The Secondary School Experience with Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ME): An Interpretative Phenomenological Analysis of the Retrospective Accounts of Young Adults

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Abstract

Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ME) is an illness with a range of symptoms, however a core feature is fatigue after physical or mental exertion (NICE, 2007). The illness affects up to 2% of secondary school children (Collard & Murphy, 2019). It is a main cause of prolonged school absence (Crawley et al., 2018), and the impacts raise potential needs across all areas of the SEND Code of Practice (DoH & DfE, 2015). A literature review for the present study found little research had been conducted into the secondary school experiences of children and young people with CFS/ME, as much as the research came from a medical perspective, of which school life was a smaller consideration.

This study aims to explore the experiences of secondary school aged pupils with CFS/ME. Semi-structured interviews were conducted with two young adults who experienced CFS/ME while at secondary school to gain a retrospective understanding of their experiences. Interviews were analysed using Interpretative Phenomenological Analysis, and four shared superordinate themes were found that highlighted the school experience with CFS/ME. These themes related to the physical impact the illness had on their schooling experience, as well as the role of systemic factors, both positive and negative. Professional implications include raising awareness of the potential social and emotional needs of young people, as well as possible learning and physical needs to consider when working with this population. Professionals should also consider ways in which young people can be represented and heard within schools so they feel supported and understood by adults to reduce barriers they may face within secondary education, particularly relating to academic demands such as the school curriculum.

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Abbreviations

CBT: Cognitive Behavioural Therapy

CFS: Chronic Fatigue Syndrome

CFS/ME: Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis

DfE: Department for Education

DoH: Department of Health

EHCP: Education, Health and Care Plan

EP: Educational Psychologist

EPS: Educational Psychology Service

IPA: Interpretative Phenomenological Analysis

LA: Local Authority

ME: Myalgic Encephalomyelitis

SEND: Special Educational Needs and Disabilities

TEP: Trainee Educational Psychologist

1. Introduction to the Thesis

This thesis explores the retrospective experiences of young adults who had a diagnosis of the medical condition Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ME) during their secondary school education. The thesis begins with an outline of the legislative picture surrounding meeting medical needs in school and the impacts of CFS/ME on children and young people. This is followed by a meta-ethnographic review considering qualitative research outlining how support is provided in practice within schools, leading to the research question to investigate how young adults experienced secondary school with CFS/ME. The methodological section considers the ontological and epistemological positioning of the thesis, and details of the chosen research method, IPA. An IPA analysis of the semi-structured interview is presented, followed by a discussion relating these to the existing literature and implications for professional practice.

1.1 Personal Interest in the Research Area

While studying for the Doctorate in Applied Educational Psychology, I received a diagnosis of CFS/ME after a viral illness. This impacted significantly on my life, including my participation in the course. In my own research into the condition, I came to realise how much about the illness is still unknown, as well as the myths and misconceptions that surround the illness. During contact with specialist health professionals during my treatment, it was brought to my attention that diagnostic rates for children and adolescents are increasing, particularly over the last few years. Due to my own experience with CFS/ME and the impact it had on my studies I began to reflect on what this experience may be like for school aged children and young people, and what research could tell us about this. My initial literature searches and discussions with professionals revealed little research had been conducted into this area, research often focussed on the medical aspects of CFS/ME rather than hearing the voices of affected children and young people. I felt that the opportunities I had available to me as a postgraduate researcher with insight into the condition would provide an effective platform to study this area further and address some of the many 'unknowns' I had found in the literature and address what I feel to be an area of inequality.

1.2 Professional Interest in the Research Area

EPs have a professional obligation to support the overall wellbeing and positive development of children and young people (Nastasi & Naser, 2014). The EP role is complex, and draws on psychological theory and models applied to real life-learning contexts (Mayer, 2018). The knowledge gap that exists surrounding the experiences of adolescents within school could therefore disadvantage these children who require EP support due to a lack of evidence-based practice recommendations. Addressing this knowledge gap is closely aligned to the professional values I hold as part of my professional practice in ensuring quality, evidence-based services for all children who require them.

Since beginning my research, and the Covid-19 pandemic has progressed, I have been increasingly concerned by anecdotal accounts of 'Long-Covid' being observed in children and young people in the media. Although Long-Covid is a newly identified condition, with no official diagnostic criteria as yet, several of the symptoms mirror those of CFS/ME, such as intense fatigue (Fernández-De-las-peñas et al., 2021). A better understanding CFS/ME in schools may provide further insight into the impacts of 'Long-Covid' and the potential impacts this could have within school systems following the Covid-19 pandemic.

1.3 Research Approach

The study adopts an Interpretative Phenomenological Analysis (IPA) approach. The research questions posed by the study are exploratory in nature and look to understand this for the individuals involved in the research, therefore IPA is therefore an appropriate methodology to examine the research question.

1.4 Unique Contribution of the Research

The research adds a unique contribution to our understanding of CFS/ME in several ways. Literature searches suggest this will be one of the first studies to specifically consider the school experiences of adolescents with CFS/ME, as opposed to considering schooling as a smaller aspect of a larger study into the impacts of CFS/ME, or focusing on a younger age range. Additionally, by speaking to young adults who have completed their secondary school career, the retrospective nature of the study captures the fullness of their experiences of CFS/ME at school. This begins to address the knowledge gap previously outlined in this area, specifically providing evidence to support EP assessment and intervention when working with adolescents with CFS/ME.

1.5 Thesis Outline

The thesis will outline the research process through the following structure:

- Chapter 2: A literature review considering the wider research evidence into the impacts of CFS/ME on adolescents and the legislative framework of meeting these needs in English schools. This is followed by a systematic literature review to consider how young people experience support within school systems.
- Chapter 3: This section considers methodological issues relating to the research and rationale for selection of the use of IPA. This is followed by a reporting of the method used.
- Chapter 4: This chapter presents the results of the IPA, illustrated using quotes from participants throughout the account.
- Chapter 5: This section discusses the findings from chapter 4 in comparison to existing literature, including implications for professional practice for professionals working with this population.
- Chapter 6: A brief overview of the thesis and main conclusions drawn from the research.

2.Literature Review

2.0 Introduction to the Literature Review

This chapter first outlines the impacts of CFS/ME on a child or young person's health and wellbeing. This is important as it sets context for their needs in school, and how they can be recognised as a form of SEN (Cline & Frederickson, 2009). The issues of equality and access to education are explored through the legislative frameworks that outline the current English school guidance to support children with long term medical needs in schools, such as the Equalities Act (2010) and 'Supporting Children with Medical Needs in School' guidance (DfE, 2015). The literature review considers the symptoms of CFS/ME on the educational experiences of children and young people, and how understanding these needs are relevant to professionals, including EPs. Finally, a systematic literature review using the meta-ethnographic review process (Noblit & Hare, 1988) evaluates papers that consider the support that is currently offered to school aged children with CFS/ME.

2.1 CFS/ME in Children and Adolescents

This section includes a summary into the current diagnostic criteria, symptoms and causes of CFS/ME in adolescence. The section considers historic misconceptions around the illness and the impact this could have on help seeking behaviour and the potential EP role within this. In this section, the term 'paediatric' refers to cases of CFS/ME in children under 18. Adolescence is used to refer to children aged 10-19, in line with the World Health Organisation (WHO) definition of the term, and childhood refers to children under 10 (WHO, 2014). These terms reflect the positioning of the literature described in this section which is closely allied with health-related fields. In reporting studies, the terms used by each individual author will be used according to the conventions and definitions of their profession, which explains why there is some potential overlap in terms. Any differences within this reporting are specified. When discussing the literature in relation to the role of the EP, the phrase 'child or young person' will be used, as this represents the 0-25 age range that is covered by the SEND Code of Practice (DfE & DoH, 2015). This background information into CFS/ME gives an overview of the physical impacts of the illness, which provides context and meaning to situate the findings of this study.

2.1.1 What is CFS/ME?

Children and adolescents commonly experience episodes of increased fatigue which are typically short-lived and resolve spontaneously (Chadler et al., 2003). CFS/ME differs from this more generalised fatigue experience in several ways. It is important to note that

globally, diagnostic criteria are variable (Cairns & Hotopf, 2005). This thesis will consider CFS/ME symptoms and their impact based on the English diagnostic criteria due to the context of the researcher's dual professional role within the English school system.

The diagnostic criteria for CFS/ME in children describe the condition as characterised by persistent fatigue which significantly reduces activity over a period of three months, that is not improved by rest or sleep, nor is explained by biological factors, such as infectious diseases (National Institute for Health and Care Excellence (NICE), 2007). NICE further specify that CFS/ME is characterised by a 'significant' reduction in physical activity and the presence of 'post-exertional malaise' (PEM). PEM is defined by NICE as the increase of fatigue following a period of exertion which takes several days to recover from. The exertion described does not just relate to physical activity but also mental or emotional effort. These factors differentiate CFS/ME from the more common, short-lived episodes of tiredness or fatigue which are improved with rest. NICE recommends diagnosis of CFS/ME for children and young people from a paediatrician.

CFS/ME is the term commonly used in the literature, however some researchers suggest they are medically different disorders (Maes et al., 2012), although this evidence is contested. The label CFS/ME remains controversial too, with some patient advocacy groups advocating for a renaming of the term due to historical stigma linked to the name (Jason et al., 2002). This will be explored further in section 2.1.5. This study uses the term CFS/ME due to its widespread use in the studied literature and its use in the English diagnostic system (NICE, 2007), however it is recognised research participant or studies may prefer to use their own terms to describe the illness.

2.1.2 Onset and Prevalence of CFS/ME

Estimates of prevalence rates of CFS/ME in childhood are highly variable, but recent estimates suggest up to 2% of secondary school aged children are affected in the UK (Collard & Murphy, 2019). The fact that diagnostic estimates are highly variable, ranging from below 1% to over 3% in some studies suggests there are challenges linked to the accurate identification in the illness (Geraghty & Adeneji, 2019). They suggest that this could be down to the range of conditions that can cause fatigue, which lead to inaccurate diagnoses of CFS/ME. This means it is important to distinguish how CFS/ME has been diagnosed as opposed to more general fatigue, to ensure research is relevant to the needs of this population. The lack of research into paediatric CFS/ME has been identified as an

issue in the field, which has been reflected in how medical professionals identify the illness, which could be contributing to the varied prevalence estimates (Rowe et al., 2017).

When considering the development of CFS/ME across the lifespan, rates of diagnosis peak jointly in adolescents between the ages of 10-19 and adults aged 30-39 (Bakken et al., 2014). Although less common, younger children can be affected (Nijhof et al., 2011). This means that a diagnosis of CFS/ME is therefore likely to co-occur with the timing of late primary and secondary school education within the UK. This is where formal examinations are undertaken, including GCSEs, which have an influence on future career and study options and is often considered a stressful time for young people (Denscombe, 2000). The timing of a CFS/ME diagnosis could therefore occur at a significant time in the education of children and young people and cause disruption to formal exams. Because of the potential longitudinal impacts of CFS/ME on education and development, early identification and treatment of children and adolescents is considered a priority to ensure they receive appropriate support (Collin et al., 2015).

The long-term prognosis for children and adolescents with CFS/ME is more positive than adults, with children more likely to make a spontaneous recovery (Cairns & Hotopf, 2005). The most positive estimates suggest around two thirds of children diagnosed with CFS/ME make a full recovery (Rangel et al., 2000), whereas other research suggests recovery rates could be closer to around a half (Van Geelen et al., 2010). It is important to note although children and adolescents may be more likely than adults to make a full recovery, a significant minority have longer term symptoms that extend into adulthood. To date there is no specific treatment or cure for CFS/ME, approaches focus on understanding and managing the condition to support overall health and quality of life (Nayak & Bhattacharyya 2017).

When considering this complex statistical picture in relation to the EP role, underdiagnosis could mean that children are not being identified to support their needs at an early stage, which is suggested as good practice for any SEN in accordance with the SEND Code of Practice (DfE & DoH, 2015). This could impact on the identification of their needs in school and represent a barrier to how children and young people are able to access an educational setting. Considering the trajectory and prevalence of the illness, it is likely to have a significant impact at a time of increasing educational demand within the school system (Denscombe, 2000), and arguably have an impact on educational attainment. Therefore, the EP has a professional role in providing early intervention to support children and young

people at this crucial time of development, using their knowledge and skills of holistic development to provide personalised support for their needs, particularly considering how the medical information suggests this can change and develop over time.

2.1.3 Symptoms of CFS/ME

The symptoms of CFS/ME are complex and highly varied, this means that the presentation of illness in individual children and adolescents can differ greatly (Crawley, 2018). Collin et al. (2015) reviewed the available clinical data from CFS/ME clinics and the symptoms observed in children and adolescents in comparison to the adults, where most of the literature was situated. Adolescents were more likely to present with sleep difficulties and headaches, as well as 'cognitive dysfunction' including memory and word finding difficulties, with 87% experiencing this. Most adolescents also presented with anxious and depressed feelings.

The range of symptoms described by CFS/ME patients impacted on both physical and mental health and have several implications for a child or adolescent's school career; it is clear to see how these factors, combined with chronic fatigue, could influence a person's ability to focus and engage with learning, particularly the cognitive impacts which are present for many adolescents. The range of symptoms is also highly variable, which suggests a complex picture of need where no two cases present the same. For children and young people, this is likely to be a confusing and stressful time, suggested by Collin et al (2015) findings that most adolescents reported feelings of depression or anxiety with CFS/ME. It is important to recognise the impacts fall beyond just the physical for children and young people, which may be thought of as a 'medical need', which affect many aspects of their development and schooling and represent various forms of SEN that require support in educational settings.

2.1.4 Precipitating and Predisposing Factors

CFS/ME is classed as a 'medically unexplained illness' as it does not have a known cause at present (Greco, 2012). This limits the firm conclusions that can be drawn from all the related medical evidence in the field, as explanations and hypothesis are often at a small scale and early stage (Morris & Maes, 2013).

However, although the exact biological mechanisms of CFS/ME is not fully understood, researchers have looked at the psychological and environmental factors that may exacerbate the impacts of CFE/ME over time. This can provide insight into the wider impacts of the condition, and potential considerations for the EP and educational

professionals. Lievesley et al. (2014) conducted a review of the available evidence into paediatric CFS/ME to collate a model considering the interaction between wider biopsychosocial factors that could explain possible triggers and precipitating factors which interact to maintain the illness over time. Certain vulnerabilities were highlighted that could make developing the illness more likely, such as perfectionistic thinking or being a high achiever. Many adolescents experienced a viral illness which triggered their illness. Several common paediatric illnesses, such as glandular fever, are implicated in the onset of CFS/ME (Katz et al., 2009). Once symptoms of CFS/ME developed, this was understandably a source of stress which could have further negative physiological impacts, such as increasing symptoms, which can become a cyclical pattern. Other risk factors within the child's family system, such as trauma, were also highlighted as possible exacerbating factors due to stress. However, biopsychosocial models of CFS/ME have been criticised due to concerns they emphasise the psychological impacts of illness over the physiological and biological impacts, and can lead professionals to misunderstand the nature of the illness (Geraghty & Esmail, 2016).

Although there have been valid criticisms of models such as that presented by Lievesley et al. (2014), they do demonstrate the complex and interactive factors that underpin CFS/ME and the impacts that this has on the life of children and young people with the illness. This is especially relevant considering the identified impacts linked to educational factors, such as school stress or perfectionistic thinking styles. The model highlights that these factors can be identified by professionals working with children and adolescents with CFS/ME as opportunities to provide support, both preventatively over traits such as perfectionistic thinking, as well as supporting coping with the diagnosis of illness and the impacts this has on education. Lievesley et al., (2014) suggest a variety of psychological techniques that could be suitable for this, including CBT and psychoeducation. These techniques are frequently used within English schools and fall into the broad scope of the EP role in supporting children and young people (Beidas et al., 2012), in this instance relating to wellbeing in education because of a biological illness.

2.1.5 Recognition of CFS/ME

Historically, the diagnosis of CFS/ME has been considered controversial with people questioning the existence of the illness (Chadler et al., 2003). Although documented since the 1930s, the illness became more prevalent in popular culture in the 1980s where it was referred to as 'yuppie flu' due to its perceived incidence in young adult professionals with

busy lifestyles (Jason, et al., 2002). Initial treatments for the condition were proposed from the field of psychiatry and both professional and public discourse centred around the suggestion that the cause of CFS/ME was psychological in nature (Spandler & Allen, 2018). Although models such as Lievesley et al. (2014) suggest psychological factors such as stress can contribute to illness, CFS/ME is a biological illness. However, despite our increasing knowledge and awareness of the causes of CFS/ME inaccurate beliefs have persisted, with surveys suggesting up to 50% of GPs do not perceive CFS/ME to be a physical illness, and instead a form of mental illness (Thomas & Smith, 2005). Parents of children with CFS/ME frequently report barriers in diagnosis or referral to specialist services when their children first show symptoms of the illness (Webb et al., 2011).

These attitudes are also important to consider as they give context to the current diagnosis and treatment of CFS/ME by both professionals and lay people and the potential impact this has on people with the condition. As many as two thirds of adult CFS/ME patients report dissatisfaction with the care they receive from their GP, closely linked to the scepticism they face around the 'realness' of the condition (Guise et al., 2010). For professionals working with these young people, including EPs, it is easy to see how these potentially stigmatising views may cause a barrier or a reluctance for children and young people and their families to engage with support services. Professionally, an understanding of the experiences of children and young people with CFS/ME and the potential barriers they face in getting recognition for their difficulties could provide valuable opportunities to inform and guide professional practice in hearing the voice of this often-marginalised group.

