who over-expend (Brown et al., 2013).

Fisher and Crawley (2012) note that anxiety may motivate young people (aged 12-18) living with ME/CFS to over-expend energy and push beyond their physical stamina, consequentially reducing chances for recovery. They did not investigate the causes of this

anxiety but as Williams-Wilson (2009) notes, young adults tend to be consciously aware of the burden they place on other family members. Adults, on the other hand, may push beyond their energy envelope due to a desire to leave the sick role behind (Cheshire et al., 2021). This is true for James who initially tried to exercise his way out of long-Covid. It has also been suggested that negative perfectionism (doubts about actions and concern over mistakes) may cause unhelpful coping strategies which predisposes individuals to fatigue (Magnusson et al., 1996). This can be seen in Olivia's account when she says, "*I was a major perfectionist. Like, I was doing everything, and doing everything to a stupidly high standard*" (Olivia, p. 9).

Arnett writes that identity development, a key feature of emerging adulthood, involves trying out various life possibilities. Emerging adults tend to explore, cultivate and incorporate several minority identities, making emerging adulthood an active period with regards to relationships, work and leisure activities (Arnett, 2000). For those living with disability status, this is a more involved and complex process (Meyer, 2015). For such individuals, identity development may take longer and involve greater self-acceptance, advocacy, and integration into a social network (Meyer, 2015). In this study, it could be argued that the pressure, frustration and denial that caused and/or arose from participants pushing beyond their energy capacities, was in fact motivated by a desire to explore, develop and (re)define the self. In other words, as emerging adults, Samantha, Olivia and James were motivated towards identity exploration, but are restricted by their condition. This results in an involved, complex, detrimental tendency to push their bodies beyond their energy threshold, ever striving for a sense of healthy identity.

5.2.1.4 GET 4 - "Not good enough": Feeling less-than and not enough.

The fourth GET in this study indicates that emerging adults living with ME/CFS can hold low subjective evaluations of their own worth. In this study, three of the five participants spoke about feeling less-than, less worthy and not enough. Peter negatively appraised himself because of brain fog. Samantha compared herself to higher achieving friends and Olivia often felt not productive enough. Reminiscing and overstressing previous accomplishments

sustained a sense of not being enough. Moreover, negative comparisons to others, especially those living without ME/CFS, also left participants feeling not enough.

Several of Dickson et al.'s (2008) participants described similar feelings of failure, worthlessness, insignificance and disembodiment. This latter sensation was likened to death and left individuals numb or without feeling. Such extreme distress was not detected in this study however one participant, Samantha, believed herself to be incomplete. This incompleteness was presumed by her to indicate imperfection, a quality which she judged herself for.

When participants in this study spoke about feeling less-than and not enough, they portrayed a sense of low self-esteem. Self-esteem can refer to an individual's subjective evaluation of worth, and does not necessarily reflect objective characteristics and competencies (Orth & Robins, 2022). Low self-esteem amongst adults and adolescents living with ME/CFS has been noted several times in the literature.

Dickson et al. (2018) assert that low self-esteem can be caused by awareness of the disparity of past-self, anticipated-self and current-self. Furthermore, once self-esteem is knocked, individuals living with ME/CFS may not feel able to defend against external scepticism (Dickson et al., 2018). In support of this Samantha portrays a sense of low self-esteem when she talks about feeling "*stupid", "*dumb" and looking "like I wasn't as smart as I was" (Samantha, p. 11), and consequentially has difficulty defending her abilities and needs, especially when confronted by her sceptical brother-in-law.

However, another IPA study (Arroll & Howard, 2013) found that adults living with ME/CFS can experience post-traumatic growth. This growth took the form of a positive rebuilding of identity and esteem, following a departure from the old pre-ME/CFS self. This finding is similar to that of Åsbring's (2001) 'illness gains', in which their participants reported a positive re-evaluation of ambitions, attitudes, strategies and pace of life following the onset of ME/CFS. These studies suggest that ME/CFS is not necessarily a primarily negative experience, however, Åsbring found that ME/CFS was seldom a predominantly positive experience either. Participants in their study fluctuated between positive insights and

expressions of hopelessness. It seems ME/CFS is a multifaceted condition: growth and gains can manifest, but so can negative appraisal, difficult experiences and loss.

5.2.1.5 GET 5 - "*Giving that up is really difficult*": Grief and longing for lost identities.

This study provides a better understanding of how ME/CFS can cause and maintain many losses. When talking about life with ME/CFS, participants in this study often contrasted their (sometimes overstressed) better pre-ME/CFS existence to their present worse-off life. This pre/post comparison has been found in other studies. Williams et al.'s (2019) participants similarly expressed a nostalgic view of their 'previous life' before the onset of ME/CFS. Fisher and Crawley (2012) again found this when they explored young people's tendency to contrast their pre-ME/CFS 'good' hobbies and activities to post ME/CFS 'not good' activities. In all three studies, dichotomous judgement is made by participants, contrasting their good/better/whole past to the bad/inferior/broken present. In disagreement with these findings, some of Cheshire et al.'s participants spoke about life before ME/CFS as an undesirable state which had contributed to the arrival of their ME/CFS. They did not want to return there. This difference in findings illustrates the idiosyncrasies of ME/CFS and the importance of understanding the condition on an individual level.

In this study, most participants described grief for lost hobbies, abilities, and opportunities. One loss seemed to impact or cause another. Participants spoke about losing, giving up or forever leaving large parts of themselves. None mentioned anything to replace these absent pieces of identity. One participant in this study, James, went through a journey of grief reminiscent of the Kübler-Ross model (Kübler-Ross, 1970). When talking about losing the ability to exercise, James spoke about transitioning between different grief states, from denial to depression to acceptance. Gray and Fossey (2003) report that individuals living with ME/CFS can grieve for previous active identities, which in the presence of ME/CFS become invalid. This is precisely what James is grieving, his ability to run and power-lift, his active identity, which is now invalid given the physical limits imposed by his ME/CFS.

Gray and Fossey's study indicates that ME/CFS can entail a loss of identity, defined here as the loss of meanings that define us in terms of the roles we have, the groups we belong to and the unique characteristics that make us different (Burke, 2020). In Dickson et al.'s (2008) study, participants lost not just their sense of self, but every sense of their being – mind and body – and an identity crisis ensued. In this study, none of the participants described such a dramatic loss but James and Morgan both spoke about the reduced size of their worlds with ME/CFS appropriating so much of it.

It has been noted previously that participants in this study live in two different countries. Morgan, Olivia and Peter reside in the UK, with Samantha and James living in the USA. This bi-national angle brought unique insights to the study. The two American participants in described a longing for a pharmacological cure to return them to their pre-ME/CFS selves. Existing research suggests that individuals living with ME/CFS can hope for a cure (Broughton et al., 2017) but are less cure-focused than individuals with other chronic conditions like MS (Lacerda et al., 2019). More often than not, individuals living with ME/CFS and carers accept that a cure is unlikely to appear (Catchpole & Garip, 2021; Waite & Elliot, 2021). Yet since the Covid pandemic, hopes for an ME/CFS pharmacological cure has increased (Scheibenbogen et al., 2023; Seton et al., 2024). Perhaps, in this study, these hopes were more pronounced in the American participants since their healthcare system, in comparison to the British system, has a greater leaning towards medical intervention and treatment.

One of the participants in the study, Peter, had experienced ME/CFS since childhood. It seemed Peter's ME/CFS was so integrated into his sense of self, his expressed losses were lower than the other participants. Identity formation is argued to be is a key developmental task of emerging adulthood (Arnett & Tanner, 2011). In a study exploring how young people incorporate chronic illness into their identity, Wicks et al. (2019) found that nurturing aspects of identity other than chronic illness, allowed young people to 'forget' about their illness and, furthermore, participants who were younger at diagnosis tended to be more occupied with group membership, acceptance and sameness. Perhaps, for Peter, his expressed losses were low due to the existence of other aspects of identity, and his tendency to compare to both in-group and out-group individuals ("*I want to get better and*

be as good as them" (p. 6) can be seen as a consequence of having lived with ME/CFS for such a long time.

5.2.2 The educational impact of being an emerging adult living with ME/CFS

The sixth GET that arose from analysis, "*It's very mixed*": Inconsistent educational support, wholly answered my second research question, regarding the educational impact of being an emerging adult living with ME/CFS. Participants in this study spoke about inconsistent, fluctuating educational support for their ME/CFS needs, with some participants finding education equality easier to achieve than others. During analysis, I expected the different educational contexts that participants lived in to reveal divergences in experiences and meanings. However no major educational divergences were discovered. All participants described fluctuating educational support, both UK and US participants described instances of disability discrimination and both UK and US participants spoke about the benefits of online learning.

5.2.2.1 Fluctuating support and understanding

All participants in this study described partial but not full understanding amongst their tutors, teachers, lecturers and placement organisers regarding ME/CFS. Education professionals didn't seem to comprehend the nuances and unique difficulties of living with ME/CFS. This lack of full meaningful understanding in educational settings has been documented within ME/CFS literature. Within schools, children living with ME/CFS can experience stigma due to professional's misunderstanding and uncertainty (Parslow et al., 2017). Furthermore, a lack of considered adaptation can mean education and socialisation is missed (Similä et al., 2021a). The experience of older students living with ME/CFS is little different. Within UK universities, students have reported poor understanding and validation from disability services and tutors (Waite & Elliot, 2021), as well as a sense of inequality and of being undervalued (Hamilton et al., 2023).

In this research, Olivia, James and Morgan described at least some inadequate educational support for their ME/CFS. For these participants, social and career opportunities were impacted, as well as the ability to learn and academically achieve. A role power differential between students and professionals seemed to be mismanaged, with the needs and wishes of students going unseen and/or dismissed, despite the existence of disability support plans. Similä et al. (2021a) noted a similar finding in their investigation of educational provision in Norway. They found that young people (aged 13-21) living with ME/CFS experienced a lack of appropriate, unambiguous, realistic educational adaptations. This was related to a lack of knowledge about ME/CFS amongst school personnel.

Three of the five participants in this study spoke about efforts made to educate others (often professionals) in the face of disbelief and misunderstanding. There are few conditions whereby those struggling must first heavily educate in order to receive kindness and understanding. Literature has revealed that UK primary schools (Brigden et al., 2021), UK high schools (Clery et al., 2022) and USA public schools (Newton, 2021) display varying levels of understanding and support for ME/CFS. Yet individuals in these establishments possess significant role power. In a condition where advocating for oneself involves energy that may not always be available, it is essential that professionals have the expertise and empathy to know how and when to best support those living with ME/CFS.

5.2.2.2 Disability discrimination

Morgan and James spoke about their experiences of educational exclusion. James was told to unenroll from classes if he could not attend in person and Morgan was excluded from spontaneous class trips. It could be said that at this core of both these experiences is disability discrimination. This type of discrimination, amongst education professionals, has been found within the literature. Hamilton et al. (2023) noted how university students with chronic illnesses felt that some staff did not class invisible illnesses as ‘real’ disabilities. This led to a sense that staff were policing university regulations inappropriately, to excuse for not adjusting support appropriately. Hopkins (2011) found that disabled identifying university students have to work considerably harder than non-disabled identifying students

to overcome a wide range of physical, attitudinal, social, cultural and political barriers. This, and other findings, led Hopkins to assert that in most education settings, support for ME/CFS is reactionary to an out-of-the-norm student (Hopkins, 2011). This conclusion is reminiscent of Olivia's comment that people living with ME/CFS will never be normal.

Toller and Farrimond (2021) write that, for university students living with ME/CFS, accepting a disabled identity can enable them to work within their limits rather than pushing beyond. Without this acceptance, students can encounter a misfit between their ill bodies and academic demands, ultimately exacerbating symptoms and making it impossible to successfully maintain an academic identity (Toller & Farrimond, 2021). And yet, research with adolescents and young adults living with disabling impairments suggests that up to 73% do not self-identify as disabled (Chalk, 2016; Nario-Redmond et al., 2013). All three participants who reported pushing beyond their energy limits also reported difficulty identifying with the term disabled. James said "*for a long time I I denied the fact that I was [disabled]"* (p. 30). Olivia stated "*I see myself as disabled, to a degree*" (p. 29). And Samantha explained "*I do believe [ME/CFS] is a disability, but… I don't want to say that I have a disability*" (p. 24). For all three participants, the reluctance to accept a disabled identity may have played a part in their inclination to push beyond energy capacity, possibly ultimately preventing the development of an academic identity characterised by positive esteem and worth (Toller & Farrimond, 2021). Yet acceptance of a disabled identity means, by necessity, acceptance of the medical model of disability. Not all individuals with a disabling impairment may wish to accept the medical model, yet they may feel they have no other choice. Perhaps James, Olivia and Samantha expressed reluctance to accept a disabled identity because they do not believe the disability to be located in them. Perhaps they believe society to possess the disability. Unfortunately, this social modelled way of thinking is not mainstream. Until is it, individuals with disabling impairments, like James, Olivia and Samantha, may continue to feel trapped or confused, sacrificing their values or sense of self to a dominant society discourse they may not fully subscribe to.

5.2.2.3 Alternative ways of learning

Two participants, Mogan and James, explicitly noted how online teaching during the Covid-19 pandemic was, for them, positive for education and socialisation. Similä et al. (2021a) arrived at a similar finding; that online teaching grants students living with ME/CFS better control, more freedom and greater equality with peers. Clery et al. (2021) maintain that online learning, adopted by educational establishments during the pandemic, should be used to provide routine accessible education for all in the future. Other academics and researchers note caution. Asanjarani (2022) hypothesises that the absence of in-person academic contact during the pandemic negatively impacted emerging adults' sense of academic belonging and wellbeing. He cites Elmer et al. (2020) whose longitudinal study with undergraduate students indicates that living alone and decreased contact from personal networks correlated with negative mental health during the first two weeks of lockdown. Yet the experiences of participants in this study sit in contrast with these findings and Asanjarani's hypothesis. All three participants who commented on online ways of learning and socialising only spoke only about the benefits and did not mention any drawbacks.

Tan et al. (2022) report that the presence of good online teaching (teaching that goes beyond imparting information and includes active engagement, collaborative group work, a mutually trusting relationship and the use of several synchronous and asynchronous tools) fulfils the basic psychological needs of emerging adult learners. These needs comprise of autonomy needs, relatedness and competence. Tan et al.'s study suggests that the quality of online education is crucial for enjoyment and achievement. This study agrees with this finding. Several participants expressed gratitude for flexible, considered, creative online ways of teaching, and they reported feeling more connected and capable as a result. James sums this up when he says, "*this one professor, he was such a great guy… he was willing to be… fully accommodating to your condition, regardless of what it was*" (p. 38) and later "*what I…want, is for teachers to try to help students… be able to attend class and participate in class to their fullest potential*" (p. 39).

5.2.3 Section summary

This section considered the current study's findings within the context of existing literature and psychological theory. Specifically, I have drawn upon the developmental theory of emerging adulthood, and I have included a consideration of the social model of disability as applied to ME/CFS. The section was structured according to this thesis' two research questions: (1) what is the psychological impact of being an emerging adult living with ME/CFS? And (2) what is the educational impact of being an emerging adult living with ME/CFS?

Regarding the former; a felt lack of understanding seemed to underpin many psychological issues. In agreement with previous research, this study found that delegitimation is common, as emerging adults living with ME/CFS have their definitions and perceptions challenged and misunderstood by others. Much of the literature mentions the highly intrusive nature of ME/CFS, characterised by a lack of personal control; this study is no different. Lombaard and Mouton (2005) portray ME/CFS as a conflict between body and self. This study noted that participants seem to be at different and fluctuating stages of such a conflict; at times the self fighting the body and at other times the self acquiescing to its demands.

A unique finding of this study was the concerns of two participants regarding their future ability to raise children. Hopelessness and dismay were particularly salient emotions, with one participant wondering what kind of partner would take on that kind of co-parenting relationship.

It is common knowledge that over-expending energy results in an exacerbation of ME/CFS symptoms, but little research has investigated the reasons for this. This study has found that emerging adults tend to push beyond their energy capacity due to felt pressure, frustration and denial. This is sightly divergent to other research which indicates that negative perfectionism (Magnusson et al., 1996), a sense being a burden (Williams-Wilson, 2009), and a desire to escape the sick role (Cheshire et al., 2021) motivates over-expenditure. This

thesis suggests that the pressure, frustration or denial that motivates participants to over-expend energy, may be underpinned by a desire to explore, develop and (re)define the self, since this, is arguably, a key developmental task of the emerging adult.

This study has also found that ME/CFS psychologically impacts emerging adults by negatively affecting self-esteem and disrupting identity. Both have been noted several times in existing literature (Dickson et al., 2008; Gray & Fossey, 2003; Larun & Malterud, 2007). Other research has revealed that nurturing aspects of identity aside from ME/CFS can help individuals temporality forget their condition, providing some degree of respite (Wicks et al., 2019).

Regarding the impact of ME/CFS on education, all participants spoke about inconsistent support and a lack of full understanding amongst education professionals. This accords with much of the literature from UK and USA secondary, further and higher educational institutes. Some participants in this study described instances of disability discrimination in educational settings. This has been found in other studies, including Hamilton et al.'s (2023) study which revealed that staff in UK universities can discriminate against invisible disabling impairments, and Hopkins' (2011) study which suggests that school support is often reactionary to an out-of-the-norm student, implying that inclusive education is uncommon. Accepting a disabled identity can help students to work within their limits rather than pushing beyond (Toller & Farrimond, 2021) but this acceptance is rooted within the medical model, which, arguably, not everyone wishes to accept. In sum, this study found that acceptance of a disability, or a disabling impairment, is not easy and can fluctuate.

This study, and others, has found that considered online learning is positive for education and socialisation for emerging adults living with ME/CFS. Yet education professionals continue to have insufficient knowledge of the condition. This is likely to present a barrier for more alternative ways of learning.

5.3 Strengths and limitations

The following section contains an overview of the strengths and limitations of the current research. Within this I outline philosophical, methodological, and practical benefits and drawbacks.

5.3.1 Improving the knowledge base

This study fills a gap in the knowledge base. While there exists a good body of qualitative literature exploring the psychological and educational implications of ME/CFS, most prior research has focused on the experiences of adults, children or adolescents. The specific experiences of emerging adults has gone unexplored. To my knowledge, this thesis is the first study that specifically explores, through IPA, the psychological and educational impact of ME/CFS on those in the life stage of emerging adulthood.

A unique finding of this study was the hopelessness and dismay expressed by two emerging adults regarding their ability to raise children. This finding has not been expressed in any other identified study regarding ME/CFS and sheds new light on the fears and worries of emerging adults with the condition. Another unique element of this study is the suggestion that emerging adults may push beyond their energy capacity because of a desire to explore, develop and re-define the self. This desire may be mediated by pressure, frustration or denial.

In support of several other studies, this thesis found that those living with ME/CFS can experience multi-faceted loss and identity disruption. Also, in agreement with several other studies, emerging adults living with ME/CFS and in education can experience inconsistent support and a lack of full understanding amongst education professionals.

5.3.2 Use of expert by experience

In the early stages of this research, I consulted an expert by experience who had both lived and research experience of ME/CFS. This improved both credibility and relevance of the research. During our meeting, I discussed recruitment, my interview schedule, managing potential harm and ongoing controversies and sensitivities within the ME/CFS community. This consultation allowed me to anticipate and manage recruitment issues, and also plan interviews that were more likely to be acceptable and comfortable for participant, in accordance with Smith et al.'s (2022) guidance for good IPA research.

5.3.3 IPA and participant numbers

My choice of methodology is a further strength of this research. I chose interpretative phenomenological analysis (IPA) due to its compatibility with my ontological and epistemological beliefs, and because I wished to focus on the personal perceptions and sense-making of my participants, whilst also acknowledging my own. IPA has allowed me to do this. IPA has also allowed a rich, reflexive and humbling insight into a sometimes hidden, frequently invisible, often misunderstood condition.

Five participants took part in this research. I intended to interview six but struggled with recruitment and forewent the final participant. For an IPA study, this is an adequate number and I was able to devote time and energy to in-depth analysis of each individual case. However, with greater participant numbers comes greater leverage in one's ability to make experiential claims (Smith et al., 2022). In this study, I have confidence in my considered analysis and have attempted to draw attention to smaller and larger patterns of convergence and divergence.

IPA is not without criticism, and this should be noted. IPA has been critiqued for its lack of standardization, ambiguous guidelines, and for its tendency to take language at face value (Tuffour, 2017; Willig, 2021). However, I found IPA to be a coherent, versatile approach. It

aligns with my philosophical positioning, and allowed me sufficient representation and interpretation of my participants' experiences.

5.3.4 Online interviewing

All interviews for this research were conducted online via the meeting platform Zoom. There were benefits and challenges to this, but overall online interviewing has been of benefit. I experienced no connectivity issues during any interview, but several were interrupted by outside distractions. This undoubtably impacted the flow of thoughts and engagement. In addition, online interviewing made it personally harder to detect and appropriately respond to discomfort and distress. A debrief sheet (appendix H) supported the management of any potential distress, but the sheet only included information regarding UK organisations and helplines, minimising its use for American participants. Despite these limitations, online research interviews have a huge benefit for those living with ME/CFS. With online interviewing all participants were better able to manage their energy levels. Furthermore, all participants could discuss potentially difficult and sensitive topics in the comfort and safety of their preferred environments. Finally, if interviews had been conducted in person, travel restrictions would have meant that neither of my American participants would have been able to take part, and unique insights gained from their experiences would not have been captured.

5.3.5 Exclusion of individuals experiencing severe and very severe ME/CFS and severe depression and/or anxiety

Within this study, exclusion criteria stated that individuals experiencing severe or very severe ME/CFS (NICE, 2021) and/or experiencing severe depression and/or anxiety would be disallowed from the research. This was to protect their physical and emotional wellbeing. Consequently, all individuals who took part could be said to have mild to moderate ME/CFS (NICE, 2021) and were not identified as experiencing severe psychological distress. This

meant that the sense-making perceptions of emerging adults living with severe and very severe ME/CFS, severe depression or severe anxiety were not captured in this research. Such individuals are, unfortunately, regularly excluded from qualitative research and their experiences, meanings, narratives and discourses largely go uncaptured and unheard. This results in a gap in the knowledge base, exacerbating pre-existing misunderstandings regarding certain elements of the ME/CFS experience.

5.3.6 Lack of intersectional consideration

At some point during data analysis, it occurred to me that the study could have generated more nuanced perspectives of ME/CFS if I had taken an intersectional lens and considered additional dimensions of the human experience where privilege can vary. Intersectionality refers to the ways that multiple identities intersect to create and maintain complex inequalities across social systems (Crenshaw & Harris, 2009). In this sense, an intersectional approach could have exposed the ways that disability interconnects with other mechanisms of power and oppression such as sexism, racism, classism and ageism.

There is both a lack of ME/CFS intersectional research and a call for studies that tackle such intersectional dimensions. Kelly et al. (2021) note that intersectional research can be uncomfortable and challenging, and that few guidelines exist for incorporating elements of intersectionality into research studies. However, several papers have since proposed a series of models, theories, and frameworks for intersectional research. I look forward to embracing such an approach in any future research.

5.3.7 Power dynamics

Considering the power dynamics in research, an imbalance always exists between researcher and participant (Kaaristo, 2022). This is, in part, because we hold different degrees of role power. This imbalance is further influenced by social, cultural, educational,

and physical factors of both participant and researcher (Etherington, 2004). In this research I have taken several steps to minimise the power differential between myself and my participants. These steps include:

- Protecting the privacy and anonymity of my participants.
- Ensuring that participants know they can withdraw from the research up until the point of group data analysis.
- Keeping analysis close to participants' meanings.
- Using participants' own language and words in the analysis and discussion sections of this thesis.
- Using reflexivity to be transparent and accountable for my values, norms and presuppositions (Karnieli-Miller et al., 2009).

However, the power differential between myself and my participants remains due to differences in role, age and status (health as well as academic). This is likely to have impacted the research. My participants may have rephrased, diluted, or omitted information due to this power differential. Conversely, they may have over-shared more than they were comfortable with. Or they may have made presuppositions about me, that I preferred or needed certain replies. This is to be considered when reading and evaluating this research.

5.3.8 Cross-national recruitment

It has been noted that three of my participants reside in the UK and two live in the USA. These two groups of people inhabit different cultures and societies, as well as different healthcare, political and education systems. Cross-national research such as this presents methodological challenges, but arguably more so for the quantitative researcher than the qualitative one. If this study was quantitative, then this cross-nationalism would have significant hampered the generalisability of findings. However, being an IPA researcher, I do

not wish to make general claims regarding emerging adults and ME/CFS. Instead, I wish to provide ideographic insight into the experiences of emerging adults living with ME/CFS.