Research also supports how inaccurate beliefs and misinformation around CFS/ME can leave people with the illness feeling stigmatised and distrusting of professionals (Blease et al., 2016). Blease et al. explored a theoretical model of how this could arise and further impact on the support people with CFS/ME received, suggesting people would be less likely to disclose the full extent of their symptoms or withdraw from offers of professional support for fear of social judgements. Although this research considered a model for how adults may experience CFS/ME, we also know that the illness frequently impacts adolescents at a time of many life stressors and vulnerabilities, including the transition to adulthood (Denscombe, 2000; Lievesley et al., 2014). Arguably, these additional stressors at a time of development and transition could leave adolescents at risk of not receiving appropriate support for their needs due to feeling misunderstood by the people and/or

services around them, which could act as further potential triggers that maintain their illness, as predicted by Lievesley et al. (2014).

These feelings of stigmatisation young people may face also has implications for the EP role. Typically, EPs bring psychological knowledge to complex systems to consider the interaction between a child and young person and their environment, and how this may be modified to bring about change (Cameron, 2006). This includes how the people within the system may perceive the child or young person, and the attributions they could have relating to the current situation, which can differ greatly (Miller, 2003). In psychological terms, attribution theory suggests that humans analyse and look for causal explanations for situations (Weiner, 2010). In the case of children and young people with CFS/ME, if adults around them make incorrect attributions regarding the cause of their illness, they may feel less able to provide appropriate support to meet the child's needs as they perceive the support to be beyond their control.

Miller (2003) highlights how the EP, as an external professional, can cross multiple family and professional systems to create a 'temporary overlapping system' and facilitate the sharing of information to support the young person across the systems in their lives. As perceptions and attributions around the cause and presentation of CFS/ME may vary, and the likely impacts this has on the young people affected by the condition, the EP therefore arguably has skills and knowledge to reconcile these differing views to support and bring about change based on the young person's needs. Furthermore, students with chronic illnesses such as CFS/ME are reported to be highly knowledgeable regarding their illnesses and needs; the EP role in gaining children's views and reporting these as a consultant with several parties is ideally suited to facilitating this (Schilling, 2014).

2.1.6 Summary

CFS/ME is a complex illness that is neither fully understood nor treatable at the current time, although models have identified the ways in which factors may interact to trigger and maintain the illness. For a significant minority of children diagnosed with CFS/ME the condition persists into adulthood. To maximise positive outcomes and chances of recovery, children and young people need rapid diagnosis of the condition and individualised support for their recovery based on the complex factors that are believed to precipitate the condition. Issues around the historic conceptualisation of CFS/ME, including how the illness is perceived by professionals and lay people may result in stigmatisation which could prevent children and adolescents from feeling supported. Addressing the wider

psychological and social influences and how they impact on the perception and management of SEN relating to CFS/ME is of professional relevance to the EP role.

2.2.1 Children with Medical Needs in School: The Current Legislative Context

2.2.2 Who is Affected by this Legislation?

Children and young people may have a variety of medical needs that impact their education. The Equalities Act (2010) protects all people with a 'long term' or 'substantial' medical condition or disability from discrimination. For children and young people, they must receive reasonable adjustments to meet their needs within education. The Equalities Act (2010) defines 'long term' as lasting more than a year and 'substantial' as having more than a minor impact on daily life. Therefore, several medical conditions are protected by this legislation, including common childhood conditions such as asthma or epilepsy, however the extent to which medical needs impact on education will be unique to each child (NASEN, 2018). The medical implications of CFS/ME outlined throughout section 2.1 clearly demonstrate this condition also has substantial impacts on a child or young person's life, therefore they are protected by The Equalities Act (2010), which must be recognised in their equal access to education.

2.2.3 Supporting Children with Medical Needs in School

The Children and Families Act (2014) means LA maintained schools and academies within England must make provision for supporting children with medical needs within their settings. The document 'Supporting pupils at school with medical conditions' (DfE, 2015) outlines the statutory measures schools must take to support children and young people with medical needs. Schools must ensure they have clear policies that allow pupils with medical needs to have the same access as their peers to activities within school. This includes the development of individual healthcare plans, which outline details of the child's medical needs and the support required in school, such as medication or emergency procedures. Staff must receive appropriate training to enable them to meet these needs.

In addition to these statutory obligations, the 'Supporting pupils with medical conditions at school' (DfE, 2015) document contains non-statutory guidance to help schools implement these steps. Although EPs are not mentioned directly within this guidance, the importance of developing individualised care plans with a wide range of professionals is suggested to meet the individualised needs of affected children and young people. Therefore, it is possible that an EP could form part of a multi-disciplinary team in developing these plans within schools due to their holistic professional knowledge relating to the positive

development of children and young people (Reilly & Fenton, 2013). This highlights the need for EPs to understand this legislation and the impacts of this on children and young people who they may encounter in their work, so they work within the guidance and standards outlined by English educational policy.

2.2.4 Ensuring Access to Education for Children Unable to Attend School

The document 'Ensuring a good education for children who cannot attend school because of health needs ' (DfE, 2013a) also outlines current English statutory guidance for medical absence from school. Presently, if a child or young person of compulsory school age will be missing from education due to a medical reason for 15 days or more, the LA has a statutory duty to provide suitable alternative education opportunities (DfE, 2013a). These suitable opportunities should be offered on a full-time basis wherever possible but may be offered on a part-time basis depending on the child's medical needs (DfE, 2013a). The guidance stresses that there are no 'hard and fast' rules when considering alternative access to children unable to attend school for medical reasons; their individual needs should be addressed on a case-by-case basis.

Further statutory guidance titled 'Alternative Provision' *c*onsiders the possible nature of these alternative provisions for children not able to attend their regular school due to medical reasons. This document highlights that although full-time education is not defined by law, children should be expected to receive the same amount of education as they would receive at school (DfE, 2013b). This would mean that certain arrangements, such as a child receiving 1:1 private tuition, the intense nature of the teaching activity would be equivalent to full time education (DfE, 2013b). For children receiving alternative educational provision, guidance states it should be of quality and consistency with their regular schooling to allow them to maintain their progress within the curriculum.

2.2.5 Education, Health and Care Plans

The SEND Code of Practice (DfE and DoH, 2015) considers a child or young person's SEND within four distinct categories: cognition and learning, communication and interaction, social, emotional and mental health and physical and sensory. The Code defines SEND as a child or young person having:

> 'A significantly greater difficulty in learning than the majority of others of the same age **or** 'has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions (pg 15-16)'

Pupils with long-term medical conditions could therefore have SEND across all areas of the Code. If the child or young person is not making expected progress within their educational placement, an assessment for an EHC needs assessment may be conducted by the LA. An EHC needs assessment considers a child's holistic needs and the provision required to meet these needs, as well as outcomes to support their educational attainment. The SEND Code of Practice provides these same protections and right to a statutory assessment if necessary, for children within alternative provision because of their medical needs. As part of the EHC needs assessment, an EP would provide advice regarding the child or young person's educational needs.

2.2.6 Summary

Increasing numbers of children and young people with medical needs are accessing educational provision. The government guidance outlined above stipulates several key points that impact on the education of children and young people with medical needs. These pupils have a legal right to a full curriculum regardless of the type of provision they access, and LAs have a responsibility to provide alternative provisions for long-term medical absence from school. The current legislative framework suggests a child-centred approach tailored to their individual needs to give them the same opportunity and enjoyment of education as their peers; this is the foundation for the quality of practice and provision expected from schools within England.

The EP role is ideally positioned to support children with medical needs within school due to their areas of expertise (Reilly & Fenton, 2013). EPs may become involved with these children and young people at a statutory level through the EHC needs process in accordance with the SEND Code of Practice (DfE and DoH, 2015), or supporting multi-agency healthcare plans (DfE, 2015). For EPs, there is arguably a professional obligation to understand the challenges children and young people with medical needs in schools face to ensure they can provide appropriate advice and support when working with this population.

2.3 Identified Impacts of CFS/ME on Children and Adolescents' Education

2.3.1 Background Information

The impact of chronic medical conditions on children and adolescent's school experiences has been identified as an area for further research over the last 20 years due to the increasing prevalence of chronic illness in childhood (Perfect & Moore, 2019). Studies considering the priority areas of research into paediatric health suggest there is a focus on

improving treatment outcomes for neurological conditions, cancer and childhood obesity, as opposed to more holistic measures of paediatric wellbeing (Odgers et al., 2018). Studies considering the functional impact of chronic paediatric illnesses suggest CFS/ME results in some of the highest levels of functional impairment observed because of illness (Garralda & Rangel, 2004). These functional impairments relate to the child's ability to perform daily activities, such as attend school, socialise with friends or do jobs at home (Garralda & Rangel). The focus of existing research into the impacts of chronic illness suggests there is a gap in our knowledge of the impacts of medically unexplained conditions such as CFS/ME and overall wellbeing. This impacts on the role of professionals supporting children with CFS/ME, including EPs, due to the lack of practice-based evidence available.

The varying symptoms of CFS/ME in adolescence can reach a level of severity that they meet the criteria for a SEN. This means the symptoms impact on their education due to the learning or physical difficulties that requires special educational provision to be made to support them (Cline & Frederickson, 2009). This section summarises the identified impacts of CFS/ME on the holistic educational and developmental experiences of adolescents from the limited research into the area. The section outlines the available research considering the impacts on school attendance, cognition and learning, preparation for adulthood and social, emotional and mental health.

2.3.2 School Attendance and Absence

There are several studies considering the impacts of CFS/ME on school attendance. This is because it is considered a key marker of school functioning for those with the illness (Knight et al., 2018). CFS/ME has been identified as a leading cause of prolonged school absence (Crawley et al., 2018). In a sample of 211 adolescents with CFS/ME, the mean length of illness was found to be around 38 months, with an average 17-month period of symptoms at their worst severity (Rangel et al., 2000). During the time of their worst symptoms, 68% of the adolescents sampled in Rangel et al., could not attend school at all while 57% were on complete bed rest. The average duration of school absence equated to around one academic year. Some research has begun to investigate the symptoms which cause prolonged absence in CFS/ME. Initial research suggests that school attendance is linked to children and adolescents physical functioning with CFS/ME, that is the extent to which they are able to physically complete daily living tasks, such as washing and dressing (Crawley & Sterne, 2008). This is in comparison to psychological factors, such as anxiety around

attending school, which suggests that support for the physical impacts of school should be considered a priority as part of any support offered to children and adolescents.

These findings have been replicated more recently, in a sample of 25 outpatients at a paediatric CFS/ME treatment service in the UK only one child was attending school full time, 48% attended school part time and 32% received home tuition with no time in school (Kennedy et al., 2010). A quarter of children missed two whole academic years of school. Kennedy et al also found a consistent illness duration of three years. Although the sample surveyed is relatively small, the consistency in findings between the larger and smaller scale studies suggests school absence has similar patterns across children with CFS/ME from the limited data available.

The school absence data has several implications for the learning of children with CFS/ME. Firstly, the impacts of CFS/ME can be highly variable, which again represents the individualised nature of the condition. Secondly, evidence suggests that some children experience periods of extreme fatigue which leave them bedbound. In this instance, part-time school attendance or home tuition are unlikely to be feasible options to support their educational outcomes. This has implications for the young person's right of access to education and how they can have opportunities to catch up on their missed learning opportunities, as part of the statutory responsibility of LAs within England (DFE, 2013a). Additionally, this raises questions for how children can 'catch up' on potentially extensive missed learning opportunities, and how this can best be facilitated within a school context to support positive outcomes for these children and young people.

2.3.3 Cognition and Learning

Research has also considered how the cognitive symptoms of CFS/ME, such as the memory loss highlighted by Collin et al. (2015), could impact on classroom learning. Haig-Ferguson et al. (2009) considered both qualitative and quantitative data from children and adolescents with CFS/ME regarding their attention and memory in class. Standardised assessments suggested that children with CFS/ME had slower processing speed and demonstrated shorter periods of sustained and focused attention compared to the mean expected for children of their age. These patterns were also reported qualitatively in observations from their teachers and parents. They reported that in class, children were observed to find it effortful to concentrate and could not remember information from lessons. Children that were interviewed as part of the study also self-identified these difficulties and highlighted difficulties in both processing information in class, which

impacted on their ability to remember and retrieve the information later. These difficulties were observed to be distressing to experience by both the young people and adults. Although this study incudes a relatively small sample of 25 children, the triangulation of children's experiences with both their voices and those of adults in their lives gives some insight into the realities of CFS/ME in the classroom context. This requires consideration of the possible impacts on wider access to learning and the support needed for this. The role of memory and it's impact on classroom learning is well understood by psychologists (Cowan, 2014), and therefore suggests one important avenue for EPs in disseminating and adapting this knowledge to meet the curriculum needs of children and young people with CFS/ME.

In comparative studies, CFS/ME directly on performance on cognitive assessments. A longitudinal study by Nijhof et al. (2016) considered the performance of children and adolescents with CFS/ME on a standardised IQ test. Their scores following a diagnosis of CFS/ME were significantly lower than when tested before becoming ill. This was independent of how long a child had been missing from school due to their illness. While the exact cause of the decline in scores was not concluded in the study, the authors hypothesised it was likely linked to processing speed, concentration, and memory as these skills are required due to the construction of these test materials. This could also explain why duration of school absence was not a contributing factor to the performance decrease; intelligence tests are designed to consider underlying ability and problem solving skills as opposed to taught knowledge (Correa Beltran et al., 2016). However, the underlying skills assessed by the test arguably do have some bearing on classroom processes, such as the ability to focus on the teacher, process their instructions and complete a task independently. The study suggests that CFS/ME can have a significant impact on the underlying skills that are required for the demands of classroom learning.

2.3.4 Preparing for Adulthood in Children and Adolescents with CFS/ME

Few studies exist that consider young people's perceptions of CFS/ME on their long-term future. The adult literature suggests that people experience a significant change in their identity upon diagnoses of the illness and go through a period of adjustment to living with the illness (Dickson et al., 2008). Emerging evidence from the paediatric population suggests similar patterns. Harland et al. (2019) interviewed adolescents with CFS/ME and their parents to consider their perceptions around the change in their life and recovery. Adolescents and their parents found it hard to think in terms of 'recovery' as they described

their illness as ‘the new normal’ for them. Their priorities for recovery were to take part in more activities and to have an increased social life. They also reported they would like to be more spontaneous and require less planning for activities. These aspirations closely linked with a wish to be more independent and have fuller lives. This holistic view of recovery and aspirations for this is important to consider when supporting adolescents with CFS/ME, particularly their individual hopes for the future and their transition to independent adult life.

The theme of regaining some control over life has been replicated in further research. Rowe (2019) identified that when receiving treatment for CFS/ME, children and adolescents frequently question when they will get better and their life return to ‘normal’. They highlighted that for children and adolescents with CFS/ME, recovery is dependent on their management of the condition, which many find daunting as these ‘life management’ skills are often new and not something that are taught at school. However, children and adolescents surveyed reported feelings of empowerment at learning these skills, which helped them feel more positive about the future despite their illness. Although the negative impacts of CFS/ME should not be underestimated, the suggested resilience and life skill development young people with the illness show within adolescence has potential positive implications when working towards their long-term goals for adulthood.

Adolescents with CFS/ME also report a stronger sense of personal values and motivations following their illness (Winger et al., 2014). Winger et al. (2014) interviewed adolescents regarding their experiences of having CFS/ME. Although many reported a sense of ‘time standing still’ for them while ill, which brought frustration, they reported increased confidence because of their illness. They felt that through adversity, they had gained a strong sense of self and what was important for their future. They were not as concerned as being seen as different from their peers, as their illness had already made them ‘different’. This study was a piece of small-scale qualitative research, which limits the generalisations that can be made. However, this does highlight how working with adolescents to identify their values and aspirations could support more positive outcomes by tailoring support and interventions to these. Winger et al (2014) highlight this could increase adolescents’ sense of being seen and understood by professionals working with them.

2.3.5 Social, Emotional and Mental Health

The symptoms of CFS/ME impact on social and emotional health, this goes beyond the associated anxiety and depression identified as a result of the illness (e.g. Collin et al., 2015). Van Middendorp et al. (2001) considered female adolescents self-perception with regards to their social and emotional health. Although, overall, girls with CFS/ME reported feeling a sense of positivity about their current social situation, they reported feeling less competent with social and emotional relationships, which are considered important markers of adolescent development. The study also found that girls with CFS/ME were more likely to conform to the expectations placed on them by others, and then report more frequent signs of internalising behaviours, such as withdrawing from social situations. Again, the study reflected that developing a sense of self is a developmental process that is undertaken in adolescence. This suggests that the social impacts of CFS/ME in adolescents could be complex and coincide with a developmentally sensitive time.

Fisher & Crawley (2013) conducted a qualitative study using IPA to better understand why adolescents with CFS/ME reported higher levels of anxiety than their healthy peers. The social impacts of the illness were reported to be one of the worst things about this illness for adolescents. The illness meant long periods of isolation within the family home, missing school and other social activities. This led to the loss of friendships. Interestingly, several children reported bullying and disbelief from peers around the cause of their illness, this led to further feelings of isolation and being 'misunderstood'. Returning to school also became a source of further anxiety, linked to increases in physical symptoms and the amount of time missing from school due to illness. Adolescents felt their illness was a highly uncertain and vulnerable time for them. The range of anxieties and intensity of these feelings was noted by the researcher; this mirrors the range and variance of physical symptoms the illness presents with. This suggests there are direct implications for educational professionals working with children and adolescents with CFS/ME, such as bullying and peer awareness around the condition.

Some large-scale cohort studies of adolescents with CFS/ME have begun to consider their emotional experiences over the duration of their illness. For nearly 700 adolescents questioned who received specialist treatment from a CFS/ME clinic in Australia, most felt that their illness management could have been improved (Rowe, 2020). Common areas of distress related to the attitudes of professionals around them in supporting them to manage their illness, including teachers. Respondents valued professionals who advocated

for their needs and provided support for their broad school experiences. Adolescents who responded to the questionnaire also reported feelings of hopelessness as a result, and of feeling out of control of their lives. Considering the nature of CFS/ME and the functional impairment the illness can have, this is perhaps not surprising but also raises issues for professionals working with children and adolescents. Ensuring adolescents' social needs, as well as learning needs, are met should be a consideration in supporting this population to support their development in a positive and healthy way.