Nevertheless, this national non-homogeneity may impact the transferability of this research to educational settings. This should be considered when applying findings and implications to educational establishments, especially where there exists significant differences between UK and USA structures.

5.4 Revisiting reflexivity

Etherington (2004) poses four questions to the reflexive researcher. The first three – regarding personal history, presuppositions and knowledge positioning – I answered in the introductory chapter of this thesis. The last I intend to answer here. This question asks how aspects of my identity influence my positioning in relation to my participants. I will focus on four aspects of identity: my non-disability status, my gender, my culture and my social class. I have positioned my answers to Etherington's final question, here, towards the end of the thesis, in order that both myself and the reader can reflect on the research process and examine my positioning in retrospect. In doing this, I can more easily consider how my identity has impacted each stage of the research journey.

5.4.1 How my non-disability status influences my positioning

The introduction chapter of this thesis noted how my outsider status as someone without experience of ME/CFS impacts upon my knowledge positioning. Here I reflect upon how this status impacts my positioning in relation to this study's participants, as well as data generation and analysis.

Kitchin (2000) writes that research on, with, and about people living with a disabling impairment, has historically been dominated by researchers without a disabling impairment.

This can lead to non-disability status researchers potentially misrepresenting and misinterpreting their participants' experiences. Participants may not wish to disclose aspects of their experience, perhaps due to anticipated stigma, misunderstanding or embarrassment (Kitchin, 2000). This may be especially true for participants living with ME/CFS, since the condition is already stigmatised and misunderstood. Or, participants living with disabling impairments may feel that researchers without such impairments simply don't hear or understand their experiences. Despite my best efforts, it must be noted that, due to my non-disability status positioning, I may have misrepresented or misinterpreted my participant's experiences and meanings. I may have also unintentionally stigmatised, misunderstood, or embarrassed my participants. This could have occurred at any stage during the research process.

5.4.2 How my gender influences my positioning

I am a female identifying individual who grew up in a family were women dominate in number and influence. Men were unfairly viewed as inferior. As a result, I learnt values of compassion, generosity and support, but have historically and ashamedly applied these unevenly to individuals of different genders.

At the same time, growing up in the nineties and noughties, I was taught the binary nature of gender: male and female. I identify as female and, for most of my life, never questioned such a dualistic way of thinking. From the twenty-tens onwards I became aware that established gender categorisations and stereotypes were being challenged. I learnt that gender is spectral, and people can have fluid gender identities. Now this way of thinking seems common sense and I respect and support individuals of all gender identities.

Throughout this research I felt a stronger sense of compassion and connection to my female identifying participants. I still felt compassion for my other participants, but that sense of shared sisterhood was lacking. As a result, I felt more curious and used more prompting questions with female identifying participants. And yet research has revealed unique complexities to living life as a male with ME/CFS. The condition can compromise men's

sense of masculinity and threaten traits traditionally viewed as masculine (e.g. strength, courage, independence, leadership, and assertiveness) (Snell et al., 2023; Wilde et al., 2020). My unconscious gender bias may have resulted in these avenues going unexplored in the current research.

5.4.3 How my culture and ethnicity influences my positioning

Studies have shown that all British ethnic minority groups have a higher prevalence of ME/CFS than the White-British group. In Bhui et al.'s (2011) study, ME/CFS was of lowest prevalence in the White-British group (0.8%), and of highest prevalence in the Pakistani-British group (3.5%). Nacul et al. (2011b) reported that yearly incidence rates for ME/CFS in Britain are highest in London (the most ethnically diverse region in England and Wales (ONS, 2022)) and lowest in East Yorkshire (where 97.4% of people identify as White-British). Similar findings have been found in America, with African-American identifying individuals and Native-American identifying individuals at higher risk of ME/CFS compared to White-American identifying individuals (Dinos et al., 2009). Furthermore, research suggests that when ethnic minority groups and ethnic majority groups both experience fatigue, those with minority group status experience fatigue to a greater and more severe extent (Dinos et al., 2009; Song et al., 2002).

My ethnicity is White-British, specifically White-Welsh. My culture and ethnicity predispose me to think a particular way. Because of this, I am likely to be inconsiderate of cultural factors, racism, non-White conceptualisations of identity and many other elements of the non-White experience. Considering the higher prevalence and severity of ME/CFS in ethnic minorities, it could be argued that I am a less appropriate ME/CFS researcher than an individual from an ethnic minority background.

My blindness to elements of the non-White experience will have affected the current research, in particular my interactions and analysis with participants who do not identify as the same ethnicity as me. Throughout the research I endeavoured to remain mindful of my

cultural and ethnic positioning, bracketing off bias and presuppositions, however, it must be noted that my culture and ethnicity will have influenced my interpretations and sense-making processes.

5.4.4 How my social class influences my positioning

The concept of social class, within this research, is affected by the geographical split within my participants: three individuals live in Britain and two in the USA. I have tended to view the US as less class-orientated and with greater potential for social mobility, yet social mobility in America has floundered in recent years (Bhashkar et al., 2021). Currently both countries have an undeniable hierarchy of privilege, opportunity and resource. In defining social class, Kraus et al. (2012) writes that an individual's class is pervasively rooted in both the material substance of social life (e.g. wealth, education, work) and the individual's understanding of their 'rank', and how they relate to the social world.

Social class differences give rise to inequalities. In Britain, being born privileged means an individual is likely to remain privileged. Being born disadvantaged means the individual will have to overcome a series of barriers to achieve equal attainment, income, and sense of control, compared to those without such disadvantage (Social Mobility Commission, 2019). Regarding my social class, I identify as middle class. Identifying as middle class means I possess more privilege than those who identify with a lower-class. This includes privilege of educational opportunity and resource. In addition, I socialise with (presumably) mostly middle-class identifying people, learn alongside (presumably) mostly middle-class identifying people and work alongside (presumably) mostly middle-class identifying people.

Lynch and O'Neill (1994) argue that middle-class norms prevail in university settings and education has been colonised by middle class academics for their own professional purposes. Academic language can serve as barrier to understanding, excluding minoritised newcomers from the middle-class dominated profession. This study is written in accessible language and will be published in an open access format, free to read, copy, reuse and

distribute to anyone who wishes to. The purpose of this is to widen research knowledge to those beyond institutional (and class) structures.

Social identity theory (Tajfel & Turner, 1979) asserts that individuals have a natural tendency to favour and promote their in-group (in this context, middle-class), at the expense of out-groups. This can manifest in various ways including a preference to recruit and interview research participants seemingly belonging to the same class system. In this study, I did not explicitly ask about class identification, but all participants seemed, to me, to also belong to the same class system as myself. This unconscious bias may have prevented me from identifying and representing the experiences of non-middle class emerging adults living with ME/CFS. Working class individuals are often excluded from higher education and research participation (Reay, 2021). Unfortunately, this research could be seen as another illustration of such underrepresentation and exclusivity.

Finally, it is important to note my beliefs and blind spots as a middle-class identifying individual. Individuals who grow up in middle or upper-class environments tend to have more material and psychological resources than those who grow up in lower-class environments (Manstead, 2018). As a middle-class individual I may have projected my privilege onto my participants. I may have been blind to the possibility that my participants may not be middle-class and may have fewer available material and psychological resources. In my blindness I may have been obtuse or patronising. Ongoing reflexivity will help in my efforts to notice and suspend bias, in any future research.

5.5 Contribution to counselling psychology

As a trainee counselling psychologist, I am professionally situated within a humanistic and social justice framework. I approach my research through this lens and these attitudes have shaped my analysis and conclusions. This study has found that feeling misunderstood is at the heart of many psychological and educational experiences. All participants reported ME/CFS limited their sense of control. Most participants pushed beyond their energy

capacity due to pressure, frustration and/or denial. Most participants grieved for lost hobbies, abilities and opportunities and most participants spoke about inconsistent, fluctuating educational support.

There are several ways that this study can contribute towards the counselling psychology profession. First, for counselling psychologists working with individuals living with ME/CFS, this thesis can provide insight into the lived experience of their clients. It can also provide guidance regarding working with clients in a way that accords with professional principles of humanism and social justice. Second, Bell (2016) notes that the process of social justice should involve respectful democratic dialogues and opportunities to critically examine institutional, cultural and individual oppression. I hope that this thesis both contributes towards and facilitates the examination of oppression of emerging adults living with ME/CFS. Third, this thesis will be published open access for all to read. This will increase the exposure of counselling psychology, which has historically been a small discipline compared to our clinical and educational psychology colleagues.

5.6 Recommendations and implications

Towards the end of each research interview, I asked participants three questions:

- If you were to give a message to healthcare professionals, what would you want them to know?
- If you were to give a message to education professionals, what would you want them to know?
- If you were to give a message to the public, what would you want them to know?

This section provides practical and actionable recommendations and implications for others, based on the existing analysis and participants' answers to the above questions. However, it must be noted that implications are interpreted by myself and are filtered through my own perceptions and sense making processes.

Four subsections are detailed below: Implications for future research, implications for health professionals, implications for education professionals and implications for friends, family and peers.

5.6.1 Implications for future research

This study, and many others, excludes individuals living with severe or very severe ME/CFS. People living at this end of the ME/CFS spectrum may be hypersensitive to light and sound, may experience extreme weakness, may have a reduced ability to speak, may experience severe PEM, and may have cognitive or neurological difficulties (NICE, 2021). All these symptoms hamper the ability to take part in interview-based research. Yet, by excluding such individuals, their experiences go undetected. One suggestion for future researchers is to employ the use of visual methodologies to research the experiences and needs of those living with severe ME/CFS. Such methods could include autophotography or perhaps photo-elicitation. Glaw et al. (2017) note that autophotography can help engage such marginalized groups because the methodology allows participants to express themselves, and their perceptions, in their own time, through the accessible medium of photography.

All participants in this study reported fluctuating educational support for their ME/CFS, but the research was limited to studying the perceptions of students only. The perspectives of educational professionals has been captured in previous research but the knowledge base is small (Brigden et al., 2021; Similä et al., 2021b). A second suggestion for future research is to further explore the experiences of education professionals in providing support to students with ME/CFS.

5.6.2 Implications for health professionals

When asked to give a message to healthcare professionals, most participants spoke about their desire to be treated more holistically and respectfully. They also asked professionals to

act with integrity, acknowledging uncertainty and unfamiliarity. Research shows that UK healthcare professionals have little formal teaching on ME/CFS and little knowledge of diagnosis, appropriate management or impact of the condition on quality of life (Hng et al., 2021; Pheby et al., 2020). A suggestion for health professionals and/or healthcare research is the potential designing, implementation and evaluation of a national training programme for doctors, within the aim of improving competency and confidence.

5.6.3 Implications for education professionals

All five participants who took part in this research wished to provide advice to education professionals. All five wished education professionals to demonstrate better understanding of ME/CFS, but each placed emphasis on different aspects of understanding. Olivia and Peter wanted to be better believed by professionals. Olivia stressed, "*I'm not making this up… people just don't believe it's real*" (p. 36). Bracketing off bias, and actively seeking to comprehend the lived experience of ME/CFS, could help education professionals in this regard.

Olivia and Morgan stated gratitude for their academic access plans. These are documented arrangements, often created by or with disability support services, and shared with other university staff. The aim of these plans is to ensure fair and equitable access to education. Such documents go by many names including reasonable adjustment plans, learning support plans, personal learning plans and academic inclusion reports. It is suggested that education professionals ensure students living with ME/CFS have access to personalised plans, and that these plans are disseminated widely (with consent) and implemented with compassion and consideration.

Samantha wished education professionals to better understand the cognitive aspects of ME/CFS. About 90% of individuals living with ME/CFS experience cognitive difficulties include difficulties with attention, memory, executive function and information processing (Robinson et al., 2019). Samantha specifically struggled with processing and comprehending

written and verbal information. She also struggled with planning written assignments. She said, "i*f you have a student, in your class that has it… reading can be impacted. Uh, listening, even just… the ability to think about trying to write a paper can be really hard… even if they look fine, there's all these things they're feeling".* A further recommendation for education professionals is to enhance or consolidate understanding on the cognitive effects of ME/CFS, specifically the ways that these impact learning inside and outside the classroom. The CDC has produced a fact sheet for education professionals supporting children and adolescents. The factsheet might also be useful for professionals supporting emerging adults and can be found in appendix O.