More recent research has looked at how children and young people can use technology to support their social and emotional as a result of CFS/ME. Brigden et al. (2018) conducted a qualitative study to investigate how children and young people with CFS/ME used online materials to inform themselves about their condition. The participants reported they found that online message boards and social media groups gave them a sense of 'community' in interacting with others experiencing similar difficulties. Participants reported this gave them a sense of being 'understood' and helped them experience friendships at a time where their 'real life' peer friendships were under strain due to their illness. For the participants surveyed, this was a very positive outcome. For EPs and professionals working with children and young people, this demonstrates it is an important point to consider when thinking of the social needs of this population, including problem solving ways in which they can support those affected to maintain relationships when physical proximity is not possible at a developmentally important time.

2.3.6 Summary

Several key impacts of CFS/ME have been identified in children and adolescents: school absence, learning, specifically attention and memory, preparation for adulthood and social and emotional development. These represent a range of holistic impacts that represent the multi-faceted nature of symptoms the condition presents with. Understanding this range of needs is particularly relevant to the EP role, due to their professional responsibility in understanding and supporting the needs of children and young people with SEN, including the wider social, emotional and mental health impacts of CFS/ME.

2.4 Conclusions

In England children and adolescents with CFS/ME have the statutory right to access broad and high-quality educational provision designed to meet their needs, summarised in section 2.1. The varying symptoms and presentation of CFS/ME has a significant impact on the ability for children and adolescents to engage with school. Children and adolescents may

also face stigma from professionals linked to their diagnosis of CFS/ME, which can cause delays in receiving appropriate support for their needs, summarised in section 2.1.

CFS/ME impacts on school experiences in a variety of ways. As summarised in section 2.3, the condition causes high rates of school absence, impacts on memory and attention as well as the self-perceptions and aspirations of those affected, which could be a form of SEN. However, despite the many difficulties the illness brings, young people may report a stronger sense of self following their experiences and increased resilience. This has implications for the professional role of the EP in recognising and supporting these needs, and acknowledging the individual wishes and values of children and adolescents as part of this. The EP can act as a consultant to support the adults close to them and promote their voice, particularly considering some of the stigma that has been identified as surrounding the illness.

The existing evidence, although limited, indicates a range of needs in school for children and adolescents with CFS/ME. There are some identified barriers for those affected having these needs met, such as the attitudes of professionals around them. Therefore, how are needs relating to the educational impact of CFS/ME addressed in school aged children in England, and what evidence exists to inform professional best practice in this area?

2.5 Systematic Literature Review: Background

2.5.1 Introduction to the Systematic Literature Review

The evidence in the literature review highlights several obligations for professionals in meeting the educational needs of children and adolescents with CFS/ME. While these needs may not be fully recognised by the current evidence base, there is a legislative obligation to meet them (DfE, 2015), which impacts on the role of professionals working with these young people, including EPs. Therefore, this systematic literature review aims to explores what is known about the support currently offered to school aged children and young people with CFS/ME using a systematic and rigorous approach to find all relevant evidence. The focus of the systematic literature review is on qualitative research to capture the detailed experiences of children and young people, using a meta-ethnographic review process to understand the key findings of this research.

2.5.2 Purpose of a Systematic Literature Review

Systematic literature reviews are long established in scientific literature; their purpose is to review and evaluate the available evidence in a specified field (Mulrow, 1994).

Traditionally, systematic reviews have been associated with quantitative research methods, such as meta-analyses, where the reported effect sizes of studies are aggregated (Moher et al., 2015). However, the key differentiating feature of a systematic literature is that it is planned, completed and reported to a standard that could be replicated by another researcher, therefore both quantitative and qualitative studies can be the focus of a systematic literature review (Siddaway et al., 2019).

2.5.3 Qualitative Systematic Reviews

In comparison to quantitative review methods, qualitative systematic reviews are a fairly recent phenomenon, and do not have the same rigidly defined procedures as quantitative review processes (Campbell et al., 2011). Arguably, this is to be expected when considering the diversity and scope of qualitative research, which tends to focus on the individual experience, as opposed to large-scale experimental studies, and the variance this would cause.

Not all qualitative researchers advocate for the place of systematic reviews in qualitative literature, citing concerns that the act of synthesis suggests a reductionist view of human experience that is incompatible with qualitative research (Walsh & Downe, 2004). However, advocates of qualitative systematic reviews argue that bringing them together in a coherent synthesis allows the researcher to focus on nuance and contrast within these rich, idiosyncratic accounts to bring a deeper understanding of the studied phenomena in an organised way, as opposed to searching for a single explanation of a phenomenon (Walsh & Downe).

2.5.4 Meta-Ethnographic Literature Reviews

Meta-ethnography is a method of qualitative literature review that aims to combine the findings of studies, bringing an additional layer of interpretation to generate deeper understanding of the literature through this interpretative synthesis (Urrieta & Noblit, 2018). Meta-ethnographic reviews are particularly well aligned with interpretative research methods, the research method adopted by this study, as they look to provide new insight and theory into the existing literature through the act of interpretation to raise considerations for further avenues of research (Lockwood & Pearson, 2013). Noblit & Hare (1988) developed a seven-phase process for conducting meta-ethnographic reviews:

Table 1: Summary of Noblit & Hare's (1988) meta-ethnographic review process

Phase	**Description**
1: Getting started	In the initial stage, the researcher develops an appropriate research question for the systematic review that will analyse qualitative research.
2: Deciding what is relevant to the initial interest	This is where the scope of the review is narrowed to the area of interest linked to the research question. This includes the inclusion and exclusion criteria for studies and how this will influence the database search strategy.
3: Reading the studies	This stage involves repeated reading of the relevant studies and noting key themes and any interpretations made through this repeated reading.
4: Determining how the studies are related.	Key themes and interpretations from studies are compared to look for links between the studies.
5: Translating the studies together	Translation is where studies are 'compared and contrasted'. This is where themes and interpretations are evaluated and considered between studies within the synthesis, as well as any conflicting themes within the accounts of studies.
6: Synthesising translations	The translated themes are considered as a whole, and the theories and explanations this generates considered. This could generate overarching higher-order themes.
7: Expressing the synthesis	The synthesis is reported, this could be in writing or aided using diagrams and images.

However, critics suggest that the original meta-ethnographic review steps from Noblit & Hare (1988) lack detail, for example in appraising the quality of studies (Atkins et al., 2008). Atkins et al. (2008) suggested using a quality screening process during phase two to address this. To provide a more rigorous meta-ethnographic review, the Critical Appraisal Skills Programme (CASP) checklist (CASP, 2018) for qualitative research will be used to appraise studies (shown in Appendix A).

2.6 Meta-Ethnographic Literature Review

2.6.1 Getting Started

As concluded from the generic literature review, CFS/ME has a range of potential impacts on the education of children and young people. Although there is a legislative obligation to meet those needs, there are some potential identified barriers to this. Therefore, this raises the review question:

- How are the needs of children with CFS/ME supported within the school system?

During the search process and completion of the general literature review above, the majority of studies identified used quantitative methods and often came from a medical perspective. There were fewer studies that addressed the individual experience of children and young people with CFS/ME and represents a gap in our understanding of the individual experience in school support. By addressing the review question through qualitative research, the study aims to build a rich and detailed picture of how needs are met within school to compliment the existing evidence base from a more legislative or medicalised perspective. Seers (2015) suggests that in doing this, it can provide a better understanding of 'what works' from the perspective of those impacted, and is therefore relevant to the EP who may work with a child with CFS/ME, their school or their family.

2.6.2 Deciding What is Relevant

2.6.2.1 SPIDER Framework

The SPIDER framework (Cooke et al., 2012) is a rigorous method of selecting relevant research papers specifically created for qualitative systematic reviews. SPIDER stands for Sample, Phenomenon of Interest, Design, Evaluation and Research Type. The framework was used to determine the inclusion and exclusion criteria for the meta-ethnographic review.

Table 2: Inclusion and exclusion criteria using the SPIDER framework (Cooke et al., 2012).

Stage of Framework	**Inclusion Criteria**	**Exclusion Criteria**
Sample *Who are we interested in?*	School aged children and adolescents (5-16) with a diagnosis of CFS/ME.	Adults with CFS/ME.
Phenomenon of Interest	Any reference to supporting CFS/ME in school settings, for	General interventions to support CFS/ME such as

What are we interested in?	those with a medically confirmed diagnosis. This could be the views of those with the illness or staff who support them.	medical trials, non-school based support for CFS/ME or support for other causes of fatigue.
Design *The type of study and method used*	Any type of qualitative method, including questionnaires, surveys, focus groups.	Any experimental or quasi-experimental design, systematic reviews. These studies were excluded as extensive scoping searches found they did not focus on the experience of school support with CFS/ME, the key focus of the review question.
Evaluation *How have they investigated the topic and conclusions made*	A description or outline of experience of how the sample are supported within school.	Statistical methods or evaluations.
Research Type	Any qualitative study, including mixed methods studies that include a qualitative description. Can be any form of academic writing, including theses and grey literature.	Studies without a qualitative element, again to capture the experiential element of the review question which was not reflected in the available quantitative research.

2.6.2.2 Justification for the Inclusion/Exclusion Criteria

As the focus of the review is how school aged children with CFS/ME are supported in school, it is necessary to focus on a sample of children of compulsory school age. Although adolescents are more likely to experience CFS/ME than younger children, due to the lack of research into the general area to ensure all possible studies linked to education are considered.

As the phenomenon of interest is support in schools for CFS/ME, the inclusion criteria is specific to children and adolescents who have a confirmed diagnosis of the illness. This is to ensure the strategies are relevant to the unique needs of this population at school, rather than other conditions that could cause fatigue.

For inclusion in the review, research must include a design element that outlines how children and adolescents with CFS/ME are supported in school, which is described as part of the study analysis. The review is focused on qualitative research to understand how support of children and young people with CFS/ME is experienced within schools, as described in section 2.6.1. For inclusion, studies can be reported in academic journals or grey literature, including theses, due to the anticipated small size of the research area.

2.5.2.3 Search Strategy

Initial scoping searches revealed that the term "ME" resulted in an unmanageable number of returned results as it also returned titles with the word 'me'. When this was modified to reflect the terms "CFS/ME" and "myalgic encephalomyelitis" and "chronic fatigue syndrome", the searches returned relevant results.

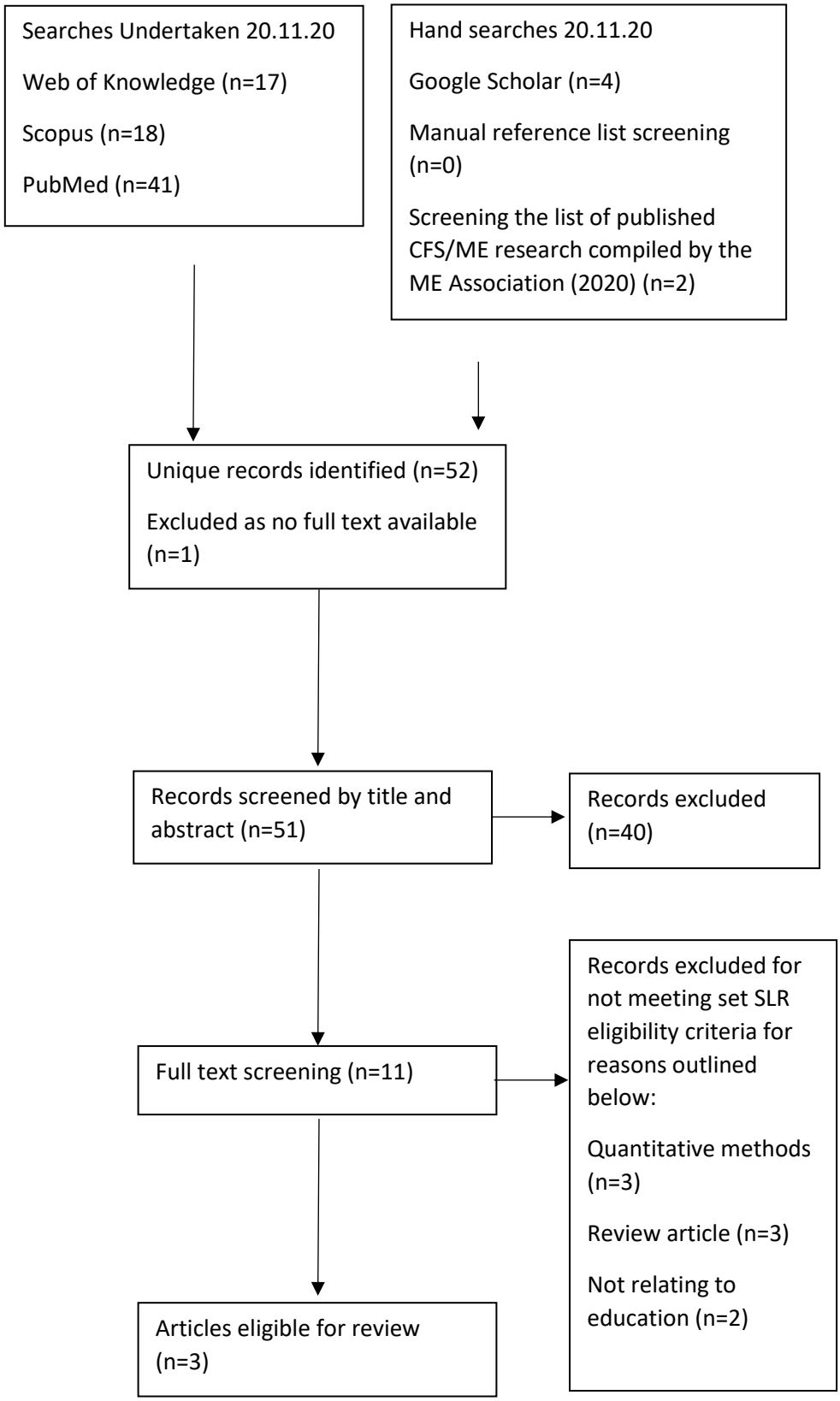
Searches were conducted in November 2020 of the databases Web of Knowledge, Scopus, and PubMed, due to the often medical nature of the literature in the field. The same search terms were used in Google Scholar, to capture any grey literature that may exist around the topic.

Table 3: Search strategy based on the review inclusion criteria

Concept	Search Terms
Child or adolescent	"Child*" AND/OR "Adolesc*"
CFS/ME	"Chronic fatigue syndrome" AND/OR "CFS" AND/OR "myalgic encephalomyelitis" AND/OR "CFS/ME"
School support	"School"

2.6.2.4 Search Results

Figure 2.1: Flow diagram illustrating the systematic search process



2.6.2.5 Appraising the Studies

Of the 51 unique records identified by the systematic search strategy, three papers met the inclusion criteria for the meta-ethnographic review, and therefore eligible for quality appraisal.

The CASP checklist for qualitative research is a 10-step questionnaire that is used to consider three aspects of a study; the validity, reporting of results and the usefulness of the research (CASP, 2018). The full CASP questions are shown in Appendix A. The CASP has been developed and used successfully by researchers to provide a scoring system for qualitative studies, with studies meeting the CASP criteria scoring a point, contributing to a maximum score of 10, indicating the highest quality of paper, with scores of 6 or above representing high quality research (Parslow et al., 2017). The quality appraisal of studies using the CASP is shown fully in Appendix B, the CASP rating for each paper is shown in the data extraction table below (Table 4).

Although there is guidance to using the CASP framework, as outlined above, critics argue that purely focusing on using the tool as a scoring framework can be overly reductionistic when considering qualitative studies (Long et al., 2020). As explained by Long et al, and shown in Appendix A, the CASP framework used a variety of reflective prompts to consider individual aspects of the study and captures a richer understanding of the processes that underpin the qualitative research process.

2.6.2.6 Study Characteristics

Key features from the eligible studies were collated into a table. This included the study reference, the stated aim of the research, the details and number of participants who took part in the study, the qualitative data collection methods and analysis used and the CASP rating. This extraction of the key features of the study provided contextual information to answer the question posed by the meta-ethnographic review process at this stage; 'deciding what is relevant' and demonstrate how the studies reflect the review criteria.

Table 4: Key characteristics from studies eligible for the meta-ethnographic review

Study	Type of participants (number shown in brackets)	Age range of children discussed in the study	Aim	Data Collection	Data analysis	CASP score
Brigden et al. (2020) Study 1	Families (n=22) Teachers (n=11) Healthcare providers (n=9)	5-11	To examine the extent to which care of younger children with CFS/ME is integrated across settings, including school. Families, teachers and healthcare providers were interviewed to understand this across settings.	Semi-structured interviews	Thematic analysis	10
Everett & Fulton (2002) Study 2	SENCOs (n=2) Teachers (n=12) Support staff (N=2)	Not disclosed	To examine teacher's beliefs around CFS/ME in children and how they supported this	Focus groups	Grounded Theory	7

			through their professional role.			
Parslow et al (2017) Study 3	Health professionals (n=15)	0-19	To gain the views of health practitioners to consider how to support children with CFS/ME, including their participation in school.	Focus groups and individual interviews	Thematic analysis	10

2.6.3 Determining how the Studies are Related and Translating the Studies Together

Following Noblit & Hare's (1988) process for meta-ethnographic review, the next stages of the process involve repeated reading of the studies to identify key themes. Key quotes and points from the data was extracted that link to highlight how support was given to school pupils with CFS/ME. Following this, similarities and differences between studies were compared and contrasted. This process is shown in Table 5.

Finally, studies were translated together, considering the findings as a whole, with overarching themes identified. These themes include interpretations and synthesis by the researcher. This process is illustrated in Table 6.