James and Morgan spoke about the benefits of considered online learning. Morgan said, "*you might not see me in the chair in your classroom, but that doesn't mean… I'm not trying*". James expressed appreciation for an accommodating teacher who allowed him to turn his camera off when he was taking online classes but wasn't feeling well. Sometimes it was these small acts of kindness that were most meaningful. Online learning may help students living with ME/CFS achieve education equality. Education professionals could consider creative and flexible online ways of working, if they haven't already, to better support individuals living with ME/CFS with energy management. If such individuals don't have to spend energy commuting to class, they may have more expendable energy for learning.

5.6.4 Implications for friends, family and peers

This research indicates that the overriding felt experience of emerging adults living with ME/CFS is one of not being understood. Participants spoke about particular friends and family members not empathically listening, trivialising, adopting a sceptical attitude and questioning symptom intentionality. And yet participants also spoke about the value of, and appreciation for, helpful peers, kind friends and loving family.

These findings highlight a potential need for family, friends and peers to identify unhelpful beliefs and negative judgements and make a conscious effort to set these aside. Ongoing empathic listening, acceptance and the demonstration of willingness to accommodate need, can all help impart understanding to a widely misunderstood condition.

5.7 Conclusion

This study aimed to provide a unique contribution to the evidence base by being the first to qualitatively explore the psychological and educational experiences of those living with ME/CFS and in the developmental stage of emerging adulthood. The use of interpretative phenomenological analysis (IPA) generated insight into the lived experience of such individuals.

This study found that a felt lack of understanding underpins many psychological and educational issues for emerging adults living with ME/CFS. Participants in this study described a felt sense that the onus to educate others regarding ME/CFS was on them. Further psychological consequences include delegitimation and loneliness. Symptom hiding can occur, possibly motivated by shame and fear of judgement. The highly intrusive nature of ME/CFS can lead to a felt lack of personal control over life, body and future.

Emerging adults in this study tended to push beyond their energy capacity due to felt pressure, frustration or denial. It is hypothesised that this is further motivated by a desire to explore, develop and (re)define the self, in line with Arnett's assertion that the primary developmental task of emerging adults is to "clarify… and find a fit between their identity and the possibilities available to them in the adult world" (Arnett & Tanner, 2011, pp. 133-134). Several participants in this study spoke about not feeling good enough compared to healthy others and their previous selves. All but one reported grief and longing for absent pieces of their pre ME/CFS identity.

Regarding the educational impact of ME/CFS, this study suggests that inconsistent support and a lack of considered, meaningful understanding exists amongst education professionals. Two participants described instances of disability discrimination in an education setting. Facilitating online learning, noticing and bracketing off bias, consolidating learning on the cognitive effects of ME/CFS and compassionate implementation of personalised academic access plans, may all help students living with ME/CFS feel better understood and supported.

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Appendices

Appendix A: Introductory letter

Dear _____

Request for research participants

I am a trainee counselling psychologist at The University of Manchester. I have several years' experience working with individuals with chronic fatigue syndrome/myalgic Encephalomyelitis (CFS/ME) and am currently on placement in a Greater Manchester chronic fatigue NHS service.

My doctoral thesis focuses on how young adults with CFS/ME talk about their identity. Adolescence/young adulthood is time of change. Often individuals are independent for the first time. Identity is formed and re-formed. Social and sexual relationships are navigated. I'm interested in how individuals with CFS/ME manage all this whilst also living with a chronic condition.

I'm recruiting individuals aged 16 to 24 who have experience of living with chronic fatigue syndrome/myalgic Encephalomyelitis (CFS/ME). A formal diagnosis isn't a requirement for taking part. Participation involves a single Zoom meeting with myself. The meeting is split into two: first an initial screen where I discuss participant's rights and issues of confidentiality and risk. I'll ask about participant's current emotional wellbeing and fatigue levels. Next, I'll conduct the research interview. This will be recorded and I will ask participants about their experience of CFS/ME. Screening and research interview should last no longer than 90 minutes.

I'm afraid there's no financial compensation for taking part in the research, just the knowledge that you're contributing towards valuable and much needed research. Please see the attached research poster and information sheet for further information. If you'd like to take part, or would just like to have a chat about the research, feel free to call or text me on _____, email _____ or message me @_____.

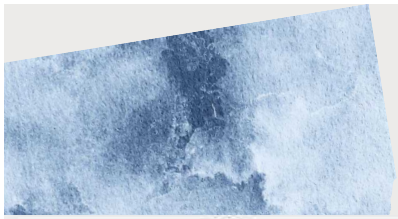
Thank you.

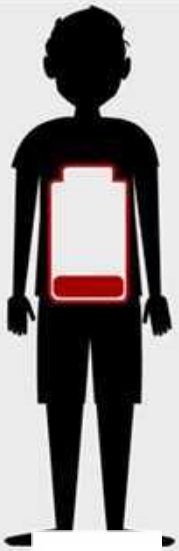
Yours sincerely,

Emma Williams

Appendix B: Research poster

An exploration of discourses around identity for young adults with experience of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME)





Call for participants

- Do you have experience of living with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME)?
- Are you a young adult (aged 16-24 years old)?
- Would you like to take part in a research study exploring how people talk about their experience of CFS/ME?

Your participation would involve a single online meeting with myself, a trainee counselling psychologist.

In the first half of the meeting, I will ask you to complete two short questionnaire about your mood. The second half will involve a research interview where you will get the opportunity to talk about what it is like to have CFS/ME. The meeting should take no longer than 80 minutes.

Unfortunately there's no financial compensation for taking part. However, your participation will contribute valuable information that will help researchers, clinicians and the general public understand more about CFS/ME. I ask that you don't take part if you think a research interview would cause a significant exacerbation in your CFS/ME symptoms.

For more information, or if you would like to take part, please contact me (Emma Williams, University of Manchester) on:

Phone:
Email:
Twitter:

Scan for more info

Appendix C: Participant information sheet

An exploration of discourses around identity for young adults with experience of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME).

Participant Information Sheet

You are being invited to take part in a research study exploring what it means to be a young adult with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) and how CFS/ME impact upon identity. This research is part of my Doctorate in Counselling Psychology. Before you decide whether to take part it is important you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully. You can discuss it with others if you wish. Please get in touch if there is anything that is not clear or if you have further questions. Thank you for taking the time to read this.

About the research

- **Who will conduct the research?**

This research will be conducted by myself, Emma Williams. I am a trainee counselling psychologist at The University of Manchester.

- **What is the purpose of the research?**

CFS/ME can be viewed as a poorly understood, controversial condition. Individuals who experience CFS/ME can face stigma and disbelief; yet they live with chronic, fluctuating, and often debilitating symptoms. The purpose of the research is to understand how people talk about their experience of CFS/ME. In particular, I'm interested in how CFS/ME is experienced by young adults and the impact of the condition upon their identity. I intend to conduct online Zoom interviews with six participants. I will record and transcribe each interview and I will use discursive psychology, a form of discourse analysis, to analysis the data. Discourse analysis studies the role of language (discourse) in everyday life.

To take part in the study you'll need to have experience of living with CFS/ME. You do not need to have a diagnosis of CFS/ME, just experience of living with it. You will also need to be between 16 and 24 years old and speak and read fluent English.

- **Will the outcomes of the research be published?**

The research will be written up into a doctoral thesis. This will be made electronically available to the public by The University of Manchester student theses webpage. Elements of the research (including anonymised quotations) may also be published in journals. All participants will be informed of the research findings if they wish. If you decide to take part, any data you provide will be pseudonymised, meaning no personal information about you would be published.

- **Who has reviewed the research project?**

This project has been reviewed by The University of Manchester Research Ethics Committee and was granted ethical approval on 5th May 2022.

- **What would I be asked to do if I took part?**

If you decided to take part in this research you will be asked to meet with me online, once, via Zoom. The first part of this meeting will be an initial screen. The second part will be a research interview. This all should take no longer than 90 minutes.

During the initial screen I'll introduce myself and the research. We'll discuss your rights as a participant, and we'll recap issues of confidentiality and risk. I'll ask you to complete two questionnaires – one about your anxiety and another about your mood – and I'll share the results with you. I will not keep your data from these questionnaires. I'll also ask about your current level of fatigue and other CFS/ME symptoms. I do not expect the research to significantly impact your wellbeing, but we'll chat through what to do if it does.

During the research interview, I will ask you about your experience of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis and how CFS/ME has impacted you as a person, your relationships with other people, your education or work, and the way you see your future. I will guide our conversation using pre-planned questions. You do not have to answer all the questions and you can skip a question at any time.

There are potential benefits and potential risks to taking part in this research. Some people find talking about their Chronic Fatigue Syndrome/Myalgic Encephalomyelitis helpful. Some people gain satisfaction from knowing they are making a contribute towards research. However, some people find talking about this topic difficult and distressing. If this were to happen we would have a break, or stop the interview.

- **Will I be compensated for taking part?**

Unfortunately, we cannot provide financial compensation for taking part in this research project.

- **What happens if I do not want to take part or if I change my mind?**

It is up to you to decide whether to take part. This information sheet is designed to help you decide. If you decide you *do not* want to take part, you do not need to do anything further.

If you *do* wish to take part, please read through the rest of this information and keep it for future reference. You will be asked to read and sign a consent form. If you decide to take part, you are free to withdraw at any point up until two months after your research interview. If you decide to withdraw you do not have to give a reason. Unfortunately you cannot withdrawn after two months from your interview date. This is because once I start data analysis your anonymised data gets pooled with anonymised data from other participants, and it becomes impossible to tell whose data is whose.

Data protection and confidentiality

- **What information will you collect about me?**

Your participation means I will need to collect information that could identify you. This information is called personal identifiable information. Specifically I will need to collect:

- Your name
- Your email address
- Your telephone number
- Your GP
- Your mental health secondary care team (if you have one)

This information is password protected and strictly kept within the research team at the University of Manchester.

The research study necessarily involves you being audio and video recorded via Zoom. This is an essential part of the study. Only the research interview part of the meeting will be recorded. After the interview, the video recording will be immediately deleted as I do not need this. The audio recording will be kept, encrypted, and stored securely for subsequent transcription and analysis. The audio recording will later get deleted once data analysis is complete. I will do my utmost to ensure you are comfortable with the recording process. Your anonymised transcript will be retained for five years following my graduation from my programme of study.

- **What are my rights in relation to the information you will collect about me?**

We are collecting and storing your personal identifiable information in accordance with UK data protection law which protect your rights. This law states we must have a legal basis to collect your data. For this study, the legal basis is that research is a public interest task and collecting minimal personal information is necessary for research purposes.

You have several rights under data protection law regarding your personal information. For example, you can request a copy of the information we hold about you.

If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our Privacy Notice for Research Participants found here: https://documents.manchester.ac.uk/display.aspx?DocID=37095

- **Will my participation in the study be confidential and my personal identifiable information be protected?**

In accordance with data protection law, The University of Manchester is the data controller for this project. This means that the university is responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way:

- To ensure your confidentiality all research participants will be given the opportunity to select their own pseudonym, a fictitious name to protect their identity. If participants do not wish to select a pseudonym one will be selected for them. A document with participants' names and their corresponding pseudonyms will be accessible only to myself and my research supervisors. This document will be password protected and securely stored on The University of Manchester's severs. In all other documents, other than your consent form, you will be referred to by your pseudonym.
- Data and documents will be stored in password protected files on password protected computers.
- Transcripts and consent forms will be stored for five years following graduation, before being destroyed.
- The final dissertation will be made accessible to the public by The University of Manchester.
- Audio recordings will be used to create transcripts. Only myself, the lead researcher, will transcribe the data. During transcription, I will remove any

personal identifiable information disclosed by participants during interview. Audio recordings will be permanently deleted once the analysis is complete.

- **Would you ever disclose my personal information to others?**

In rare circumstances I may need to disclose information about you, to others. I would only do this:

- If, during the study, you reveal information that suggests you are a serious risk of harm to yourself and/or others then I will inform your GP, secondary care team, crisis team or other mental health professional. I will endeavour to speak to you before I inform others, although this is not always possible.
- If, during the study, you disclose information about any current or future illegal activities, I have a legal obligation to report this to the police.
- If The University of Manchester, or regulatory authorities, needed to look at the data collected for this study to make sure the project was being carried out as planned. This may involve looking at identifiable data such as your name and contact details. All individuals involved in auditing and monitoring the study would have a strict duty of confidentiality to you as a research participant.