Table 5: Translations of key themes, similarities and differences between the studies

Study	Key Findings and Themes	Examples of Themes and Relation to School Support	Similarities/Differences
Brigden et al. (2020) Study 1	• Child-centred care is seen as essential by school staff and clinicians, however there is a need to acknowledge that the child has limited capacity to self-manage, so relies on adult support • The distinct responsibilities of parents, clinicians and teachers in providing support was identified • Communication across the home, school and clinical settings was necessary to support the pupil • Optimising integrated and shared-care improved pupil care	• Medical staff and parents feel schools should observe and provide evidence to support diagnosis of CFS/ME, and the difficulties pupils face, to inform support planning • Ensuring medical staff communicate needs clearly to educational professionals: *"the cases that I've worked best with school is the one where I've done regular meetings with school especially at primary school age*"* • Children find it difficult to articulate their needs and require support:	• Study 1 relates closely to study 3 in terms of themes and findings. • This could be because both used thematic analysis, and took the views of healthcare providers, which formed a significant part of the reporting for study 1. • Study 1 advocates for a more active role in teachers in the management of CFS/ME,

		"when I'm at school I feel kind of scared to tell people so I don't normally tell like the teacher" • Teachers are keen to support children in their care, emotionally and physically, however they can find this difficult without a formal diagnosis or guidance, Parents experienced more frustration in these cases • Breakdowns in support related mostly to differing expectations between school and home, with regards to attendance and absenteeism.	which is in contrast to teacher's perceived efficacy discussed in study 2. • Study 1 is unique as it focuses on the views of families and children, teachers and healthcare providers. It also considers the experience during the primary phase of education only, in comparison to study three where clinicians work across all ages.
Everett & Fulton (2002)	• CFS/ME was perceived to affect girls more frequently than boys	• School staff reported that drama could provide a creative outlet that allowed students to live outside	• Different to studies 1 and 3, in that it is a much older piece of research

Study 2	• Students with CFS/ME were perceived to have experienced trauma • Students with CFS/ME can benefit from taking part in drama activities • Staff feel uncertain what support to provide, but are motivated to do so	their experiences for a short period of time, and felt these activities should be prioritised. There seemed to be a high proportion of children with CFS/ME who were also interested in drama in two of the three focus groups. • Staff reported that they used strategies such as providing catch up work pupils had missed and giving them extra rest breaks in school. They described a 'trial and error' process of finding what worked, in the absence of official guidance - *"It would be nice to know who to contact to come in and run a session"*	• The reported data and supporting quotes and analysis was shallow in comparison to studies 1 and 3, which reduced the CASP rating • The findings are different to studies 1 and 3, with some very specific themes identified, such as participation in drama, which could be explained by these methodological issues and timing of the study • The study is different in that it only focuses on school-based support,

		• Staff felt information was lacking in comparison to other illnesses and conditions managed within school	rather than family, child or clinician views
Parslow et al. (2017) Study 3	• Clinicians feel the broad symptoms impact on the support they can offer • Clinicians view school attendance as part of a wider holistic element of wellbeing • Emotional needs require as much support as school attendance, such as social anxiety and school phobia • School support and understanding is a critical factor in supporting engagement in education	• Clinicians reported a highly variable picture of school support which directly related to outcomes - *"schools really vary as to how sympathetic they are. Um, we have had a few young people who have developed sort of anxiety about going into school"* • Health professionals feel the most effective outcomes are where they provide advice and training to schools on managing needs - *"…schools also have unrealistic expectations of what they can do as*	• The themes from study 3 are linked closely to the themes in study 1. • Study 3 presents more of an emphasis on the holistic wellbeing of children and young people. • Study 3 differs from studies 1 and 2 as it only considers the views of clinicians.

		well. It's about educating them about what they can do" • Health professionals may advise children to leave mainstream school based on their needs - *"…we encourage them to leave mainstream school and go into colleges and further education, they are much better at handling people with needs".* This impacts on choices and decisions regarding their education. • Clinicians identify school can be a source of fatigue, and in managing school children can experience great difficulty in other areas of their life. They encourage school to be part of the wider picture, with this clearly	

		communicated to school to set a holistic care plan, of which school is one area, to mitigate the impacts of CFS/ME on normal development. Without this balance there are greater perceived risks for negative outcomes such as social isolation - *"…if they are getting into school more and more but their wellness score is staying the same or going down, I would be concerned and talk with them about decreasing the amount of school they do."*	

**Participant quotes from the original research are show in italics*

Table 6: Key overarching themes identified through the meta-ethnographic review

Overarching theme identified by the meta-ethnographic Review	Themes Identified by the original study authors included in the meta-ethnographic review	Studies including this theme	Studies excluding this theme
CFS/ME is a complex illness with a range of needs in school	• Clinicians feel the broad symptoms impact on the support they can offer • Emotional needs require as much support as school attendance, such as social anxiety and school phobia	Studies 1 and 3	Study 2
Holistic well communicated support gives better outcomes	• The distinct responsibilities of parents, clinicians and teachers in providing support was identified • Communication across the home, school and clinical settings was necessary to support the pupil	Studies 1 and 3	Study 2

CFS/ME is still poorly understood, which impacts on school staff's ability to meet needs	• Staff feel uncertain what support to provide, but are motivated to do so • School support and understanding is a critical factor in supporting engagement in education • CFS/ME was perceived to affect girls more frequently than boys • Students with CFS/ME were perceived to have experienced trauma • Drama was considered a way to support children with CFS/ME	All studies	
The voice of the child or young person can be lost	• Child-centred care is seen as essential by school staff and clinicians, however there is a need to acknowledge that the child has limited capacity to self-manage, so relies on adult support • Clinicians can advise different school placements to settings they perceive as more able to meet their needs	Studies 1 and 3	Study 2

	• Children can feel scared to articulate their support needs		

2.6.4 Synthesising the Studies

Table 6 shows the translation of the studies in the meta-ethnographic review, and the superordinate themes identified through the review process. The utility of these themes in relation to the education psychology are reflected in the analysis below, considering the gaps they identify in meeting the educational needs of children and young people with CFS/ME.

Theme One: CFS/ME is a complex illness with a range of needs in school

Both Brigden et al. (2020) and Parslow et al. (2017) highlighted the range of needs children and young people with CFS/ME present with in schools, drawing particular attention to the social, emotional and mental health implications of the condition, such as anxiety and school phobia. This is missing from Everett & Fulton's (2002) analysis, however this could be linked to the methodological limitations of the study, such as using focus groups.

Theme Two: Holistic, well-communicated support gives better outcomes

Brigden et al. (2020) described the theme 'the child's got a complete circle round him', which captures the ideal outcome of the schoolchild receiving appropriate and person-centred support for CFS/ME. Parslow et al. (2017) themes identified the role clinicians perceived themselves to have in this, drawing on factors such as building school staff awareness and training. Interestingly, although not mentioned as a theme directly, school staff in Everett & Fulton (2002) felt excluded from this communication, which led to them to using 'trial and error' strategies to support pupils. This theme encapsulates both the positive and negative experiences of children and young people as highlighted in the research. For professionals, including EPs, it represents a key consideration when working with children with CFS/ME, and how this can be facilitated effectively within schools.

Theme Three: CFS/ME is still poorly understood, which impacts on school staff's ability to meet needs

All studies highlighted the impact that school staff can be unprepared to meet the needs of children and young people with CFS/ME. In Everett & Fulton (2002), school staff perceived training was not widely available in comparison to other medical conditions within school. This pattern was replicated more recently in Brigden et al., (2020) and Parslow et al., (2017), suggesting that knowledge from medical professionals and understanding of the condition is not transferred to applied settings. Clinicians identified gaps in staff understanding and sympathy to the illness, which impacted on how children and young people received support.

This suggests a significant gap between the theory and clinically generated knowledge and how this can be used to manage needs in an educational setting. Increasing opportunities to educate and inform staff is a potential direction for educational psychology involvement. This is particularly relevant as the position of the EP role as highlighted by Miller (2003), in working with adults around children to shift their attributions and gain empathy for the child.

Theme Four: The voice of the child or young person can be lost

Out of the three papers eligible for review, only one study, Brigden et al. (2020) spoke to the child for their views of their school experiences. This gave some insight into how younger primary aged children may view their support and raised some of the difficulties they have in articulating their views.

Parslow et al. (2017) highlight how clinicians may encourage children and young people with CFS/ME to leave mainstream school and consider specialist provision due to their needs. Arguably, decisions such as this have implications for the rights of children and young people to access educational provision of their choice, detailed fully in section 2.1.4. This suggests a tension between the wishes and legal rights of children and young people with CFS/ME and the provision they need to support them.

2.6.5 Limitations of the Meta-Ethnographic Review

The search criteria only returned a small number of eligible studies, however this is likely to be due to the lack of research into the area, as the studies were cross referenced against compiled lists of available research in the area (e.g., the ME Association, 2020) and hand searching of reference lists. It is possible that, by extending the search to consider the experiences of young adults of university or college age, there could have been more research papers to draw from in the fields of further and higher education.

The limited number of studies also limited the depth of analysis and number of overarching themes that can be developed through the review process, particularly considering the limited data available in Everett & Fulton (2002). However, this limitation of the review further serves to highlight the extent to which more research is needed in this area to better understand how to support schools in meeting the needs of pupils with CFS/ME, as little is known about the experiences of children and young people within the school system.

2.6.6 Comparison of the Review Question and Findings

The original question posed by the meta-ethnographic review was framed to consider how children with CFS/ME were supported within schools. Initially, it was anticipated this would include information like specific support strategies that were used. However, the lack of literature in the area in general, combined with the lack of research directly asking school pupils about their experiences, has meant that the findings of the review have taken a more abstract systemic view. The themes identified focus on some of the facilitators and barriers to support in school from the perspectives of those working in this area, including medical staff who indirectly support children's needs in school. This has meant that the initial review question, which hoped to synthesise a range of support strategies, has been addressed in a different way due to the availability of literature in the area.

2.6.7 Conclusions of the Meta-Ethnographic Review

The meta-ethnographic review suggests that the evidence base in supporting needs relating to CFS/ME in schools are an under researched area, highlighted by the minimal papers eligible for review. Of the 51 papers returned by the systematic search strategy, only 3 were eligible for full text review. Most unsuitable studies at the title and abstract screening phase were quantitative in nature with a medicalised focus, rather than the lived experiences of school aged children within education systems, which would provide a greater understanding into how we meet and support these needs within schools.

The overarching themes identified by the meta-ethnographic review suggest the needs of children with CFS/ME are met when school staff understand their unique presentation of the illness and how this impacts them. Outcomes are most positive when supported by multi-agency working, including medical guidance for school staff. Without this, school staff are more likely to experience feelings of unpreparedness to meet needs, and parents are more likely to be dissatisfied with the support their child receives.

All studies suggest that misconceptions of CFS/ME persist into the nature and understanding of the illness, which is a risk factor for poorer outcomes for children and young people and the school support they receive. The voice of the child is sometimes minimised in these discussions, which can marginalise them further from education.

For the EP role, this suggests opportunities in promoting the voice of the child or young person and involving them in decisions about their school support and planning for the future. Communicating and collaborating with all involved with the care of the child or young person to bring about a shared understanding of holistic need in schools is another avenue for potential involvement, linked to the aspirations and views of the pupils themselves.

2.7 Conclusions, Rationale and Research Question Formulation

As the first half of the literature review demonstrates, CFS/ME is a condition that has a significant impact on the education and development of those affected. The prevalence rates suggest as many as 3% of children and adolescents may develop the illness (Friedman et al., 2019). Although this means CFS/ME is not a common illness, the prevalence rates mean that there are likely to be several cases in a school population that would require appropriate support, as is determined by statutory processes within the school system (e.g. 'Supporting pupils with medical needs in schools, DfE, 2015). The needs of children and young people with CFS/ME have been identified in areas across the SEND Code of Practice (DfE & DoH, 2015), with significant implications identified for cognition and learning, including memory and attention. This is also exacerbated by the estimated duration of illness and the onset during crucial school times, such as sitting GCSEs, which has negative impacts for educational attainment and children and young people's own aspirations for their future (e.g. Harland et al., 2019). There are also identified social impacts of the experience of illness while at school, including social isolation and feeling disconnected from peer groups. Identifying these needs and reducing their impact on the education and development of those affected is highly relevant to the professional role of the EP.

Although the literature suggested several needs that require support for children and young people with CFS/ME, the systematic literature review returned very few papers considering how these needs are met in practice, a limitation of our knowledge of the area. It was recognised the illness had complex impacts on school life, and multi-disciplinary professional support could provide more positive outcomes for children and young people. However, themes suggest the availability of this support is lacking, and staff do not fully understand how to meet these in practice, which has negative outcomes for children and young people with CFS/ME. In this lack of clarity and understanding, the voices of children and young people are sadly lost, including their participation and role in this multi-disciplinary process to support

their needs. There is a gap between the identification of needs from the literature, how they are supported in school and our understanding of how children and young people view their experiences of education with CFS/ME.

This gap is significant, as it raises questions as to how not only the statutory educational needs of children with CFS/ME are met within the educational system from a legal and rights-based perspective, but how EPs and other educational professionals can appropriately provide support and advice to this population when so little is known about the experiences of individuals. With secondary school being the main peak age of onset for CFS/ME (Bakken et al., 2014), and the educational significance of this time (Harland et al., 2019), there is a need for professionals, including EPs, to better understand the experiences of children and young people with CFS/ME to provide appropriate support in applied educational settings.

The research aims to address the research gaps expressed above through the following question:

- How do young adults who had a diagnosis of CFS/ME while at secondary school describe and perceive their experiences of education with the illness?

The question is exploratory in nature and aims to hear the voice and experience of those impacted, from their perspective, bridging the gaps between what is known medically about the illness, and how this is represented in the lives of those impacted. By considering the retrospective experiences of young adults aged 18-25, considering their time at secondary school, the study aims to capture the longitudinal nature of CFS/ME and it's impacts over time, and how this may change. The study aims to give voice to an under researched group in the literature, while potentially providing insight in to how best to support their needs that is relevant to the EP role, as well as wider educational professionals.

3 Methodology

3.0 Chapter Introduction

This section considers the links between paradigms, epistemology and ontology, and how this is reflected in the research method employed in the current study, Interpretative Phenomenological Analysis (IPA). The strengths and limitations of IPA as a research method are discussed, as well as the philosophical underpinning of the approach. Alternative research methods are evaluated to justify the rationale of selecting IPA as the research method for this study. The latter part of this chapter explains the research methods used, including key details relating to participant recruitment, ethical issues, data collection and methods of analysis.

3.1 Research Paradigms, Ontology and Epistemology

A research paradigm is a set of beliefs about the world that influence the philosophical underpinnings and associated methods of data collection for a study (Mackenzie & Knipe, 2006). Research paradigms are informed by our ontology, which is concerned with our beliefs about the nature of our reality, and epistemology, which is concerned with how we explain and measure this reality (Cohen et al., 2002). A thorough understanding of research paradigms is essential for clarity and quality of research, as well as ensuring appropriate methods are used to answer the research question (Kivunja & Kuyini, 2017).

3.1.1 Positivist Paradigm

Traditionally, psychology has been focussed on research from the positivist/realist paradigm, where experimental methods are typically employed for rigorously controlled studies under laboratory conditions (Ponterotto, 2005). The positivist paradigm assumes that there is a 'truth' that can be investigated through the research questions posed within the paradigm, which can be measured and analysed through the position of the external researcher (Aliyu et al., 2014). However, as the social sciences, including psychology, have grown in research output since the 20th century, critics of the positivist have questioned the extent to which the complexity of human experience can be quantified and studied through positivists methods (Guba & Lincoln, 1994).

3.1.2 Constructivist Paradigm

The constructivist/relativist research paradigm emerged from critique of the positivist paradigm (Parker, 1998). The constructivist paradigm proposes that research cannot be

conducted impartially, as positivism proposes, as human knowledge and understanding is constructed through experiences and interactions with the world around us (Robson, 2011). Constructivists further propose that through research, we can co-construct an understanding of the research phenomena through exploring individual viewpoints, but these will always be dependent on the context they have been studied in (Robson, 2011).

3.1.3 Critical Realist Paradigm

The critical realist paradigm aims to reconcile these conflicting positions. Pilgrim (2019) details three core assumptions of the critical realist paradigm. Firstly, is that of ontological realism. This is the concept that there are universal constants in the world that exist regardless of if we know or understand them, this could be considered a form of reality. Willig (2013) gives the example that within psychology, this means we accept that there are processes of human behaviour that we can observe and monitor as a researcher. However, the second assumption of the critical realist paradigm as explained by Pilgrim (2019) is epistemological relativism. The systems and power structures of the world we live in shape our interactions with our external reality, which means we have unique and individual constructions and interpretations of events. The final assumption is judgemental rationalism. This is where, through our ontological realism and epistemological relativism, we interpret, analyse and make judgements about what we believe to be more or less 'true'. Pilgrim (2019) argues that without this evaluation, research becomes 'stuck' when valuing all constructions of knowledge equally, or searching for a single 'truth' that cannot reconcile these individual experiences. Willig (2013) further proposes that this interpretation of human experience and the interaction of this with reality is essential to the critical realist approach, bringing the 'critical' element to our understanding and representation of the world through research. However, the paradigm has attracted criticism from both the positivist and constructivist paradigms, questioning the extent to which they can ever be reconciled (Blaikie & Priest, 2017).

The present study adopts a critical realist approach. Critical realism lends itself to social research, particularly when considering issues that face marginalised groups and how these can be supported through policy development and recommendations (Fletcher, 2017). The judgemental rationalism assumption of critical realism allows researchers to consider the power structures and systems that could influence the external 'reality' of policy and procedure behind the lived experience of research participants. Critical realist approaches are

often used in health-related research to interrogate these concepts, which relates to the aim of the current study considering the experiences of young people with medical needs in school (Haigh et al., 2019). Policy and law exist to meet the needs of children and young people with medical conditions such as CFS/ME within schools, this could be argued to be an external 'reality' that could impact on their lives. However, the little existing literature suggests children and young people with CFS/ME have unique experiences of the illness, including how this is perceived and supported by those in the educational system. Exploring these experiences and interpreting them in relation to the structures of education including the power children and young people with CFS/ME have within this, relates strongly to the social justice agenda that underpins the motivation for the research project.