- **What if I have a complaint?**

If you have a compliant and wish to speak to another member of the research team please contact my research supervisor, Terry Hanley, at **terry.hanley@manchester.ac.uk.**

If Terry Hanley is unavailable, I suggest you contact my secondary supervision, Erica Burman at **erica.burman@manchester.ac.uk.**

If you wish to make a formal complaint to someone independent of the research team, or if you are not satisfied with the response you have gained from the above, then please get in touch with:

The Research Ethics Manager
Research Office, Christie Building
The University of Manchester
Oxford Road
Manchester
M13 9PL

You can also contact the research ethics manager by emailing research.complaints@manchester.ac.uk or by telephoning 0161 306 8089.

If you wish to contact the university about your data protection rights, please email dataprotection@manchester.ac.uk or write to:

The Information Governance Office
Christie Building
The University of Manchester
Oxford Road
M13 9PL

You also have a right to complain to the information commissioner's office about complaints relating to your personal identifiable information. **You can get in touch with the Information Commissioner's Office by telephoning 0303 123 1113**.

Contact Details

If you have any queries about the study or if you are interested in taking part then please contact the researcher, Emma Williams (trainee counselling psychologist), on:

Email: _____
Phone: _____

Appendix D: Consent form

An exploration of discourses around identity for young adults with experience of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME).

Consent Form

If you are happy to participate, please complete and sign the consent form below.

	Activities	Initials
1	I confirm that I have read the attached information sheet (version 4, date 07/04/2022) for the above study. I have had the opportunity to consider the information and ask questions, and I have had my questions answered satisfactorily.	
2	I understand that my participation in the study is voluntary. I understand I am free to withdraw up until two calendar months after the date of the research interview. I understand I do not have to give a reason for withdrawing and this can be done without detriment to myself. I understand that it will not be possible to remove my data from the project beyond two months after the date of research interview. This is because my data will have been anonymised, analysed and pooled as part of a larger data set. I agree to take part on this basis.	
3	I agree to an initial screening immediately before the research interview. I understand that at this screening I will be asked about the severity of my CFS/ME symptoms. I will also be asked to complete two questionnaires, one about anxiety and another about depression. Regardless of the result of these questionnaires, I will still be able to take part in the research. However, should my anxiety or depression fall into the severe range, I will be advised as to the potential consequences of taking part.	
3	I agree to the interview being video and audio recorded. I understand that after the interview, the video recording will be immediately deleted and only the audio recording will be retained.	

4	I agree that my quotations may be included in anonymous form in publications and/or conference presentations.	
5	I understand that data collected during the study may be looked at by individuals from The University of Manchester or regulatory authorities (e.g. for auditing purposes). I give permission for these individuals to have access to my data.	
6	I understand that there may be instances when information is revealed which means the researchers will be obliged to break confidentiality. This would happen if I reveal information that suggests I am a serious risk of harm to myself and/or others. The researchers would also be obliged to break confidentiality if I reveal information regarding a serious crime, terrorist or trafficking offence. This has been explained in more detail in the information sheet.	
7	I agree to take part in this study.	

The following activities are optional, you may participate in the research without agreeing to the following:

I agree that the researchers may retain my contact details in order to provide me with a summary of and link to the final thesis.	

Data Protection

The personal information we collect and use to conduct this research will be processed in accordance with UK data protection law as explained in the Participant Information Sheet and the Privacy Notice for Research Participants.

_____	_____	_____
Name of participant	Signature	Date
_____	_____	_____
Name of researcher	Signature	Date

Thank you for your consent. The original version of this consent form will remain with the research team and a copy will be sent to you.

Appendix E: screening template

Screening template

Thank you for meeting with me today. During this meeting I'll tell you about my research and you can decide if you'd like, and are able, to take part. I'll also ask you a few questions, to see if you're suitable for the research. You do not have to answer a question if you don't want, although if you chose not to answer this may impact your ability to take part in the research. You may stop the screening at any time.

Your answers will be confidential. No one will know your answers except for the research team.

Before we start I'll explain a bit about the research.

1. **Explain reason for undertaking research**

CFS/ME can be thought of as a poorly understood, controversial and contested condition. Individuals, like yourself, experience CFS/ME can face stigma and disbelief; yet they live with chronic, fluctuating, and often debilitating symptoms.

The reason for undertaking this research is to understand how people, in particular students, talk about their experience of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis. I'm interested in the impact of CFS/ME upon identity and how CFS/ME is experienced by people in higher education.

2. **Explain procedures of research**

If you wish to continue to take part in the research, and if you're eligible, then we would need to meet again, on Zoom, for a one-to-one research interview. The interview should last around an hour. I'll have a few guiding questions to direct the conversation. I understand that CFS/ME symptoms can fluctuate and can be hard to predict, so it's ok if you need to cancel the interview. We can always rearrange if necessary.

The interview will be recorded. After the interview I'll delete the video recording and just keep the audio. I'll create a transcript from the audio recording and analyse it for discourses and themes. At this stage your data will get pooled with data from other participants.

You are free to withdraw your consent at any time up until two months after the date of interview. This is because by this point your data will have been anonymised, analysed and pooled as part of a larger data set.

If you'd like I can forward you a summary of my final thesis when it's completed

3. **Outline inclusion criteria and check if participant fulfils all criteria**

Are you…

- 16-24 years old?

Do you…

- have a diagnosis of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME)?
- speak and read fluent English?

4. **Outline exclusion criteria and check if participant possesses any of these criteria which disqualify them from the research**

- Do you feel emotionally well to take part in this research?

- Some people find talking about their ME/CFS helpful. Others find it more difficult and distressing. How do you think you'd feel talking to me about your ME/CFS?

- Do you think that taking part in an online interview of up to 90 minutes would result in a significant exacerbation of your ME/CFS symptoms?

- If so, how do you think this would this impact you?

5. **Ask participant to complete two questionnaires, GAD-7 and PHQ-9. Explain their purpose to assess participants emotional wellbeing.**

6. **If participant does not fulfil inclusion and exclusion criteria explain reasons why and thank them for their time. Answer any questions**

7. **If participant does fulfil exclusion and exclusion criteria make appointment for research interview. Answer any questions**

Appendix F: Blank copy of PHQ-9 and GAD-7

Patient Health Questionnaire and General Anxiety Disorder
(PHQ-9 and GAD-7)

Date_____ Patient Name:_____ Date of Birth: _____

Over the last 2 weeks, how often have you been bothered by any of the following problems?
Please circle your answers.

PHQ-9	**Not at all**	**Several days**	**More than half the days**	**Nearly every day**
1. Little interest or pleasure in doing things.	0	1	2	3
2. Feeling down, depressed, or hopeless.	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much.	0	1	2	3
4. Feeling tired or having little energy.	0	1	2	3
5. Poor appetite or overeating.	0	1	2	3
6. Feeling bad about yourself – or that you are a failure or have let yourself or your family down.	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television.	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual.	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting yourself in some way.	0	1	2	3
Add the score for each column				

Total Score (add your column scores): _____

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people? (Circle one)

Not difficult at all **Somewhat difficult** **Very Difficult** **Extremely Difficult**

Over the last 2 weeks, how often have you been bothered by any of the following problems?
Please circle your answers.

GAD-7	**Not at all sure**	**Several days**	**Over half the days**	**Nearly every day**
1. Feeling nervous, anxious, or on edge.	0	1	2	3
2. Not being able to stop or control worrying.	0	1	2	3
3. Worrying too much about different things.	0	1	2	3
4. Trouble relaxing.	0	1	2	3
5. Being so restless that it's hard to sit still.	0	1	2	3
6. Becoming easily annoyed or irritable.	0	1	2	3
7. Feeling afraid as if something awful might happen.	0	1	2	3
Add the score for each column				

Total Score (add your column scores): _____

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people? (Circle one)

Not difficult at all **Somewhat difficult** **Very Difficult** **Extremely Difficult**

UHS Rev 4/2020

Appendix G: Interview schedule

1. Just before we start can I just check is there a term that you prefer to describe your condition?

- Do you prefer CFS or do you prefer ME?

2. **What does CFS/ME mean to you?**
3. **Do you feel your CFS/ME has influenced the way you see yourself? If so how?**
4. **If you are/were a student, what is it like to be a student with CFS/ME?**

   - How do/did you feel supported, if at all, by your university/ college?
   - If at all, how has CFS/ME affect(s)/ed your ability to participate in student activities?

5. **How, if at all, has CFS/ME affected your relationships? If so how?**

   - What about personal or intimate relationships?
   - What about relationships with family?
   - What about relationships with friends?

6. **On a societal level CFS/ME can be seen as a disability. What do you think of this?**

   - Do you or do you not see yourself as disabled?

7. Has CFS/ME changed the way you see your future? If so how?

   - Have you changed since you began to experience CFS/ME? If so, do you think this change will have lasting effects?

8. **If you were to give a message to healthcare professionals, what would you want them to know? What about education professionals?**
9. **If you were to give a message to the public, what would you want them to know?**

END OF RESEARCH INTERVIEW

- **Thank participant for their time**
- **Ask if they want to do breathing/mindful exercise or grounding exercise before ending Zoom**

Appendix H: Debrief sheet

Thank you for participating in this research. Your contribution is greatly appreciated. I hope that you have found it interesting and have not been upset by any of the topics discussed. However, if you have found any part of this experience to be distressing and you wish to speak to one of the researchers, please contact:

Emma Williams, trainee counselling psychologist

Email:

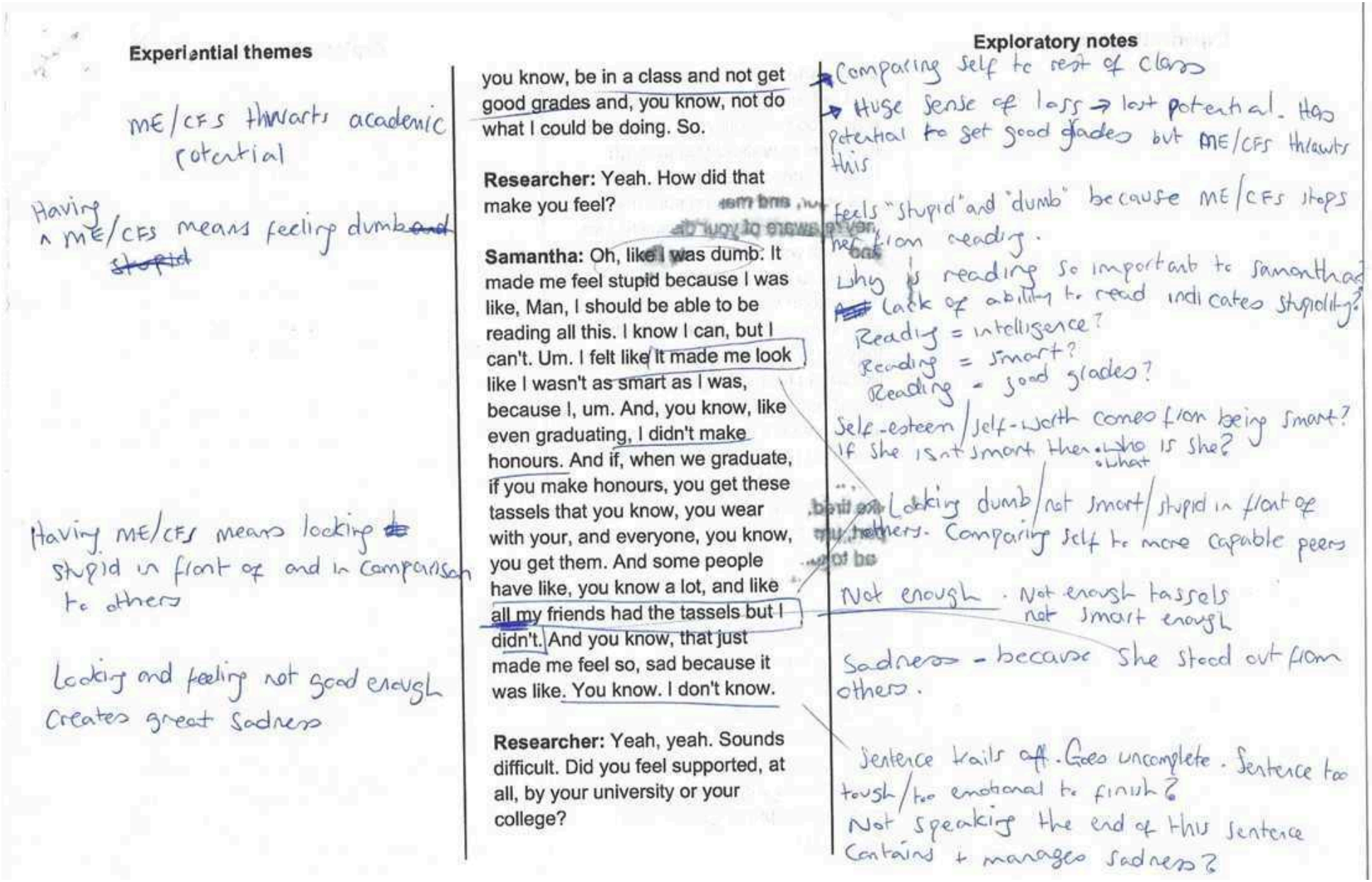
Telephone:

There are also several organisations listed below that you can contact.