3.2 Potential Research Methods

Several qualitative research methods were considered in line with the ontological and epistemological stance of the thesis with the aim of answering the experiential nature of the research question. This section considers the strengths and limitations of each potential research method, including an in-depth description of IPA, the chosen research method.

3.2.1 Grounded Theory

Grounded Theory has several different methodologies nestled within the overarching approach, but was founded by Glaser and Strauss (Mills et al., 2006). Broadly speaking, Grounded Theory uses data collection and analysis simultaneously, and constantly compares themes developed within participants' accounts, which are used to further develop potential avenues for questioning as the research develops (Charmaz & Belgrave, 2007). This data is then assimilated into categories and theories that aims to explain the processes behind the gathered data as an inductive process (Charmaz, 2014). This is then represented as an explanatory model of the studied phenomena (Chun Tie et al., 2019).

3.2.2 Thematic Analysis

Thematic analysis (TA) is a flexible method of data analysis that allowed research to look for themes within a set of qualitative data, often through interview transcriptions or focus groups (Braun & Clarke, 2006). Braun & Clarke (2006) stipulate TA can be used for either rich description of specific themes within a data set or provide a broader description of all themes across a data set. TA can also be driven by an inductive analysis of the data set itself, or a

theoretical application of existing theories to the data. However, TA focuses specifically on themes across a data set, rather than allowing for the exploration of the experiences of individuals within a wider data set (Braun & Clarke, 2013).

3.2.3 Interpretative Phenomenological Analysis

IPA focuses on phenomenology, which is the study of the lived experience of individuals (Braun & Clarke, 2013). However, IPA goes beyond just 'describing' an individual's experience and looks to analyse this through adding interpretation of the phenomena being described through the researcher's application of psychological knowledge; this is a dynamic process that is influenced by the researcher, known as hermeneutics (Willig, 2013). IPA also adds richness to our understanding of a phenomena by analysing the experiences of individuals in turn, then considers how overarching themes can be constructed from these ideographic accounts that provide insight into the overall nature of the phenomenon being studied, making sense of the participants' experiences in the social context in which they occurred to develop our knowledge of the world (Larkin et al., 2006).

3.2.4 Rationale for the use of IPA in the Current Study

IPA has been selected as the research methodology for several reasons. Firstly, the focus on the individual allows us to give voice to populations who have typically been considered 'unheard' in research, adolescents with CFS/ME appear to be one of these groups based on the lack of published research in this area (e.g. Parslow et al, 2017). Due to the existing literature that suggests CFS/ME is a highly heterogeneous condition, considering participants experiences as a homogenous group, with only their diagnosis in common, risks failing to fully represent the voices of the group the study aims to promote. This would also be in contradiction with the critical realist positioning of the research, which values the experience of the individual in relation to the research question posed. As noted above, in comparison to TA and Grounded Theory, IPA allows for greater comparison of experiences between individuals. This is also relevant to the proposed study, as the exploratory nature of the research question requires a methodology that can capture the potential diversity of participant experiences, closely aligned to the ideographic stance of IPA. This is opposed to the qualitative approaches of TA and Grounded Theory that although look to explain a phenomenon from the perspective of research participants, do this through similarities between groups rather than the individual

experience, which lead to the rejection of TA and Grounded Theory as suitable analysis for the research question.

3.3 IPA Methodology

This section builds on the explanation of IPA in section 3.2.3 above and considers the core aspects of the philosophy of the approach, as well as the methodological processes associated with these.

3.3.1 History of IPA

3.3.2 Phenomenology

As noted above, IPA is phenomenological approach, which can be defined as the study of lived experience (Braun & Clarke, 2013). Phenomenology is a philosophical approach with various subdivisions that have developed over time, with key philosophers in the area proposing their own methods to understanding questions related to lived experience (Alase, 2017). Therefore, the varying phenomenological approaches can be considered different ways of understanding how we experience the world around us, opposed to 'one' prescriptive research method or tradition that represents the discipline as a whole (Dowling, 2007). Researchers caution that because phenomenology is such a broad area, without clear research guidance, research that claims to use these approaches can appear methodologically unclear in how it has answered research questions relating to participant experience (Norlyk & Harder, 2010).

When considering the role of phenomenology in IPA, Flowers et al. (2012) highlight although IPA has roots in the discipline it does not aim to align itself with one branch in search of the 'correct' subdivision within this; rather it adopts an eclectic approach. They posit that phenomenology exists within IPA as a psychological framework, and the focus of the individual furthers our research understanding of the lived experience by examining the meanings people place upon this. Therefore, the structures of IPA remain true to the phenomenological philosophy of the approach, drawing on a series of set processes to help us relate this to deeper understanding of the psychology of lived experience. In short, IPA uses phenomenology to answer the question of *how* a research participant understands their experience of the phenomenon of interest (Larkin et al., 2006).

3.3.3 Hermeneutics

Hermeneutics is another key philosophical underpinning of IPA, which is the theory of interpretation (Smith et al., 2009). Hermeneutics provides a deeper level of understanding of an experience than phenomenology alone, as it introduces the concept of the potential hidden meanings behind the description of an experience (Kacprzak, 2017). Like phenomenology, there are several differing perspectives on how hermeneutics can and should be applied in research, with no single correct way of applying the approach (Dowling, 2007).

IPA adopts a similar stance to hermeneutics as it does phenomenology, as in it draws from a range of philosophical approaches and considering relevant ideas in the context of a psychological research framework (Tuffour, 2017). Eatough & Smith (2017) highlight that hermeneutics plays two roles in IPA, focusing on both making meaning of the participant's experience in their account detailed in the research, as well as how the researcher's own life experiences, perceptions and biases may impact on this process. This is referred to as the 'double-hermeneutic' process within IPA, as the researcher is making sense of the participant making sense of their experience (Smith, 2011). Smith argues that through this process the interpretative element of IPA is clearly demonstrated, as the researcher should be interrogating and developing their analysis through a dynamic process of reflection and revision based on their progressive experience of the research. The hermeneutic process is embedded throughout all levels of IPA analysis, and known as the hermeneutic circle, from the initial reading of the transcript and making notes at the individual text level, to the final development of themes and cross-case comparison (Eatough & Smith, 2017).

3.3.4 Idiography

IPA is focused on the particular detail of an experience, as opposed to focusing on general observations or trying to apply concepts at a widespread level (Smith et al., 2009). This idiographic focus is a key area of difference of IPA in comparison even to other qualitative methodologies and can provide a unique opportunity to consider the depth of an experience as opposed to breadth (Spiers & Riley, 2019).

3.3.5 IPA Analysis

Smith et al. (2009) state that IPA is a flexible research method, and there is not one 'fixed' way to use the method. However, they note that frameworks in the use of IPA can be useful to the

novice researcher, providing structure to adhere to the principles of IPA while maintaining enough flexibility to adapt the analysis to their research context. The core IPA analysis steps are summarised in the table below:

Table 7: IPA data analysis method summarised by Smith et al (2009)

Stage	**Description of Activity**
Data preparation	Data is transcribed by the researcher to remain close to the data
Familiarisation	The researcher reads through all data and makes notes on initial areas they find interesting
Initial noting	The researcher begins with the first interview, which represents the first data set. The researcher makes notes based on three levels of the data; descriptive comments of what is said, linguistic comments on how it is said and conceptual comments, considering potential deeper meanings behind what is said.
Emergent themes	From the initial noting, common areas are grouped into themes of similar meaning, based on both what was said by participants and the researcher's analysis.
Superordinate themes	Emergent themes are grouped into superordinate themes, with emergent themes nestled under these. Themes and codes are consistently reviewed and refined. This is represented in a tabular analysis or visual map for the individual data set, including quotes or numerical references to provide data that highlights these themes in the transcripts.
Cross data analysis	The process above is repeated for each individual interview. Once all data sets are analysed themes and superordinate themes are analysed across all data sets. These are represented in a tabular form or a visual map for all data sets.
Writing up	The analysis is synthesised and recorded

3.3.6 Limitations of IPA

IPA has been criticised for a lack of transparency when researchers make and report the interpretations they make through the 'double hermeneutic loop' process (Brocki & Wearden, 2006). IPA acknowledges that the positioning and views of the researcher are essential to understanding the analysis made (Miller et al., 2016). Therefore, if this information isn't clearly reported it limits the usefulness of IPA research, as it becomes unclear as to the origins of conclusions made and how these relate to the issues posed by the research question (Pietkiewicz & Smith, 2014). Palmer et al. (2010) suggest that to ensure fidelity to the IPA model and transparency, IPA researchers should pay particular attention to the context of their research and subsequent reporting to clearly illustrate how interpretations have been made. In section 3.3.2 I outline the steps I have taken to clearly outline my analysis process to ensure transparency in my use and reporting of IPA in mind of these points.

Further limitations of IPA have also been raised relating to the language-dependent nature of the approach; as it depends on participants ability to articulate their experiences to be interpreted by the researcher (Smith & Shinebourne, 2012). Smith & Sherbourne explain that this also includes a participant's willingness to share their experiences. Ensuring participants felt comfortable during the interview was therefore a key ethical and research design consideration, detailed in section 3.4.2.

3.4 Research Rigour and Reducing Potential Bias

As a researcher, it is important that I acknowledge my interests and motivations in the research area as an important aspect of its' context. This is an important step of quality control as outlined by Palmer et al. (2010). I, as an adult, received a diagnosis of CFS/ME while completing postgraduate study. This means I share some similarities with my participants in that I have a diagnosis of the illness which I manage in an educational context. However, the circumstances of my illness are very different, and I did not manage a diagnosis while at secondary school.

Despite these differences, it is important to acknowledge my position as a researcher with CFS/ME and my own personal experience could have influences on my interpretations and represent a potential form of bias. Frost (2011) highlight that in interpretative research

methodologies such as IPA, analysis can be challenging as there are not definitive prescriptive guidelines for the process, and it will be impacted by the researcher. However, Frost also proposes there are ways in which the researcher role and analysis can be clearly documented that allow transparency of their role and decision making.

3.4.1 Reflexivity and Bracketing

Reflexivity is the process whereby researchers consider their reactions throughout the research process and the responses they have to information participants disclose, acknowledging the impact their responses may have on the study in turn (Holloway & Biley, 2011). To support my reflexivity, I adopted several measures specifically related to IPA suggested by Clancey (2013):

- I will state my position to participants as someone who is diagnosed with CFS/ME.
- I will keep a reflective journal of thoughts and feelings that rise throughout data collection and analysis and reflect on the influence of these on her work.
- I will use tutorial support with my research supervisor for an alternative view on interpretations made.

Throughout the thesis, key dilemmas relating to the study process and analysis are highlighted in text boxes to show the actions taken to resolve these.

Within IPA, reflexivity in the research process is linked to the concept of 'bracketing'. Bracketing is the process where a researcher aims to contain and separate their views and experience of the phenomenon being studied (Chan et al., 2013); although as this paper adopts the critical realist paradigm the researcher believes there are limits to which they can be an impartial observer to the research process. Chan et al. (2013) suggests several strategies to support a researcher bracketing their knowledge in IPA, including asking participants open ended questions, keeping a genuine curiosity to the topic at study, using a reflexive diary, and using a guided data analysis framework underpinned by a thorough research plan. The study has adopted these measures in design to support the researcher in bracketing their experiences as much as possible. Bracketing will be used as a continual process throughout the research, to ensure the researcher approaches each interview and its subsequent data analysis from the most neutral position possible to ensure the analysis is a valid reflection of participants views.

3.4.2 Reliability and Validity

In qualitative research, debate centres on how researchers can demonstrate quality in their work when quantitative concepts relating to the replicability of a study (reliability) or how accurately it measures the phenomenon being studied (validity) cannot be measured due to the epistemological and ontological positioning of the research (Reynolds et al., 2011). To resolve these issues, researchers look to identify quality control criteria frameworks to ensure rigour in data collection and analysis from the initial design stage to final research write up (Braun & Clarke, 2013).

I have adopted the following quality control framework as outlined by Yardley (2000):

Table 8: Steps taken to ensure research quality outlined by Yardley (2000).

Principles	Measures taken
Sensitivity to context	The researcher has provided open ended interview questions to allow participants to answer fully to describe their own experiences. The researcher has made provisions for the possible health needs of participants by offering rest breaks etc. The researcher will complete a reflexive log to consider the impact of the context on their own role in the research process.
Commitment and rigour	The researcher has a personal motivation for researching the topic area. The researcher has a rigorous research proposal. The researcher has read widely to inform research methods and best practice in IPA research.
Transparency and coherence	The researcher will use participants' own quotes as information The researcher has aligned paradigm, epistemology, ontology and research methods. A full method section will detail the steps taken in data collection and analysis.

	The researcher's reflexive accounts will be included throughout the data write up.
Impact and importance	The research provides an opportunity to hear the voice of an under-represented group of young people to increase our awareness of an under-researched area of need

3.5 Method

This section outlines the steps taken to design a study appropriate to answer the research question:

- How do young adults who had a diagnosis of CFS/ME while at secondary school describe and perceive their experiences of education with the illness?

This section outlines my participant selection and recruitment and data collection processes.

3.5.1 Participant Selection and Recruitment

Initially, my aim was to recruit at least three participants, with a maximum of six, which is suggested as a useful target number to guide research planning by Smith et al. (2009). However, Smith et al. also stress that IPA methodology allows a great deal of flexibility, and there is no 'right' number of participants for an IPA study, as the focus of the methodology is understanding the individual experience and the richness of this data. There is published literature ranging from single-case IPA analysis, through to papers with 15 participants (Pietkiewicz & Smith, 2014).

I adopted a purposive sampling strategy in order to target participants who would be eligible for my study. The participant inclusion criteria, and rationale for these, are shown below:

Table 9: Participant inclusion criteria and relevance to the research question

Participant criteria	Relevance to the Research Question
Aged between 18-25 years old	Participants will have completed all their secondary education, so can describe their longitudinal experiences As young adults, their secondary experiences would be fairly recent

	The needs of young people up to the age of 25 are considered under the SEND Code of Practice (DofE and DofH, 2015),
Had a confirmed diagnosis and symptoms of CFS/ME at secondary school	This will ensure that the research is accurate and focuses on the needs relating specifically to CFS/ME
Able to conduct a video interview for about one hour with the researcher	This is an ethical consideration to highlight the physical demands of the interview and allow participants to understand the nature of the research prior to expressing interest

Initially, I hoped to recruit participants through University of Nottingham student support services, however this was not possible. I therefore had to consider wider recruitment opportunities by contacting charities and support groups for people with CFS/ME, who offered to advertise my study on their social media channels and email newsletters. I also posted an advert on EPNET, a free professional forum for EPs and those interested in the profession.

Participation was on an 'opt in' basis, participants were invited to contact the researcher for a study information sheet in the social media and email advertisements. If participants were happy to proceed based on this information, they were sent a consent form to return via email. Once this was received, a time was arranged for a video interview.

In total, two participants were recruited for the study. The barriers to recruitment I faced during the study are explored fully in the 'Discussion' section 5.3.1.

Reflexivity:

During recruitment, participants got in touch to explain their different CFS/ME histories, which raised issues I had not thought of, such as a late diagnosis received in post-16 education, which affected their A-levels. As my focus was on secondary school experience, this made the participants ineligible for my study. As my research aim is to hear the underreported voices of those with CFS/ME, I was concerned my initial participation criteria may not reflect the reality of the group I hoped to represent if there were also needs for young adults in this age group. I raised this with my supervisor to consider my recruitment strategy, and if I should look to widen the criteria. On reflection, I felt that extending my criteria could make it more difficult to draw themes between cases and lose some of the 'richness' associated with IPA, so I decided to keep my original criteria with fewer participants.

3.5.2 Data Collection

Semi-structured interviews were used to collect participant's data. Interviews are particularly useful in qualitative research as they capture the rich details of an experience, as well as gaining participants' insights in their own words (Yin, 2018). This experiential, individualised approach is particularly important when considering the ideographic nature of IPA (Fade, 2004).

The semi-structured interview schedule was developed to cover five broad themes, to consider the circumstances of a participants CFS/ME diagnosis, their school experiences and how they described these (the full interview schedule is shown in Appendix C). These questions were reviewed with the research supervisor through a reflective discussion to consider their alignment with the critical realist positioning of the research.

The interview questions were kept open and broad in focus. Prompts or examples were then given for clarity depending on the context of the question, but these were not pre-determined. This was not only because of the chosen research method of IPA, which looks for rich description in the participant's own words, but also the potential differences in individual experience of CFS/ME while at secondary school. As so little research exists on the topic, I did not want to be overly prescriptive in my approach to questioning to truly reflect the experience of the participants. When interviews were played back for transcription, any questions that

seemed to require additional prompting, or prompts that supported participants to give detailed answered were recorded in my notes to be used as prompts in subsequent interviews if appropriate.

Reflexivity:

Ideally, I would have liked to conduct a pilot interview to test my interview schedule. Due to my constraints in recruiting participants this was not possible. However, in having reflective discussions with my supervisor, as well as EP colleagues who were experienced qualitative researchers, to help ensure my questions were clear and in line with my epistemological and ontological positioning, which helped ensure quality control.

Interviews took place online using Microsoft Teams, secure video conferencing software available through the University of Nottingham. Interviews were conducted online in part due to social distancing measures relating to Covid-19 in England at the time of the research.

As part of the interview process, I chose to disclose that I had received a diagnosis of CFS/ME as an adult, which inspired my interest in the research area. Views around personal disclosures are mixed, however advocates of the approach suggest a well-planned disclosure can help build rapport (Braun & Clarke, 2013).

During the interviews, I was conscious that participants were discussing emotive topics (as discussed in section 3.6.3) During the interviews, if I perceived any signs of distress from participants, such as if they became visibly tearful, I checked in with them, and gave them time to take a moment to decide if they wanted to carry on, or if they needed a break or wished to terminate the interview. If they decided to take a break, I made it clear they were under no obligation to complete the interview, although participants chose to return or reschedule an interview after a break. At the end of each interview, I shared personal strengths and qualities I had observed in their accounts to end on a positive note and sent debrief information following each interview section.