ME Connect A helpline specifically for individuals with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis. **Telephone: 0344 576 5326** **ME connect is staffed 365 days a year and at the following times:** **10am-12noon, 2pm-4pm. 7pm-9pm**	**The Samaritans** A volunteer led listening service. Available on the telephone 24 hours a day, 365 days a year. The Samaritans aim to respond to all emails within 24 hours. **Telephone: 116 123 Email: jo@samaritans.org**
NHS psychological therapies service (IAPT) IAPT (Improving Access to Psychological Therapies) services offer:	**Your GP** You can get in touch with your GP if you feel they may be able to help you with your distress. GP's can listen to you, prescribe medication and/or refer you onto other suitable services.

• talking therapies, such as cognitive behavioural therapy (CBT), counselling, other therapies, and guided self-help • help for common mental health problems, like anxiety and depression You can self-refer to your local IAPT, details of which can be found here: https://www.nhs.uk/service-search/find-a- psychological-therapies-service/ There is often a waiting list for talking therapies provided by the NHS. You can talk to your local IAPT about this.	
 **PAPYRUS** PAPYRUS is the national charity dedicated to the prevention of young suicide. They provide confidential support and advice to young people struggling with thoughts of suicide. Their contact details are below: **Call:** 0800 068 41 41 **Text:** 07860 039967 **Email:** pat@papyrus-uk.org	If you live in Greater Manchester or the City of Manchester, Greater Manchester NHS Mental Health Crisis Care Services can help you. A crisis hotline is available 24/7 and can be reached using the following numbers: If you live in Bolton, Salford, Trafford or the City of Manchester call **0800 953 0285** If you live in Wigan call **0800 051 3253**

Appendix I: Example of transcript analysis for Samantha



Experiential themes

ME/CFS thwarts academic potential

Having ME/CFS means feeling dumb ~~and stupid~~

Having ME/CFS means looking ~~de~~ stupid in front of and in comparison to others

Looking and feeling not good enough creates great sadness

you know, be in a class and not get good grades and, you know, not do what I could be doing. So.

Researcher: Yeah. How did that make you feel?

Samantha: Oh, like I was dumb. It made me feel stupid because I was like, Man, I should be able to be reading all this. I know I can, but I can't. Um. I felt like it made me look like I wasn't as smart as I was, because I, um. And, you know, like even graduating, I didn't make honours. And if, when we graduate, if you make honours, you get these tassels that you know, you wear with your, and everyone, you know, you get them. And some people have like, you know a lot, and like all my friends had the tassels but I didn't. And you know, that just made me feel so, sad because it was like. You know. I don't know.

Researcher: Yeah, yeah. Sounds difficult. Did you feel supported, at all, by your university or your college?

Exploratory notes

Comparing self to rest of class

Huge sense of loss → lost potential. Has potential to get good grades but ME/CFS thwarts this

feels "stupid" and "dumb" because ME/CFS stops her from reading.

Why is reading so important to Samantha?

Lack of ability to read indicates stupidity?

Reading = intelligence?

Reading = smart?

Reading = good grades?

Self-esteem/self-worth comes from being smart?

If she isn't smart then who/what is she?

Looking dumb/not smart/stupid in front of others. Comparing self to more capable peers

Not enough. Not enough tassels not smart enough

Sadness - because she stood out from others.

Sentence trails off. Goes uncomplete. Sentence too tough/too emotional to finish?

Not speaking the end of this sentence Contains + manages sadness?

Experiential themes

Appreciation of disability service

No universal and assumed understanding of ME/CFS, so responsibility to educate others is on Samantha

It is important that others truely understand ME/CFS

Being disabled but struggle to accept ownership of disability

Academic support was a welcome surprise.

Samantha: I would say yes. I, like I said before. Well, so there was a really good disability services, and they kind of walked you through how you need to approach each professor, and making sure that, they're aware of your disability. Um, and so it was really up to the student to make sure that they understood where you're at. And I'd say I really tried to make sure that they knew and really understood, like what chronic fatigue was, why I would not be, if I was missing class, like because it was, I had a crash or something. I wanted them to know, like, it wasn't like, no, I'm not just like tired. And I think for the most part, um, because we did that, we had to turn in like a sheet every semester that they signed and the student signed. And it was like an agreement that, you know, you could do this because you have this documented disability. And I would say that they were really, I never had a professor who gave me, you know, was mad at me for anything. And that was surprisingly yeah, I mean, it was pretty good in that sense. Um.

Exploratory notes

Well supported by disability service at university.

Need to make others aware of ME/CFS. Responsibility to educate is on her

ME/CFS as a disability.

Educating each professor needs individualised approach? No universal understanding of ME/CFS.

Speaking in the third person. Why the shift from 1st to 3rd? Getting some distance from emotion in previous paragraph? Getting some distance from the disability service - doesn't want to be associated with them?

It is important that others understand what ME/CFS is like. "I'm not just like tired" ME/CFS too easily trivilised by others.

Contractual agreement regarding university work in the presence of ME/CFS

Surprised that no professor was "mad at me" expecting to be treated badly? Because of ME/CFS? Because of lower grades?

In that sense - felt academically supported but were there other ways that the experience was not "pretty good"

Experiential themes

Empathy and some understanding from others, but lack of ~~full~~ complete understanding

feeling not fully understood

Samantha's

Many people think ME/CFS is just tiredness, ~~to extent~~ but actually there are many more symptoms

extent of Post exertional malaise not fully realised by others

Tendency to push beyond comfortable ~~physical~~ limits

Lack of communication regarding physical limitations

Researcher: Did you feel like there was, or not, um, a decent amount of understanding about chronic fatigue syndrome?

Samantha: Umm, I think people were sympathy-, sympathetic and empathetic to it, and I think they understood that I was tired a lot. And that might explain some things, but I don't think they fully understood. Like, um. How can, you know I don't think they actually fully understood the disease. To it being It's also pain and inflammation. Sometimes you can get sick a lot easier. Um. You're physically, like, just like, I mean and didn't blame them for not knowing any of this, but like, you know, if they're like, hey, could you bring like a couple boxes of some equipment or something, you know, like I would do it. But it was also like, that was really hard for me. Stuff like that. Any fault of their own, you know?

Researcher: Yeah. Yeah. So we're around about halfway through the questions.

Exploratory notes

Other people sympathetic and empathetic to ME/CFS

Other people understand somewhat, but they don't fully understand.

feeling not fully understood

ME/CFS is more than just fatigue. It's
- pain
- inflammation
- physically limiting
- lowered immune system

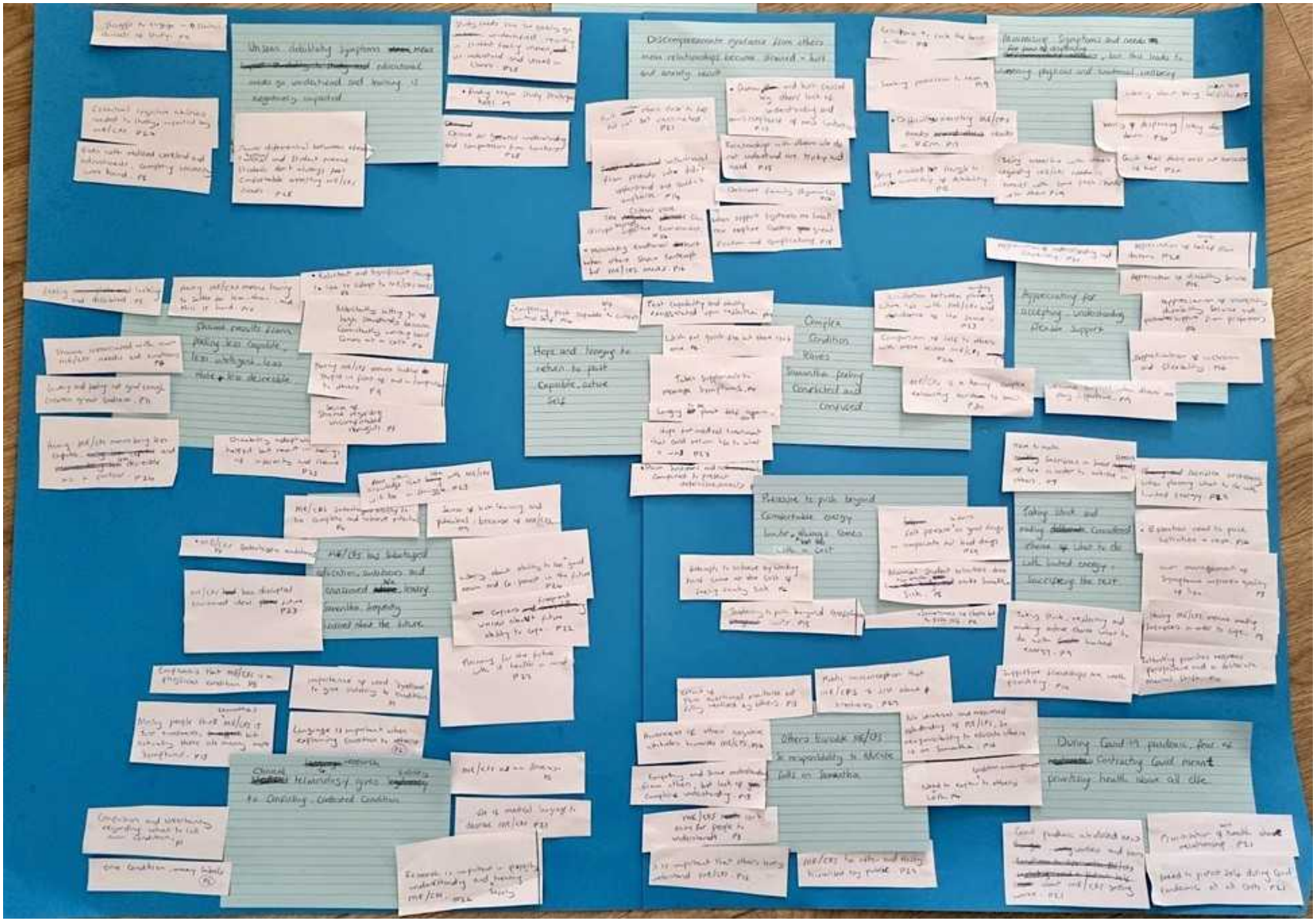
Switching between 1st, 3rd, 1st, 3rd person

→ Other people's perceptions/expectations are higher than Samantha's capability

→ Samantha would push herself beyond comfortable capability - rather than asserting boundaries/displeasing - at least with individuals at uni

↘ Was this ever said/spoken or just thought?