Following the initial interviews, as part of the IPA process, participants were invited to take part in a follow up interview to discuss the study analysis. One participant chose to take part in the follow up discussion. This was offered due to the aim of the research to highlight the experiences of this population and explain what I had found and the professional relevance of this, as opposed to a step taken to 'confirm' the IPA analysis.

Reflexivity:

I considered if disclosing my diagnosis could have a negative impact on interviews, or if I personally felt comfortable to disclose this information. However, as a person with CFS/ME, and knowing other people with the condition, I am aware of the pressure or worries that can surround some of the symptoms of the illness which may not always be understood by others, or the worry that someone may not understand. Ethically, I felt it was important to make the disclosure to support participants to feel safe in requesting any physical needs they may have, such as taking a rest break or halting the interviewer, without the potential social pressures they may feel 'justifying' their illness. On reflection, I think that this did help my interview process, as I felt able to prompt one of my participants to check if they needed a rest break, which they then accepted, and the interview took place over two separate sessions.

3.6 Data Analysis: IPA Process

3.6.1 Data Preparation: Transcription

As the first stage of data analysis, I transcribed the interviews to increase my familiarity with the data, an important IPA quality control step suggested by Larkin et at (2006). Once transcribed, interviews were listened to twice through with the transcript to check accuracy before moving onto the next step. As part of the transcription process, I noted any significant non-verbal cues, such as laughter or long pauses, to capture further detail about the context of the interview. After I confirmed the accuracy of the transcription, I copied the information into a table to begin the analysis. Transcript extracts for both participants are shown in Appendices D and E.

3.6.2 Familiarisation

Working with the transcript, I read through the participant interview I was working on twice through. I made a column on the left-hand side of my transcript for my initial thoughts, feelings and reflections on reading the transcript. Once this step was complete, I hid the data in the column from view as I moved on to further stages of analysis. This provided a way of

bracketing off my initial assumptions before moving onto the next stage, However, by keeping the information hidden from view, but available in the transcript if needed, I had a way to check back and interrogate my future coding and theme development by comparing it to my initial reflections to consider possible sources of bias, as well as clearly showing the development of my thinking and how this can be related back to the data as part of my quality control process.

3.6.3 Initial Noting

For this stage, I created a second column to the left of my transcript, next to the hidden 'Familiarisation' text. I applied the coding strategy suggested by Smith et al. (2009) and used colour coding to categorise the types of coding. An extract of coded data is shown in Appendices F and G each participant.

In the transcript, descriptive comments were identified, which were the actual content regarding what the participant had said. Smith et al. (2009) suggest that in this phase, comments by participants should be taken at a surface level and focus on their description of what matters to them in their account. These descriptive comments focus on the relationship of the participant to the people, objects and events in their account. They were made in blue on the coding table.

I also looked for linguistic comments in the transcript, which Smith et al. (2009) describe as things such as hesitations in participant responses, their tone of voice or if they laugh. Through observing these linguistic features of an account, we can look for possible sources of incongruence between what is said and how it is said (Larkin, 2006). These comments were made in green on the coding table.

The final layer of coding was at a conceptual level and draws more on the 'interpretative' elements of IPA. Smith et al. (2009) describe this step as more challenging and is where the researcher looks for a deeper meaning of how the participant is understanding their experience in context, beyond what is explicitly stated. Smith et al. caution this phase should be clearly documented, and analyses linked back clearly to the text to ensure interpretation stays true to the participant's words. These conceptual codes are shown in purple on the coding table.

During this phase, I discussed and showed my codes to my research supervisor for full transparency of my data and interpretations, as per my quality control steps (Yardley, 2000). Additionally, I took part in peer supervision where I discussed my coding process with fellow qualitative researchers in my course cohort to gain their views and ensure my coding was grounded in the participant's data and words.

3.6.4 Developing Emergent Themes

Smith et al. (2009) describe the development of emergent themes as a way of extracting the key points of both the original transcript and researcher's comments, capturing the hermeneutic loop process of IPA. At this stage, they describe that the analysis moves away from being bound specifically to the participant's exact words, and 'zooms out' to a more conceptual level, where the relationship between the coded sections of transcript begin to relate to the whole interview at a thematic level.

After reviewing my initial emergent themes it became clear that there was some duplication of emergent themes, as well as similar emergent themes that represented different aspects of a common central idea. I reviewed and renamed my emergent themes at this point to characterise the concept they represented, which became subordinate themes. I arranged themed by printing a list and cutting them into individual labels, that could be grouped and regrouped as needed.

Although this step is not explicitly detailed in the procedure guidance by Smith et al. (2009), they also make it clear that IPA analysis is not prescriptive, and researchers may adapt and develop their own methodology. Due to my small study sample, and the depth of my interviews, developing these subordinate themes allowed me to stay closer to the depth of participants experiences while managing the volume of emergent themes to ensure robust analysis of interviews.

Reflexivity:

When considering grouping emergent themes into subthemes, I was concerned in case I was not doing IPA the 'right' way. This led me back to reflect on my ontological and epistemological positioning, and the theory of IPA. I realised I needed to trust there is no one way of completing an IPA study, and what is appropriate depends on the individual data and context. In developing subthemes, I could represent the ideographic experience of my participants much more deeply, capturing the breadth *and* depth of their experience, reflecting both my research questions and aims of the study more effectively.

3.6.5 Developing Superordinate Themes

In this stage of analysis I grouped my subordinate themes into categories known as superordinate themes, which represent a common feature of the subordinate themes, and in turn the underpinning emergent themes. Smith et al. (2009) suggest several strategies to search for connections across themes that I used:

- Abstraction: similar themes are grouped together and renamed to convey shared meaning
- Subsumption: a prominent emergent theme becomes a superordinate theme, with clear subthemes that fall under this category
- Polarisation: considering the opposite experiences described by subthemes to capture the complexities of a superordinate theme
- Contextualisation: themes may describe the temporal progression of an event which tells the 'story' of an experience as a theme

A table for each participants' superordinate, subordinate and emergent themes are shown in Appendices H and I.

3.6.6 Moving to the Next Case

I repeated steps 1-4 for my second transcript. Smith et al. (2009) advocate considering each participant transcript in turn to support an ideographic approach to data analysis. They advocate for the researcher to bracket off their previous analysis as much as possible to allow for unique themes to develop for each transcript.

Reflexivity:

To help with my bracketing of ideas between participants, I found it useful to schedule stages of analysis with breaks in-between, for example returning to a transcript to begin coding after a weekend break. I was concerned that when I was generating my second set of superordinate themes, they were too similar to my first participant. I could see that the subordinate themes had variance, which highlighted different aspects of the superordinate themes, but overall they were very similar. I reflected that by trying too hard to bracket off my previous knowledge I was inadvertently missing the participant's ideographic experience because I was concerned about the similarities and looking for something different in the themes. I went back to the transcript and the participant's words to find quotes to illustrate the themes, and was confident that although there were similarities, these came from the participant, not a preconceived idea I had about the 'right' analysis.

3.6.7 Looking for Patterns Across Cases

Smith et al. (2009) describe this stage as a way to move an IPA study to a more theoretical level from the purely descriptive level, by considering the experiences of participants as both individuals and a whole.

Once analysis was completed for both transcripts, a list of the subordinate themes and superordinate themes for each participant was printed to represent them visual and regroup themes as necessary. Themes between each participant were compared to look for core similarities and differences in the underpinning subordinate themes. During this process, themes were refined and edited to capture the shared qualities participants experienced. The superordinate themes and underpinning subordinate themes for both participants were represented as a master table of themes for the group (Table 10), showing the distribution of themes across both participants.

3.7 Ethical Considerations

The study received ethical approval from the University in Nottingham in August 2020 (application and approval letter shown in Appendices J and K). The study fully considered guidance from both the British Psychological Society (2014) Code of Human Research Ethics and University of Nottingham Code of Research Ethics. Due to the nature of the study, particular ethical issues were relevant as explained in further detail below.

3.7.1 Consent

As participants were recruited through external organisations' social media, an opt-in approach was used. Study adverts (Appendix L) relied on participants contacting the researcher for a full information sheet (Appendix M), then choosing to return this and fill out a consent form to arrange an interview time (Appendix N).

Participants were informed of their right to withdraw for any reason, without penalty, including after the initial interview up until the deadline two weeks post interview given in the debrief letter (Appendix O). After this date, they were informed data transcription would begin and their data would be used in the analysis. Participants were also invited to take part in a follow-up interview to discuss the findings if they wished in the debrief document, again this was an opt in process following an email from the researcher.

3.7.2 Confidentiality and Anonymity

Participants were informed that their data would be transcribed under a pseudonym, with the removal of any potential identifying information, such as a school name. Participant's ages were included in the write up to consider factors relating to education, such as the time that they left school and their current education/ work situation, as part of understanding the potential impacts CFS/ME had on their secondary school experiences. As the study was conducted via video interview, participants were informed of the potential risk of hacking by external agents which could compromise their anonymity.

3.7.3 Protection from Potential Harm

The study included recollection of potentially distressing memories. A full debrief, giving information regarding NHS services to contact in the event of mental health difficulties after the study, was provided to participants (Appendix O). Interviews ended with a summary of observed strengths participants had shown to end on a positive note.

Steps were also taken to consider any potential physical health needs participants may have because of CFS/ME. Participants were offered interviews at times suitable for them, depending on their energy levels. Participants were offered rest breaks as needed during interviews, as well as screen breaks if required due to the video interviews. Participants also had the option to arrange several interviews, scheduled for a duration they would find tolerable, instead of committing to a single hour-long interview. The debrief letter provided also advised participants to contact their GP or healthcare provider if any health needs had been identified to them as a result of the interview.

4 Findings

4.0 Introduction to the Analysis

This section reports the findings of the Interpretative Phenomenological Analysis. All themes identified within this chapter are a result of the interpretative process and are therefore subjective to my views as the researcher. Where language is used to draw conclusions about the data, it is therefore important to note they have been generated as a result of this process and represent my interpretation of the data alone.

Four superordinate themes were identified that represented a shared experience for both participants, which is shown in Table 10 below. The subordinate themes underpinning the superordinate themes had some divergence within the theme and highlighted the unique different experiences of each participant. Tables have been used to illustrate who each subordinate theme belongs to in the reporting of each master theme. The written analysis considers the subordinate themes for both participants, and how this is reflected in their own experience through description of subordinate themes and use of direct quotes to illustrate key elements of each participant. Due to the small sample size and exploratory nature of the study, all subordinate themes for each participant have been reported to capture the rich and detailed data gained through the interview process.

4.1 Context

As part of my quality control process described by Yardley (2000), it is important to note the context of the research. Key details around each participant and their background are described below, using a pseudonym and removing any potential identifying personal details to protect their anonymity.

4.1.1 'Ben'

Ben was aged 25 at the time of the interview. He was diagnosed with CFS/ME while in Year 8 or 9 in secondary school, as the subsequent consequence of a gastro-intestinal ill ness he developed in primary school, which required hospital treatment. Ben had made a recovery from CFS/ME throughout his time at secondary school into adulthood. Ben had been to college and university and was now working. Ben refers to his illness as ME throughout his account.

4.1.2 'Emily'

Emily was aged 23 at the time of interview. She was diagnosed with CFS/ME after her illness developed suddenly around the Christmas of Year 8, and she had a period of eight weeks off school before attempting to return. Emily stated she still had CFS/ME as an adult, which impacted on her day-to-day life. Emily reported her health had started to improve recently, and she had recently began studying for a degree through distance learning. Emily refers to her illness as ME throughout her account.

4.1.3 Educational Context

Based on the ages of my research participants, some of the legislation described in the literature review came into effect after they had completed their secondary schooling. Similar guidance existed to consider the needs of pupils with medical conditions, including the statutory guidance 'Managing Medicines in Schools and Early Years Settings' (DofH & DofE, 2005), which was superseded by Supporting Pupils with Medical Conditions at School (DFE, 2015). There was also legislation to protect the rights of students with SEND, including the Equalities Act (2010) and the 2001 SEN Code of Practice (DoH & DoE, 2001). This guidance mirrors the principles of the present legislation, in that children and young people with SEND must have access to an equivalent educational provision to their peers.

4.2 Master Table of Themes

This section presents an overview the four superordinate themes identified through the IPA process that were shared between participants. A detailed analysis of the subordinate themes that make up the overarching superordinate themes are presented for each participant, with tables used to show the distribution of themes.

Table 10: Master table of superordinate and subordinate themes from the IPA process

Superordinate Theme	**Subordinate Theme**
The complex physical impacts of CFS/ME	• Supporting physical needs within school • Impacts on attendance • Recovery is fragile

The social and emotional experience of school	• The role of wider social support • Social exclusion • Reduced aspirations • School as a strange experience • The emotional strain of managing CFS/ME in school
The impacts of adults on the school experience	• Staff communication • Consistency of support • The young person as an advocate • Do we hear the 'voice of the young person?'
Managing the demands of the curriculum	• Pre GCSE • During GCSEs • Playing 'catch up' • The (in)flexibility of the school system

4.2.1 Superordinate Theme: The Complex Physical Impacts of CFS/ME

This theme captures the physical experience of having CFS/ME while at secondary school, and the impacts this had on daily school life. This theme 'sets the scene' for the subsequent analysis of themes, outlining the clear and identified impacts of the illness. The physical experience of CFS/ME raised several needs and barriers for both Ben and Emily which required adjustments within the school context. The physical needs of CFS/ME were reflected throughout both transcripts as being well identified by school.

Table 11: The distribution of subordinate themes within 'The Complex Physical Impacts of CFS/ME

Subordinate Theme	Ben	Emily
Physical needs within the school environment	X	X
Impacts on attendance	X	X
Recovery is fragile	X	

Supporting Physical Needs in School

Both Ben and Emily identified a range of needs as a result of their physical symptoms of CFS/ME.

> *I just couldn't concentrate, I couldn't (pause) you know physically pay attention to what he was trying to teach me about maths or English or anything* (Ben, 58-60)

> *…not having the ability to stand up long, so it's very difficult to stand in queues outside classrooms while feeling dizzy and fatigued, headaches, nausea, having no energy left* (Emily, 341-344)

Both identified the need for a physical space in school to rest when they needed to manage their fatigue, and the importance to them that they could access this flexibly. Although these were provided by their school, both described aspects of the space that suggested they were not always appropriate.

> *And I think as good as that space in the Library, that just having a quiet room or something that they could have… it would be nice if there had been more designed for space that was just a bit more relaxed where you could go and sit* (Ben, 363-366)

> *There was a lot of sitting in offices, but that was incredibly uncomfortable you know, when you're a sort of teenage girl and you don't feel like you belong in a lot of these places* (Emily, 119-121)

Both participants highlight the inadvertent consequence of these spaces, in that they were not always entirely restful to be in, which would potentially impact on their energy levels and physical health within school.

Emily described school as a physical stain for her, which further exacerbated her symptoms of CFS/ME. Although the school attempted to meet these needs, the strategies were not always beneficial:

> *The school gave me a locker but it was just so impractical because it meant more walking to get to the locker* (Emily, 448-449)

Although the strategies described by both participants seem well intentioned, there is a sense that perhaps the support did not capture the underlying physical needs presented by CFS/ME. Emily hypothesised that this could be due to the nature of CFS/ME, as a 'very, very misunderstood' illness (Emily, 311). Ben also described the experience of some teachers 'not having quite the same understanding' (Ben, 100) of his illness. Again, this suggests that the physical impacts of CFS/ME were perhaps not realised by staff. Without this understanding, it raises the question of how well the physical needs of CFS/ME can be fully met, which is represented through some of the well-intentioned, yet inappropriate, strategies above.

Impacts on Attendance

Ben and Emily experienced prolonged school absences as a result of their CFS/ME. Ben experienced approximately three to four months off school when his illness was at its worst, whereas Emily was off for an initial eight-week period when she became ill.

Although initially both talked about times they were completely absent from school, there were also extended periods of absence linked to missing lessons through attending school part-time.

> *I was still doing part time school, I basically did part time school and never did a full day again and so (tails off)* (Emily, 76-77)

For Ben, there were also times where although he was physically at school, he was not well enough to learn or participate.

> *I'd go through stages where I was really ill and couldn't go to school and times I was there most of the time but not really feeling very well, you know well enough to do things and learn* (Ben, 7-10)

Emily also described being so fatigued in lessons she was unable to concentrate.

> *I was very visibly tired in lessons. I'd be like this (puts head down), I'd have my head on the desk, I'd sort of take rest breaks in the lessons with my head on the table* (Emily, 330-222)

Initially, both participants described their school absence as physically not being in school, however over the course of the interview more and more examples of the 'hidden' forms of school attendance were raised. However, their descriptions suggest that there are several ways in which school absence can be experienced by young people with CFS/ME that may not always be obvious at first, even to the young person themself. Although young people may be in school, if they are so fatigued they cannot focus, as both Ben and Emily experienced, there is potentially a 'hidden' form of school absence, despite them being physically at school. It is not clear from the accounts if these 'hidden absences' were recognised as such by adults within the school systems, but it suggests a potential risk for a loss of learning opportunities.

Recovery is Fragile

This subordinate theme was experienced by Ben, who experienced a gradual process of reintegrating into school full time. During this process, he described 'progression… with a few minor setbacks' (Ben, 213) throughout his time at school. The process of retuning to school was not linear, and needed review.

> *I think gradually I did build up over time but there were relapses as well. I know it wasn't as straightforward, like I was in two days one week then three days the next* (Ben, 208-210)

Interestingly, the concept of recovery and progression continues through to the present day for Ben.

> *I'd like to say I've recovered but I don't want to jinx it too much (both laugh) but I think it's just about there* (Ben, 48-49)

This theme highlights the complexity of CFS/ME, and the variable nature of the illness. For Ben, this meant a gradual and careful process that required long-term management at school, which is an approach that he is mindful of, to an extent, in the present day.