Appendix J: Samantha's personal experiential themes (PETs) in development



Appendix K: PET table for Samantha

Personal experiential theme	*Experiential statements*
Unseen debilitating symptoms mean educational needs go unidentified and learning is negatively impacted.	Struggle to engage in essential elements of study. p. 9 Essential cognitive abilities needed to study impacted by ME/CFS. p. 27 Even with reduced workload and adjustments, completing university was hard. p. 8 Power differential between educational professionals and Samantha meant she didn't always feel comfortable asserting ME/CFS needs. p. 28 Desire for greater understanding and compassion from teacher. p. 28 Unique study strategies help. p. 9 Study needs can too easily go unidentified, resulting in Samantha feeling unseen, ununderstood and unwell in class. p. 28
Personal experiential theme	***Experiential statements***
Others trivialise ME/CFS, so responsibility to educate falls on Samantha.	Extent of post-exertional malaise not fully realised by others. p. 13 Awareness of others' negative attitudes towards ME/CFS. p. 17

	Empathy and some understanding from people, but lack of complete understanding. p. 13 ME/CFS isn't easy for people to understand. p. 3 It is important that others truly understand ME/CFS. p. 12 ME/CFS too often and easily trivialised by public. p. 29 Need and wish to explain condition and management to others. p. 14 No universal assumed understanding of ME/CFS, so responsibility to educate others is on Samantha. p. 12 Public misconception that ME/CFS is just about tiredness. p. 29
Personal experiential theme **Complex condition leaves Samantha feeling conflicted, confused and uncertain.**	***Experiential statements*** Oscillation between thinking and planning future life with ME/CFS and avoidance of the same. p. 23 Comparison of self to others with more severe ME/CFS. p. 27 ME/CFS is a heavy, complex, exhausting burden to bear. p 30 Confusion and uncertainty regarding what to call own condition. p. 1 One condition, many labels. p. 2

Personal experiential theme	*Experiential statements*
Hope and longing to return to past capable, active self.	Comparing past capable self to current limited self. p .14 Past capability and ability exaggerated upon reflection. p. 14 Wish for quick fix but there isn't one. p. 4 Longing to be past self again. p. 23 Hope for medical treatment that could return life to what it was. p. 23 Past activities and achievements compared to present under-achievements. p. 5

Personal experiential theme	*Experiential statements*
Minimising ME/CFS needs.	Reluctance to rock the boat. p. 17 Seeking permission from others to rest. p. 19 Difficulties asserting ME/CFS needs results in post-exertional malaise. p. 15 Being disabled but struggling to accept disability. p. 12 Being assertive with others regarding ME/CFS is easier with some people, harder with others. p. 19 Worry of displeasing and letting others down. p. 20 Worry about being seen as selfish. p. 17
Personal experiential theme	*Experiential statements*
Lack of consideration mean relationships become strained	Hurt when others close to her did not get vaccinated. p. 21 Withdrawal from friends who didn't understand and couldn't emphasise. p. 14 One critical voice can disrupt seemingly supportive environment. P. 17 Minimising emotional hurt when others show contempt for ME/CFS needs. p. 16 When support systems are small, one rupture causes great friction and complications. p. 18

	Delicate family dynamics. p. 17 Relationships with others who do not understand are tricky and hard. p. 18 Friction and hurt caused by others' lack of understanding and non-acceptance of new limitations. p. 15

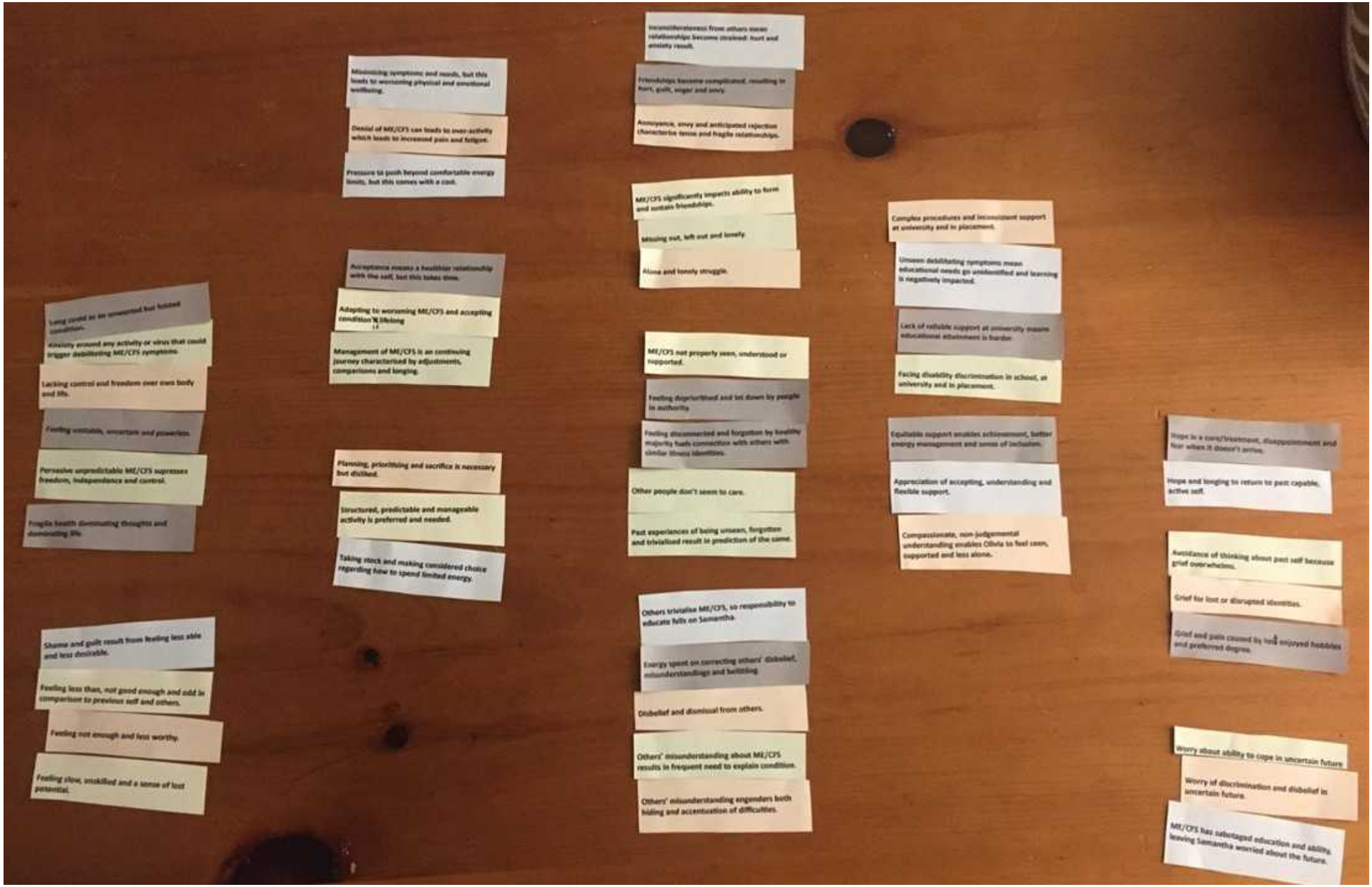
Personal experiential theme	***Experiential statements***
Appreciation of accepting, understanding and flexible support.	Appreciation of understanding, inclusive and flexible support. p. 16, p. 20 Appreciation of trust and belief from doctors. p. 26 Appreciation of university disability service and support from professors. p. 7, p. 12 Welcome surprise when others are very supportive. p. 19
Personal experiential theme	***Experiential statements***
Shame and guilt result from feeling less able and less desirable.	Feeling lacking and disabled. p. 3 Guilt results from belief that others miss out because of her. p. 20 Shame associated with own ME/CFS needs and associated emotions. p. 17 Having ME/CFS means being less capable and less desirable as a partner. p. 24

	Looking and feeling not good enough causes great sadness. p. 11 Disability adaptations helpful but result in feelings of inferiority and shame. p. 25 Sense of shame regarding uncomfortable thoughts. p. 5 Having ME/CFS means looking stupid in front of and in comparison to others. p. 11 Having ME/CFS meaning having to settle for less and this is hard. p. 10
Personal experiential theme **Pressure to push beyond comfortable energy limits, but this comes with a cost.**	***Experiential statements*** Attempts to achieve by working hard come at the cost of feeling really sick. p. 6 Tendency to push beyond comfortable limits. p. 1 Sometimes no choice but to push self. p. 9 Late nights studying hard makes Samantha sick. p. 9 Felt pressure to be productive on good days, to compensate for bad days. p. 29
Personal experiential theme **Taking stock and making considered choice regarding how to spend limited energy.**	***Experiential statements*** Making sacrifices in some areas of life to achieve in others. p. 7 Reluctantly letting go of high standards because consistently working hard comes at a cost. p. 7

	Reluctant and significant change to life to adapt to ME/CFS needs. p. 5 Reflecting and making active choice regarding what to do with limited energy. p. 9 Supportive friendships are worth prioritising. p. 10 Rethinking priorities requires perspective and a deliberate mental shift. p. 10 Having ME/CFS means making sacrifices to cope. p. 8 Own management of symptoms improves quality of life. p. 3 Essential need to pace activities with rest. p. 16 Sacrifice necessary when planning what to do with limited energy. p. 29
Personal experiential theme **During covid pandemic, fear of contracting covid meant prioritising health above all else.**	***Experiential statements*** Covid pandemic introduced new worries about ME/CFS getting worse. p. 21 Need to protect self at all costs during covid pandemic. p. 21 Prioritisation of health above relationship. p. 21
Personal experiential theme	***Experiential statements***

ME/CFS has sabotaged education and ability, leaving Samantha worried about the future.	ME/CFS sabotages ambitions. p. 5 ME/CFS has disrupted envisioned ideal future. p. 23 Planning for the future with ill health in mind. p. 22 Copious frequent worries about future ability to cope. p. 22 Worry about ability to be a good mum and co-parent in the future. p. 24 Sense of lost learning and potential. p. 9 Fear comes with knowledge that life with ME/CFS will be a struggle. p. 23 ME/CFS sabotages ability to be complete and achieve potential. p. 6

Appendix L: GETs in development



Appendix M: Tables of GETs, sub-GETS, PETs and engendered quotes

GET 1	Sub-GET	Participants					PETs
"They're not seeing all of me": Others don't understand.	**"Invisible disabilities" : Feeling unseen, forgotten and dismissed.**	Morgan ☒	Samantha ☐	Olivia ☒	Peter ☒	James ☒	**Missing out, left out and lonely.** *"I spent a lot of time not able to see like, the whole of that side of my family". Morgan, p.21.* **Being unseen, forgotten and trivialised.** *"I kind of just kept feeling like they're not seeing all of me". Morgan, p. 33* **Alone and lonely struggle.** *"Nobody was there to help me. I was, I was on my own". Olivia, p. 5* **ME/CFS not properly seen, understood or supported.** *"A lot of the time, they're more like, they want to treat it like a you have a cold". Peter, p. 27.* **Feeling deprioritised and let down by people in authority.** *"I feel completely screwed and completely utterly helpless". James, p. 26* **Feeling disconnected and forgotten by healthy majority fuels connection with others with similar illness identities.**

							"you feel a pretty profound sense of alienation". James, p. 15.