4.2.2 Superordinate Theme: The Social and Emotional Experience of School

This theme captures the social and emotional experiences of managing CFS/ME within secondary education. Although there were some aspects of this theme that were positive, such as the role of social support from peers and family, several challenges were raised relating to managing a chronic illness within school. For both Ben and Emily, CFS/ME had impacts beyond what was identified as a physical need in school, which were not necessarily planned for and addressed when considering how to support them within school.

Table 12: The distribution of subordinate themes within 'The social and emotional experiences of school'

Subordinate Theme	Ben	Emily
The role of wider social support	X	X
Social exclusion	X	X
Reduced aspirations	X	X
School as a 'strange' experience	X	
The emotional strain of managing CFS/ME in school		X

The Role of Wider Social Support

Both Ben and Emily identified that there were people within their social circle they could draw on for support, which was a positive for them, and included their wider family groups. For both Ben and Emily, while at school, their relationships with peers were impacted by their illness, and therefore required a certain level of maturity and understanding about this.

Ben described how he had friends who he kept in touch with when he wasn't at school through the use of social media:

> *I knew what they were up to so they would make sure to let me know like on FaceBook and things like that what was going on which was really nice of them, so my friends were really good like that* (Ben, 139-141)

These links enabled Ben to be invited to and included in social events, when he was well enough. Ben describes what could be considered a supportive and understanding relationship with his friends, he describes they were:

> *…there for me, even if I did disappear for months at a time and they didn't stop talking to me or anything like that but they knew I was rubbish and might not turn up* (Ben, 109-111)

Emily also described a supportive peer friendship that she had, and the importance this had to her:

> *And luckily I did have a friend who stuck by at school and I probably wasn't a very good friend for her to have as I wasn't there very much* (Emily, 122-124)

Both Ben and Emily's accounts both acknowledge the ways in which CFS/ME can impact on even positive social relationships, particularly with their perceptions of their role as a friend. Ben describes how he could be 'rubbish' with showing up to social events because of his illness. Emily acknowledges that she was 'probably wasn't a very good friend' due the unpredictable nature of her illness meaning she had to miss things at school. Although both experienced positive peer support, which was a benefit to them, there were limits to how much they could participate within the adolescent social world while managing their illness.

Social Exclusion

In contrast to the role of understanding peers who could offer social support, both Ben and Emily experienced some challenging peer interactions while at school. Ben described an incident when he returned to school after an absence, and peers made insensitive comments:

> *… there were enough incidents of people like 'oh, Ben is here, I thought he'd died' or something like that you know people saying things like that. And I'm sure it doesn't make you feel the best you could be in those situations*
>
> *I: Do you have any memories of how you handled that at the time?*

> *Er, well I don't think they was ever said deliberately (pause) spitefully or horribly or anything like that. I don't think I ever really properly reacted to it. It was only later when thinking about it I thought 'wow, that was a ridiculous thing to say to someone', like why would you say that?* (Ben, 113-120)

Ben's account of this arguably difficult social situation suggests that these comments come more from a lack of understanding about his illness and absence rather than a desire to upset him. At the time, he didn't let it impact on him, and he can reflect back and see the situation as 'ridiculous'. However, as Ben points out, even though he didn't react, his use of the phrase 'I'm sure it doesn't make you feel the best you could be' highlights the potential impact of these experiences, particularly when considering the physical challenges overcome in order to be well enough to return to school.

Both Ben and Emily described illness as making them different from their peers, which was another form of social pressure. For Ben, he 'didn't want to draw attention to the fact he was ill' (Ben, 300). Emily described her illness as making her feel like an outcast:

> *…what I was experiencing wasn't something other kids could relate to so I was a bit of an outcast, at least I felt like I was a bit of an outcast because I just didn't know anyone* (Emily, 257-259)

For Emily, this difference was experienced as a form of social pressure and in her words, feeling like an 'outcast' as she did not have anyone who could share her experience. Throughout her account, Emily used the phrase 'out of place' to describe her physical location in the classroom in comparison to others, when she returned to lessons to find her seat was taken (Emily, 377). Emily's reiteration of these concepts of being 'an outcast' or 'out of place' in her words emphasise her sense of difference from her peers and their lack of understanding of her, which from her descriptions suggest the social aspects of school became a challenge for her, which limited how comfortable and secure she could feel within the environment.

Reduced Aspirations

Both Ben and Emily experienced a change in the aspirations professionals and others in their lives held for their futures, as well as their own aspirations. Ben described how he went into his GCSE exams 'expecting to fail a little bit' (Ben, 463). However, Ben did not find this a negative experience, instead he rationalised this against his previous experiences.

> *I wanted to do well and study and things but I was never like 'oh no I did terrible' after if I didn't get what I wanted because like 'oh well, I've missed three years before this, it's not the end of the world* (Ben, 467-469)

In his account, Ben highlights the longitudinal impact that his absences from school have had over time, the use of the phrase 'not the end of the world' suggests that the impacts of this are more significant than reducing his GCSE grade predictions. Ben also shared that his parents took the same approach.

> *And certainly (laughs) it sounds bad but my parents, their expectations were like 'oh my God, Ben's at school, like that's the big achievement in of itself like if he gets any grades we'll be happy'* (Ben, 454-456)

Ben's laughter, and acknowledgement that it 'sounds bad' suggests he is aware of how his experience differs from what parents may typically expect from their children at school. However, both Ben's views and his description of his parent's views of his exams suggest that his illness has been prevalent throughout his school life and has arguably had a significant impact on his education. From this, Ben's description of both his and his perception of his parent's attitudes suggest an approach that sees aspirations and achievement beyond school grades, with progress and success throughout his journey to get to the point he could take exams at school.

Emily described how her longer-term aspirations were impacted at school with her diagnosis of CFS/ME, particularly as her illness progressed. She described in being someone who was unwell, she 'might not be able to go out and work immediately or study and go to university' (Emily, 419-420). She felt that professionals were limiting their aspirations for her.

> *…the school and hospital feeling like if you pass your subjects it's good enough for you, there were no sort of, not very aspirational, because you're in the confines of your illness. And I accept that, everything is very confined and you can only do half as much revision as everyone else and that kind of thing* (Emily, 393-395)

Emily's use of the phrase 'confines of illness' was an interesting concept, particularly in relation to the thought of future aspirations. In Emily's description, she recounts the hospital's attitudes were that she should just pass subjects. As Emily described throughout her account, her personal aspiration were to get good grades.

> *Well I was very focused on my grades but not excessively…I wanted to stay I the classes I was in, I think I measured a lot of my self-worth by success against my grades* (Emily, 397-398)

For Emily, there was a clear disconnect between her ideals and aspirations and the hospital's. The hospital appeared focused on the 'now' whereas Emily identified the impact of grades on her future, as well as for her own self-esteem and what she felt she could achieve. The tension between the concept of being 'confined' by illness and the practical limitations this puts on Emily and also aspiring for the future is clear, especially with the value she herself put on her grades, and the difficulty in trying to reconcile these different these positions.

School as a 'Strange' Experience

This subordinate theme relates to Ben's experience of school with CFS/ME, and centres around how different his experience was to the 'normal' school experience. Words such as 'strange' and 'weird' when describing school were used throughout his transcript when describing his experience of school. In the interview, he identified that talking or even thinking about school for any length of time was in itself an unusual change for him:

> *I think I just tend to try not to think about it (laughs) It's an odd change around from usual when I'm actively not thinking about how weird school was* (Ben, 589-591)

Although Ben did not seem bothered by his experience of school, although he considered it to be 'weird', he acknowledged that there are times in adulthood school experiences come up in conversation where he then reflects on how much he missed at school:

> *It's only when we have conversations at work like 'what was school dinners like at your place?' and I was like 'oh I literally never set foot in the dining hall in my secondary school' which it's just weird thinking about it* (Ben, 79-81)

Ben's account highlights how even though it might not consciously be recognised at the time, the impacts of CFS/ME can mean missing a lot of the typical school experience, such as going to the hall for lunch. Although Ben does not appear to perceive this as a negative thing, there is an acknowledgement of the 'typical' school experience and markers of social markers of this, even extending into adulthood conversations about school dinners and the perception of shared experiences of school life as an expectation of your peers. Managing CFS/ME reduced

participation into many of these school experiences for Ben, giving an arguably limited school experience in comparison to his peers, which could explain the 'strangeness' he described in that situation.

The Emotional Strain of Managing CFS/ME in School

This subordinate theme related to Emily's experience of managing CFS/ME within school, particularly as her illness worsened and became a further source of strain on her which was exacerbated by school stress. She described how she would try to separate her experience of CFS/ME from her school life, which in turn became extremely difficult to manage.

> *Well I think ultimately it's about not separating being unwell from school stress because being in school when you are unwell is very stressful for numerous reasons, like just even existing in school, walking round site, walking up and down stairs, carrying bags, not having the ability to stand up long, so it's very difficult to stand in queues outside classrooms while feeling dizzy and fatigued, headaches, nausea, having no energy left to interact with other students. And so I always felt I had to separate how my experience of school and then my symptoms because I was so sort of disbelieved, or treated with contempt about my physical symptoms, that I felt very much I had to prove that it was physical by showing that I wanted to be in school even when I didn't, so I got stuck in this very loop situation* (Emily, 339-346)

Emily's listing of her physical symptoms suggests she faced a number of challenges, all of which she identified as a source of stress she had to continue to manage, which left her in a 'loop' of her situation worsening. In the present day, Emily was clearly going through her own hermeneutic loop during the interview to understand the impact it had on her. This was illustrated through her ongoing reflection of her views at the time relating to her views now, as she had moved on from secondary school. However, at the time, Emily's account suggests the attitudes of others and the feeling she was 'disbelieved' made this much harder to manage in the context of school and was a source of stress for her.

Linked to this sense of 'disbelief' of her physical symptoms, Emily also described feeling she needed to hide her illness while at school.

> *…it's really interesting to look back at myself and think why was I do… almost seems secretive weirdly like trying to hide something…. Erm and I think it's because I just*

> *didn't know any other way to make it work. It just felt so impossible trying to manage school* (Emily, 153-136)

Again, in hindsight, Emily herself identifies her own hermeneutic loop, and that it is 'interesting' to look back on her behaviour. Emily's account clearly details the pressure she felt in the situation. Her powerful choice of language, that it felt 'impossible' to work any other way other than to hide her illness suggests the impacts this had on her, all while trying to manage the psychical demands of school. Ultimately, it was the stress of this situation that led to Emily leaving school.

> *It's just a major struggle at that point I just dropped out of school. I completely broke down, I was so unwell and I realised probably the huge amount of stress and fear I was feeling probably made me a lot worse really* (Emily, 161-163)

Emily's account shows an escalation of this experience over time, placing her under an increasing strain, again demonstrated through her highly emotive language, such as 'broke down'. For Emily, this had a significant impact on her school experience, in that she felt she had no choice than to leave the school system due to her health, the impact of which was a further source of emotional strain.

Reflexivity:

This subordinate theme was the most challenging for me to interpret and write about, on a professional and personal level, as it is the only aspect of my participants' experienced that is similar to my personal experience of CFS/ME. I felt great empathy with my participants in describing things they found challenging, and it caused me to reflect more deeply on some of the personal challenges I have experienced with CFS/ME. To ensure my reflexivity as much as possible, I have used extended quotes from participants telling the story of their experience to ground my analysis in their words to impartially demonstrate the links between this and the analysis I made.

4.2.3 Superordinate Theme: The Impacts of Adults on the School Experience

This superordinate theme considers the role school systems and structures had on participants, as opposed to the first two themes that identified the more individual experience of CFS/ME. This theme captures the role adults in school had as either facilitating support for participant's needs, or inadvertently creating barriers that led to the participants having to take an active

role in their own support to ensure their needs were met. The order of the write up explores these oppositional concepts further, outlining Ben and Emily's experiences of what school staff offered by way of support, followed by the actions they had to take to manage difficulties this posed.

Table 13: The distribution of subordinate themes within 'impacts of adults on the school experience'

Subordinate Theme	Ben	Emily
Staff communication	X	X
Consistency of support	X	X
The young person as an advocate	X	X
Do we hear the 'voice of the young person?'	X	X

Staff Communication

Both Ben and Emily reflected the role of staff communication as a way to understand their needs in school and respond appropriately. Ben experienced that teachers who were informed of his needs treated him differently compared to those who were not aware of his illness.

> *Like teachers weren't acting very nice, but I don't think they had heard of any issues, before they got an email saying 'this is what's happening, it's occurring'* (Ben, 356-358)

Ben identified there were ways in which this was significant, for example if he needed to leave the classroom due to illness in a lesson.

> *…everyone was always very nice, I'd sometimes just be in the middle of a lesson like 'I don't feel very well' they would never say 'well you're making it up' or 'are you sure' or anything like they might do to some other pupils. The teachers were always very happy and accommodating if something did crop up* (Ben, 270-274)

This demonstrates a case where communicating Ben's needs to staff directly related to his medical needs, such as a needing a rest break if he felt unwell. Ben described the experience of other pupils, who may be disbelieved if they said they felt unwell at class, and as this didn't

happen to him can link it back to the role of staff communication. Ben's account demonstrates the way discipline and power dynamics in class could have been a potential barrier to receiving the support he needed, so therefore staff being aware was essential so they could hear of 'any issues' to avoid putting him in this situation where his medical needs were ignored.

Emily described her experiences of staff communication around her needs as less positive. As part of provision for her medical needs, for example Emily was permitted to be later on time to lessons due to walking around the school. Although she had been informed all staff knew of this, in practice she did not feel that this was the case.

> *The teachers knew I was unwell but I still felt a pressure to you know, be on time for lessons. Things weren't… the teachers were never really explicit where you know, saying 'we understand' or something. So for homework for example, I did have explicit permission from the SEN department… to be able to hand in homework late and stuff like that. So they did give me that and I had permission to not do any homework that wasn't essential. But of course every teacher thinks their homework is the most essential (laughs) so….* (Emily, 137-142)

Emily's account suggests although staff may have been told about Emily's needs, how it was demonstrated in practice was variable. There may have been communication at the staff level, but how that was then filtered down to Emily was not 'explicit'. This left her in an uncertain position of how to manage this, and often meant that she felt a pressure to not use her medical adjustments as she did not feel she had identified permission to. Arguably, from an interpretative perspective, it is clear to see how this could be a source of additional strain in school for her, and one Emily later identified within herself as she became more unwell within school.

> *I was very emotionally distressed as well, I was just very unhappy and I was often very teary and it's just kind of like, there wasn't, no alarm raised* (Emily 332-333)

Emily's experience of the communication in school appears quite one way. Staff may have been told about her needs, however when she was showing signs of these escalating and the distress this was causing her, adults did not communicate things to make changes for her.

Both Ben and Emily experienced poor communication when they returned to lessons in school, either after a period of absence or as per their part time timetable.

> *…you go back and a new person had joined the class and they were sitting in your seat, and there weren't enough chairs in the classroom anyway, so you had to spend every lesson that I was there finding a spare chair or somewhere to sit. So it felt like 'oh, we don't expect X to be here' it's like 'oh we forgot to communicate this to people'* (Ben, 84-89)

> *Or teachers kind of making you feel guilty for missing a previous lesson even if I was scheduled to be out of it because they were just not very focused on that* (Emily, 388-389)

Although both Ben and Emily's accounts show they were expected to be missing sessions and returning at set times, they share an experience of a lack of preparedness for this from staff. For Ben, this was physically related to his space available in the classroom, and he was therefore using his energy while he was in school to find a chair. For Emily, this was around the expectations staff communicated to her about the importance of work she was missing, when the message should have been delivered she was missing school due to her illness. Both of these scenarios impacted on their experience of school in different ways but can ultimately be linked back to the role of staff communication.

Consistency of Support

Both Ben and Emily experienced mixed experiences relating to the consistency of support they received while at school, which impacted on the quality of support they received. Ben found that staff who knew him well provided more consistent support.

> *I had the same English teacher for three or four years in a row and she was better at proactively checking in and seeing and helping and things like that. .... So it depended. Like the people who were teaching me the longest were the ones that knew and got it and were more helpful generally* (Ben, 422-427)

The experience of staff being 'proactive' meant Ben had less responsibility to manage the impact of his school absence. However, Ben identified variability in the responses of staff members.

> *I just think some of them were more forgetful than others or just paid less interest in the email they got saying 'oh can you be nice to me' or whatever* (Ben, 295-296)

Emily had a similar experience, her support was arranged through the SEN Department, and changes in staffing meant Emily did not have a consistent person who was 'in charge' of her needs, meaning there was a lack of consistency across school.

> *See the problem was that there was no one was really (pause) no one was really in charge of me basically, even though I was under the SEN department the person who was in charge of me was my mum…. There were various staff members with various job titles who oversaw various aspects of my school life but they were continually changing, it felt like I was always being passed on as someone else's problem basically* (Emily, 277-282)

Without this consistency and a key person understanding her needs, Emily relied on her mother to managing and arranging much of her school life.

When their illness meant they could not attend school, both Ben and Emily received work sent home from school. For both, this was also inconsistent.

> *Like they did send stuff to the tutor and it was definitely things that my peers were doing, but they weren't all necessarily fully up to date at the same time or you know (pause)… I'd still be going over a book they'd finished three months earlier and no one had bothered to tell me* (Ben, 575-578)

> *It was kind of sporadic, it wasn't like I was sort of being included…. They provided me with bits and bobs and I just had to try and make the best of it* (Emily, 177-183)

In both examples, the inconsistency impacted on the quality of home education Ben and Emily received. Emily also highlights the need she felt to 'make the best of it', representing another form of external pressure placed on her in managing her illness.

The Young Person as an Advocate

Both Ben and Emily described their need to self-advocate when they were placed in positions within school that could impact their illness, or needing to catch up on the demands of school work. In having to self-advocate, Ben and Emily also both describe incidents in where they had

to take proactively take responsibility for their own needs, rather than adults supporting them to meet those needs within the school system.

For Ben, there were issues around his participation in PE.