	Sub-GET	Participants					PETs
	"They didn't understand": Relationships become complicated, fragile and lost.	Morgan ☒	Samantha ☒	Olivia ☒	Peter ☐	James ☒	**Other people don't seem to care.** *"And then I was doing school part time, so then it was like, when I wasn't there, they didn't really care". Morgan, p. 20.* **Lack of consideration mean relationships become strained.** *"He didn't understand why it hurt me that I, that he wasn't going to get vaccinated." Samantha, p. 21.* **Family dynamics change over time.** *"It's taken all this time, to reach some kind of level of understanding with my family". Olivia, p. 42.* **Friendships become complicated, resulting in hurt, guilt, anger and envy.** *"It's helped weed out, who, who really cares about me and who doesn't". James, p. 22.*
	Sub-GET	**Participants**					**PETs**

	"I wanted them to know": Educating others in the face of disbelief and misunderstanding.	Morgan ☒	Samantha ☒	Olivia ☒	Peter ☐	James ☒	**Others' misunderstanding about ME/CFS results in frequent need to explain condition.** *" And they're like, well, ME's just the one where you get a bit tired. Why are you in a wheelchair for?". Morgan, p. 16.* **Others trivialise ME/CFS, so responsibility to educate falls on Samantha.** *"I wanted them to know… like no, I'm not just like tired". Samantha, p. 12.* **Disbelief and dismissal from others.** "*I tell people the extent of it, they are shocked". Olivia, p. 39.* **Energy spent on correcting others' disbelief, misunderstandings and belittling.** *"I've had people say to me that my condition is just me being lazy". James, p. 30.*

GET 2	Sub-GET	Participants					PETs
"It literally does disable you": lacking control.	**"I can't do that anymore" : Lacking control over body and life**	Morgan ☒	Samantha ☒	Olivia ☒	Peter ☒	James ☒	**Anxiety around any activity or virus that could trigger debilitating ME/CFS symptoms.** *"I overthink going up and down the stairs too many times in a day". Morgan, p. 6.*

							Pervasive unpredictable ME/CFS supresses freedom, independence and control. *"I can't plan next week, let alone like years down the line". Morgan, p. 27.* **Complex condition leaves Samantha feeling conflicted, confused and uncertain.** *"It's just it's so complex, that think you have to approach it with, just there's so many different aspects to it". Samantha, p. 26.* **Lacking control and freedom over own body and life.** *"I have to work when I am well. Not work when I'm not well. And, I don't know whether I'm going to flare up tomorrow and then not be able to do much for four months". Olivia, p. 12.* **ME/CFS impacts ability to get out and form friendships.** *"I can go out for, like, ten minutes if I'm, if it's a good day, but that's not really much to go anywhere". Peter, p. 12.* **Health dominating thoughts and dominating life.** *"I figured it would just be better if I stayed home". James, p. 9.*

	Sub-GET	Participants					PETs
	"Your future's in the air": lacking control over future.	Morgan ☒	Samantha ☒	Olivia ☒	Peter ☐	James ☒	**Worry about ability to cope in uncertain future.** "*Constantly having to reassess, what your body can do now… but in three months' time, that plan might be completely out the window". Morgan, pp. 28-29.* **ME/CFS has sabotaged education and ability, leaving Samantha worried about the future.** *"I think about, how I'll have to live with this for the rest of my life". Samantha, p. 23.* **Worry of discrimination and disbelief in uncertain future.** *"It's something that I worry about, the future and employment and discrimination". Olivia, p. 8* **Long covid as an unwanted condition.** *"for a long time I I denied the fact that I was [disabled]… I didn't want to believe that my options, you know, for my future and for my education were limited". James, p. 30.* **Feeling unstable, uncertain and powerless.** *"Your health is completely up in the air, your future's in the air". James, pp. 40-41.*

GET 3	Sub-GET	Participants					PETs
"You'll be fine": Pushing beyond energy capacity because of pressure, frustration or denial.	N/A	Morgan ☐	Samantha ☒	Olivia ☒	Peter ☐	James ☒	**Minimising ME/CFS needs.** *"if they're like, hey, could you bring like a couple boxes…like I would do it. But it was also like, that was really hard for me." Samantha, p. 13.* **Pressure to push beyond comfortable energy limits, but this comes with a cost.** *"they would be like, why? It's not that far, you'll be fine. And, you know, then I was so sick". Samantha, p. 15.* **Denial of and frustration with ME/CFS leads to over-activity.** *"I am fed up with doing nothing, and I'm fed up of feeling like I'm going nowhere". Olivia. p. 4* **Acceptance of condition means a healthier relationship with the self, but this takes time.** *"exercise is a huge part of my life before I got sick". James, p. 33*

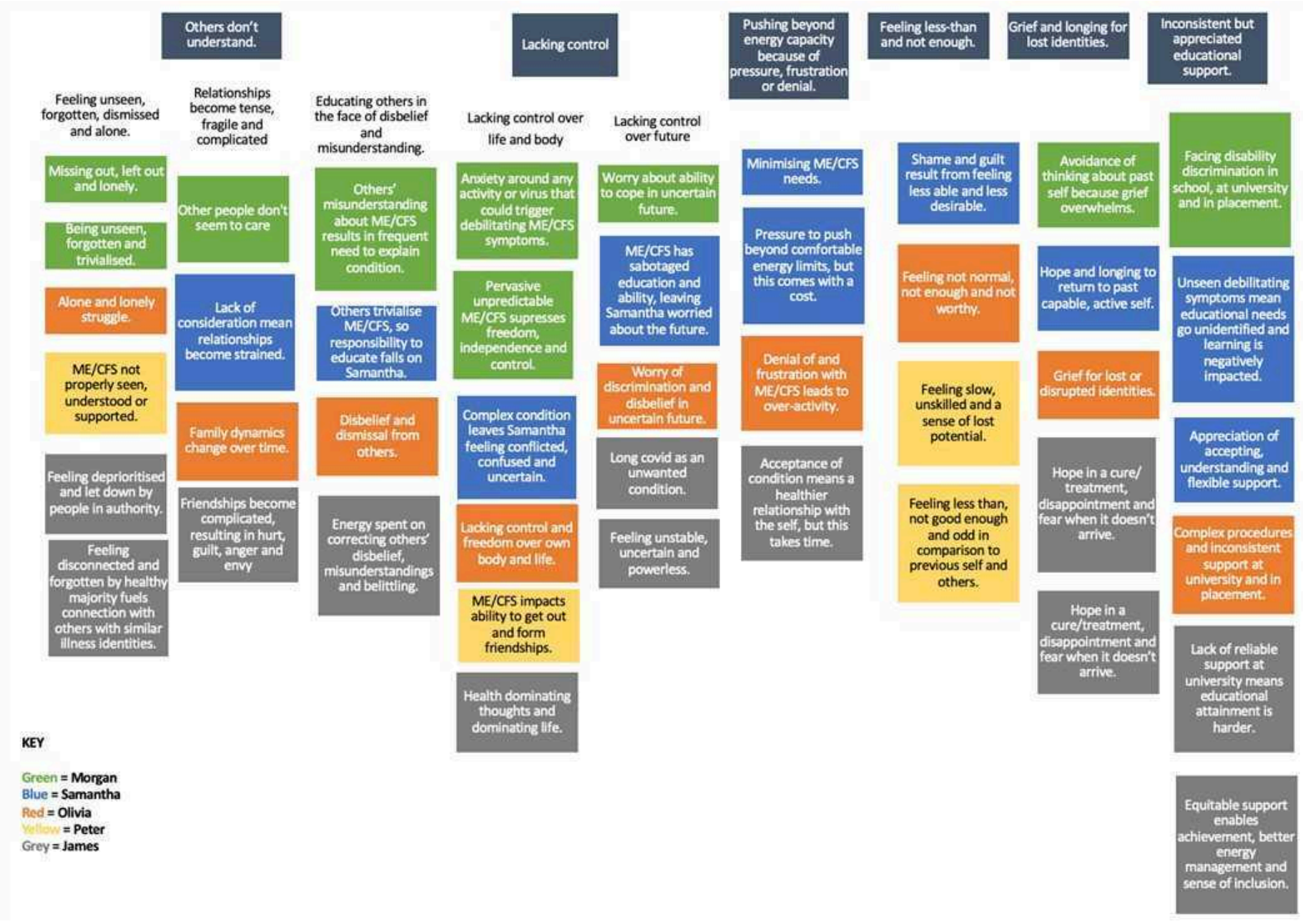
GET 4	Sub-GET	Participants					PETS
"Not good enough": Feeling less-than and not enough.	N/A	Morgan ☐	Samantha ☒	Olivia ☒	Peter ☒	James ☐	**Shame and guilt result from feeling less able and less desirable.** *"When we graduate, if you make honours, you get these tassels… and like all my friends had the tassels but I didn't". Samantha, p. 11.* **Feeling not normal, not enough and not worthy.** *"We will never be normal". Olivia, p. 28.* **Feeling slow, unskilled and a sense of lost potential.** *"You can't be the best that you can be when you're tired". Peter, p. 6.* **Feeling less than, not good enough and odd in comparison to previous self and others.** *"I want to, get better and be as good as them". Peter, p. 10.*

GET 5	Sub-GET	Participants					PETS
"Giving that up is really difficult": Grief and longing for lost identities.	N/A	Morgan ☒	Samantha ☒	Olivia ☒	Peter ☐	James ☒	**Avoidance of thinking about past self because grief overwhelms.** *"If I think about it too much, then it's like, how much smaller it's made, like, my world is quite scary." Morgan, p. 9.* **Hope and longing to return to past capable, active self.** *"Hopefully treatment could come… then it will just be like I've always planned". Samantha, p. 23.* **Grief for lost or disrupted identities.** *"work has been one of the biggest parts of my identity since I was fourteen. And giving that up is really difficult". Olivia, p. 14.* **Grief and pain caused by lost enjoyed hobbies and preferred degree.** *"I tried to still go on runs, right. And I thought… that I could exercise my way out". James, p. 33.* **Hope in a cure/treatment, disappointment and fear when it doesn't arrive.** *"I've seen pretty much every type of doctor there is to see". James, p. 34*

GET 6	Sub-GET	Participants					PETS
"It's very mixed": Inconsistent educational support.	N/A	Morgan ☒	Samantha ☒	Olivia ☒	Peter ☐	James ☒	**Facing disability discrimination in school, at university and in placement.** *"they said they were wheelchair accessible. Yes, but now I've got to have somebody follow me around the whole school opening every door". Morgan, p. 18.* **Unseen debilitating symptoms mean educational needs go unidentified and learning is negatively impacted.** *"I couldn't read and I couldn't erm, do as well". Samantha, p. 9.* **Appreciation of accepting, understanding and flexible support.** *"I was able to really get the grace when I needed it". Samantha, p. 8.* **Complex procedures and inconsistent support at university and in placement.** *"So then it's trying to go through occupational health to get a part time placement, and, it's all, very, complicated". Olivia, p. 4.* **Lack of reliable support at university means educational attainment is harder.**

							"Some of them… have been extremely understanding. Others have, have haven't been understanding whatsoever.". James, p. 7. **Equitable support enables achievement, better energy management and sense of inclusion.** *"I was really struggling with managing my energy, he was okay with that". James, p. 39.*

Appendix N: Flow chart of GETs, sub-GETs and PETs



Appendix O: CDC factsheet for education professionals

Accessible version available at: https://www.cdc.gov/me-cfs/me-cfs-children/factsheet-educational-professional.html

Helping Students Who Have Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

Fact Sheet for Education Professionals

When teaching adolescents or younger children with ME/CFS, it can be helpful to understand more about the problems faced by these students. A key to helping students with ME/CFS is to work as a team with their teachers, parents, administrators, other education professionals, and healthcare professionals. This team approach can provide flexibility with educational plans and school resources that are customized to target and reflect the student's needs.

ME/CFS affects each student differently. Each child may experience different symptoms and the duration of their symptoms may differ as well. Symptoms can fluctuate from day to day and week to week, affecting a young person's ability to attend school regularly and perform consistently.

ME/CFS can affect children and adolescents in many ways, including their:

- Attendance
- Ability to participate both inside and outside of the classroom
- Relationships with peers
- Ability to complete assignments
- Overall school success

Understand How ME/CFS Affects Students Inside and Outside the Classroom

Teachers and administrators who are not familiar with ME/CFS could mistake a child's illness and fatigue for laziness or avoidance of social interaction. Below are a few examples of how ME/CFS can affect students:

- School performance or attendance can be affected by a student's ME/CFS symptoms, such as memory or concentration problems, unrefreshing sleep, and headaches.
- Adolescents and younger children with ME/CFS can experience problems when trying to do several things at once—for example, doing their homework and keeping track of time.

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Division of High-Consequence Pathogens and Pathology

CS280267

- Many children with ME/CFS experience more severe symptoms in the morning hours and may have trouble getting to school on time or staying alert in the morning at school.
- Children with ME/CFS can have problems with attention, response time, information processing speed, and delayed recall of verbal and visual information.
- Teachers may notice that students with symptoms mentioned above may be able to complete grade-level tasks, but might require more time to do so.

Tips for Teachers and Administrators*

Because ME/CFS is a complex disorder that affects how students learn and participate in school, teachers and administrators may want to be creative in developing strategies to foster an encouraging learning environment for their students with ME/CFS. Teachers and administrators may want to:

- Help students with note taking.
- Give them extended time on exams and assignments.
- Schedule rest periods during class or throughout the day.
- Avoid information overload.
- Be open to combining school and home tutoring.
- Permit students to attend school in shorter periods rather than a full day, as necessary.
- If advised by the student's doctor, allow students to participate in modified physical education classes, or exempt them from class, if needed.
- Give students an extra set of books to use at home.
- Offer and encourage the use of organizers, schedulers, and other tools for time management.

*NOTE: The list above is not exhaustive. Teachers and administrators may need to explore other strategies to accommodate the particular needs of each individual student with ME/CFS.

For more information about ME/CFS, visit www.cdc.gov/me-cfs

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