> *the PE teachers were the worst for paying attention to the fact that I was ill… they would ask me to come and help me run the sections and help out a bit and just if any teachers ever made any digs about 'are you really ill?' type thing it was always the PE teachers… but I had two PE teachers who were like 'oh maybe you could just try five minutes?' and it's like 'no, I know I can't', I know that would be a stupid idea'* (Ben, 524-533)

As well as having to refuse an adult request in the situation Ben describes having to escalate the situation to his head of year, who would speak to the teacher involved (line 537). When asked how he found this experience Ben described it as 'interesting' (line 536) as he identified himself as someone who is 'not the firmest person in the world' (line 535). Although, in his account, Ben appeared able and confident to advocate for his needs, he identified the tension of the 'interesting' experience of doing so, arguably because within school a student would not typically go against the teacher in a system of authority.

Emily described her experience of the advocate role as less comfortable, and being something that she was not ready for at that age within school.

> *I had to take a lot of responsibility on my shoulders and sort of negotiate in this sort of mature way which I wasn't really ready to do, because also I didn't really understand ME myself. It felt like, it felt very cheeky to go up to a teacher and say 'is this extra bit important, is it important I do this thing at home or can I leave it?' And I didn't have that sort of confidence* (Emily, 487-490)

Emily also identified the strangeness of having to disobey a member of staff, feeling 'cheeky' in doing so, even when she had permission to from people in authority above her. Emily's own identification of her lack of confidence in doing this suggests how this would have been a strain for her to do so, and a possible source of additional pressure within school. Emily describes herself as being a 'bit of a people-pleaser' (line 99), and that she would 'say a lot of kind of

what they wanted to hear I think maybe' (line 100), indicating there were times she felt unable to advocate for her own needs.

Do we Hear the Voice of the Young Person?

Both Ben and Emily described experiences where they had little agency in the decision-making processes that impacted on their school life. Ben describes how on returning to school for his phased return, he was often completing subjects that were not a priority for him.

> *So I definitely think it's right for the school that they're focusing on the important things, the core subjects that everyone does and that their league tables are judged on and things like that. But I think it would have been nice if I would have been asked a bit more which other subjects are you most keen to go back to (pause)* (Ben, 389-393)

In this account, Ben recognises the school's priorities may be linked to factors like league tables, and that he also sees these subjects as important. However, for the other subjects, he describes scenarios in which his schedule did not enable him to take part in his preferred lessons, such as being in school to take part in an art lesson rather than history (line 396), which did not reflect his interests or future aspirations. Ben described the value he felt in being listened to as one of the most important aspects in supporting young people with CFS/ME (line 346).

Emily also placed value on listening to the young person with CFS/ME, but then debated if this captured the essence of what she valued.

> *… well people would listen but they wouldn't have a solution. I'd sort of express to my tutor or whoever, there were so many heads, but also I wonder if it's not even about listening, it's about.. it's not like these people really raised an alarm for sort of what was right in front of them* (Emily, 324-326)

Emily's account highlights the tension between listening to the young person, as opposed to 'hearing their voice' and acting on it. Emily also experienced this pressure when speaking to professionals, where her hospital team had different priorities to her education to her.

> *The hospital's main aim, they were focused on me still having a school life, they saw that as the most important thing but I, that wasn't for me, it just felt, I just felt frustrated* (Emily, 398-400)

Emily herself identifies the difficulty of being in this position, and the 'frustration' it caused her at the time, which was then continued by working within a school system that she did not feel was right for her. Ultimately, Emily attributes this lack of voice as contributing to her leaving school due to illness and placing more pressure on her.

> *But then what happened was I became too ill to go to school so then it was, I just couldn't do that and then I had to desperately, well not desperately, but really try to get those GCSEs when I was really unwell* (Emily, 413-415).

4.2.4 Superordinate Theme: Managing the Demands of the Curriculum

This theme represents how both Ben and Emily experienced demands linked to the school curriculum, however in very different ways. Although this theme represents divergent experience for each participant, at their core it represents how the curriculum, and choices available relating to school systems, impacted on their school experience in unique ways.

Table 14: The distribution of subordinate themes within 'managing the demands of the curriculum'

Subordinate Theme	Ben	Emily
Pre GCSE experience	X	
The experience of GCSEs	X	
Playing 'catch up'		X
The (in)flexibility of school systems		X

Pre GCSE Experience

Prior to deciding subjects for his GCSEs, Ben described the pressures of managing subjects across the whole curriculum, depending on when he was in school as according to his phased return. He experienced a lot of variability in how manageable it felt to keep up with specific subjects, with language subjects being a particular strain due to the amount of vocabulary missed between lessons.

> *Sometimes when you go back into a classroom for some things it feels like 'oh I was here last week' in some lessons whereas others were like 'what on Earth is going on, what is this French word you're throwing at me?*' (Ben, 332-325)

Because Ben missed the context and background of lessons, when he was in school he also missed out on some of the more practical subjects in school, as he had not learnt the pre-requisite skills to take part in the sessions.

> *Like if I suddenly discovered a love of cooking it was never going to happen while I was at school because I'd turn up one week and didn't know what the ingredients were supposed to be or you were supposed to have made several things before, like I'd never made flapjacks or whatever* (Ben, 233-237)

The Experience of GCSEs

When Ben reached GCSE stage, which coincided with increased attendance at school due to his improving health, he was able to select subjects to take exams in. This removed the previous pressures of having to manage the whole curriculum and represented a turning point in his education.

> *I had one less choice, which I don't think was a planned thing, but I think that was really helpful actually because it let me have one less thing to focus on and learn about. And it was really useful for the next two years to have that two or three hours time off the timetable, just to have to myself and just to catch up and things like that was really nice* (Ben, 226-230)

When the change at GCSE occurred, Ben had more opportunities for rest within the curriculum, as well as naturally prioritising. Ben acknowledged the change in the GCSE curriculum was also beneficial to him.

> *I mean generally in the different topics anyway a lot of the subjects aren't what you learnt in years 7 8 and 9 so it wasn't like… although I had missed out on things they weren't relevant to the exams necessarily* (Ben, 412-415)

Ben could make a distinction between his previous learning and GCSEs, which he sees could benefit him. Even though he may have missed more general subject learning, he wasn't dependant on this knowledge for his GCSEs, and had additional time through reduced subject

choices, which were partially influenced by the fact he had missed the opportunity to take part in experiences in previous years. Although he felt this was helpful, he did acknowledge it could have perhaps limited his choices in planning in ways he wasn't aware of at the time.

> *'It definitely impacted on (pause) I don't think I would have done things differently… but I can't say that for sure* (Ben, 237-239)

GCSEs represented a change in education for Ben, that was mostly positive and supportive to his experience of the curriculum, however he acknowledges there could have been some less beneficial impacts of this.

Playing 'Catch Up'

This subordinate theme represents Emily's experience of managing the whole curriculum across her school career on a part-time basis. Emily remained on a limited part-time timetable throughout her time at school until she left when she became too unwell to attend school. Emily initially picked a full set of GCSE options and had to manage them all on a part-time basis

> *I had picked the initial 10 subjects, I dropped art after pretty much a term in year 10 and after that probably about a term before the GCSEs I dropped history which was a shame but I couldn't keep up* (Emily, 175-177)

Emily did reduce her subject demands, but this was as a response to the demands on her at the time and her difficulties in 'keeping up' with subjects, rather than as a planned approach from the beginning of her GCSE options.

Emily described the experience of attending school part-time school as very challenging for her.

> *Part-time school doesn't work I don't think because you're always catching up, it's just adding more stress basically it's like more stressful to show up to a lesson where you missed the previous lesson, quickly you just feel very out of place, and that was that kind of outcast feeling, everyone knows something that happened in the previous lesson and you don't* (Emily, 367-371)

Here, Emily highlights how the experience of missing so much school not only impacted on her being behind on her work, but also impacted on her sense of belonging within school.

In order to try and catch up on school work, Emily would work at home as well as school, which put her under further strain (line 435). Emily acknowledged the strain keeping up with the curriculum placed on her, and the personal strength it took her to do so.

> *I just don't know how I got my GCSEs, it was terrible* (Emily, 183)

Ultimately, Emily could not keep to the timetable decided by her hospital prior to leaving school and ended up changing it as she saw best to make it work for her.

> *I wasn't able to keep to it, and that didn't seem to be an issue for the school and the hospital that I wasn't keeping to it, and eventually just sort of adapted it to my needs, so if there was an important English lesson I would go to the important English lesson, miss the next, just do it on my own accord basically* (Emily, 458-460)

As Emily points out, the decisions were being made for her by the hospital, by someone who did not have to live with the daily impacts of them.

> *It's alright them saying it but I'm the one having to work really hard* (Emily, 427)

Again, this highlights the role of having someone to organise the process, and how this impacted on her while at school. Although Emily did not identify anyone was responsible for her, her account suggests the hospital would decide her care, but there was then a gap in how this was implemented within the school system, with no one taking control of this process, which left her having to catch up with the demands set for her.

The (in)Flexibility of School Systems

Throughout Emily's account, she referenced the importance of markers within education such as GCSE exams, and the timescale pressures that this put on her at the time. When it came to taking her GCSEs, Emily was unsure if she was well enough.

> *I sat them at home I had this exam conditions of extra time and rest breaks and that was what I needed and I was extremely ill, like I would sort of do an exam and just be so exhausted and just so unwell it really took everything out of me, really took everything out of me. And the debate after was 'was it worth it, was it worth putting everything into my GCSEs?' and I don't know but they're your GCSEs and there wasn't really any other option if I hadn't sat them I don't know what I would have done. There wasn't any anything like you can sit them next year, or maybe there was and I just*

don't know. I was so unwell it was like I might as well sit them because I don't even know if I will be better next year (Emily, 185-191)

Emily identified her understanding that there were no other options available if she hadn't have sat her GCSEs, it was not clear what she would have done instead. Although she had flexibility in how she sat her exams, taking them at home, she still took them at the end of year 11 in line with her peers.

Emily described how she wished she could have been offered home tuition sooner before she dropped out of school due to her illness.

I'm of the opinion you're either well enough to go to school or you're not, I think I should have been offered home tuition (Emily, 463-464)

Emily's account suggests that she perhaps felt she was not well enough to go to school, and that decision should have been made by someone for her.

Once Emily had left school due to illness, and was offered home tuition, she found some benefits in the increased flexibility this gave her.

My general experience of being taught at home by the tutors is better than being taught at school because at home as I can conserve my energy and take it at my own pace (Emily, 249-251)

Tuition gave Emily some benefits in terms of managing her energy in terms of attending school, where a lot of her energy was 'wasted' (line 421) in managing the environment, rather than being able to focus purely on her learning. Emily also received tuition for her A-Levels, she received an EHCP which enabled her to study at home. This did allow her greater flexibility but came at a late stage in her school career.

4.3 Summary of the Analysis

Four superordinate themes were analysed from the participants' accounts. Two of these themes, 'the complex physical impacts' and 'the social and emotional impacts' highlight the ways in which the young person is impacted on an individual level. School support often attempted to meet the physical needs of participants but did not identify the less obvious social and emotional impacts of managing CFS/ME within the secondary school environment.

The second two superordinate themes, 'the impact of adults on the school experience' and 'managing the demands of the curriculum' highlight the more systemic experiences, including the barriers that the participants experienced in getting their needs met while at secondary school. Links between themes have been briefly explored through the outline of the analysis.

Both participants shared the majority of subordinate themes across three of the superordinate themes, with some minor variations within each. However, for the final theme 'managing the demands of the curriculum', both participants represented very different experiences within this theme, representing a diverse experience of the school curriculum, linked by the common experience of secondary education.

5 Discussion

5.0 Introduction to the Discussion

This section considers the answer to the research question through exploration of the themes generated through the IPA. The four identified superordinate themes highlight key experiences of both participants in relation to the research question. Following discussion of the themes in relation to the research question, the professional implications of this are outlined, followed by a brief critique and acknowledgement of some of the limitations I faced in the research process, including the implications for further research.

The discussion addresses the research question posed by the current study:

- How do young adults who had a diagnosis of CFS/ME while at secondary school describe and perceive their experiences of education with the illness?

The question will be addressed through further exploration of the similarities, tensions and conflicts identified through the double hermeneutic loop within the analysis in chapter four, as well as research evidence in relation to the four superordinate themes identified, those being:

- The complex physical impacts of CFS/ME
- The social and emotional experience of school
- The impacts of adults on the school experience
- Managing the demands of the curriculum

5.1 Superordinate Themes and Their Impacts on the Secondary School Experience

5.1.1 The Complex Physical Impacts of CFS/ME

This physical experience of CFS/ME, and the impacts it had on the participants' ability to engage with education is represented throughout their accounts as a continuing thread. Both participants describe a range of physical symptoms consistent with the broad range identified within the CFS/ME literature, with a significant functional impact on their daily lives (Garralda & Rangel, 2004). Ben and Emily's physical experiences of CFS/ME, and the associated school absence, reflect the patterns commonly observed in the illness, with the majority of students left on part-time timetables, or completely absent from school (Kennedy et al, 2010). This study is therefore well situated in the identified physical experience of CFS/ME during secondary school. Ben and Emily both experienced physical needs arguably at a level requiring SEN support, with their symptoms of CFS/ME impacting on their education that required special educational provision to be made to support them (Cline & Frederickson, 2009). In her account, Emily described how her support was arranged by the SEN department within school, although she did not necessarily feel as if she belonged within the department, as she did not feel there was any support that would meet her needs on offer there.

There were clear physical impacts on attendance through illness, as well as more subtle, 'hidden' forms of absence that both participants experienced within school that influenced their ability to engage with education. This represented reduced opportunities to participate in school, which was key to the school experience with CFS/ME. What is interesting about these explicit and 'hidden' forms of absence is the impact this had on the rest of the participants' school experience. The superordinate themes, 'the social and emotional impacts' and 'the impacts of adults on the school experience' directly relate to this theme. While participants were managing the initial and identified 'physical' side of CFS/ME, this was a precipitating factor for other difficulties within school, such as managing peer relationships on return to school or having to negotiate catching up on work with adults, which will be discussed in depth under each relevant theme.

Both Ben and Emily reflected that a major physical impact of CFS/ME was that it left them unable to take part in sports, both at school or personally. This was disappointing to both of

them, as they actively took part in and enjoyed sports prior to their illness and meant that they lost a preferred activity within school.

Within school, both participants experienced that their physical needs were the first to be addressed, through adjustments such as the provision of rest breaks. Both Ben and Emily describe this experience as both helpful, but with some drawbacks. Both Ben and Emily described the discomfort of being given inappropriate rest spaces, such as teacher offices, and having to move around school if they became taken by other people. Although both acknowledge the benefits of this provision, their experience suggests that in offering support, it was not always appropriate to their needs. This raises questions around the possible impacts this could have on young people's sense of belonging, or inclusion within the wider school community, if much time within school is being spent isolated from peers in a 'different' space.

In Emily's account in particular, an explanation for this may come from the sense of frustration regarding CFS/ME as a 'misunderstood' illness, although there are also references to staff understanding in Ben's account. From her account, Emily identifies that she, as well as school staff, didn't fully understand her diagnosis at the time, particularly as her illness was progressing. As Emily frequently reflects, CFS/ME can be considered a strange illness, and despite people having good intentions no one appeared to know how to actually manage her condition in school due to the complexity of the illness. One of the few studies found in the literature review looking at teacher experiences of supporting children and young people with CFS/ME found school staff perceived their own confidence in this to be low, although they wanted to help (Everett & Fulton, 2002). This could explain Emily's experience, in that staff simply did not have the knowledge and confidence to know where to provide support.

This raises the question, who did understand these needs in school, and plan for them? Both Ben and Emily describe receiving hospital treatment and support for their illness, and both were aware of contact between the hospital and school. Considering the statutory guidance, 'Supporting pupils at school with medical conditions' (DfE, 2015), all children and young people with medical needs in school should have a support plan identifying their needs, and how they will access the same activities as their peers. To ensure this is in place, staff must be trained to meet these needs. Emily recounted some training linked to the needs of young people with CFS/ME at her school, however in her experience nothing changed after the training. Ben was not aware of how his medical support needs were arranged within school. Both Ben and Emily

describe their hospital experience as being separate from their school experience, emphasised by poor communication between professionals, which could explain why the physical impact of their illness created the barriers they experienced in receiving support for these medical needs. Recent research (e.g. Brigden et al., 2020) suggests that this is key to success in planning appropriate support in schools, although their research was focused on primary aged children's experiences it seems this is also a valid consideration in the secondary population.

5.1.2: The Social and Emotional Impacts of CFS/ME

The social and emotional impacts of CFS/ME were less explicitly identified in both Ben and Emily's accounts, with the initial focus coming to the physical experience of the illness, as well as school absence. However, throughout both accounts, there were references throughout to social and emotional factors, which built a picture throughout the interview about these wider impacts.

Both Ben and Emily experienced some difficult situations with their peers as a result of their illness, particularly when coming back into school following periods of illness, or if they had missed lessons as a result of their part-time timetable. In these instances, it appears that peers would identify if they had received 'different' treatment. Both Ben and Emily's accounts represent they felt uncomfortable with this, with Ben reflecting he would prefer to not mention his illness at school and carry on as 'normally' as possible, otherwise it would have been embarrassing for him. Ben and Emily both seem to have come to a place where they can understand their peer's behaviour to an extent, considering it to be linked to a misunderstanding of what CFS/ME is. Again, this links to the complex physical nature of the illness. This has been identified in the existing CFS/ME literature, and supports the findings of Fisher & Crawley (2013) where adolescents with CFS/ME experienced bullying or disbelief from peers as a result of their illness. In both Ben and Emily's case, these difficult peer situations do not seem to have been proactively addressed by school staff at the time, instead they became another aspect of the illness that they themselves had to manage. Fundamentally, these difficulties can be linked to the attributions those around them made about their illness, and highlight Miller's (2003) research about the role of those around the young person, which in this case extends to the influence and impact of peers on their experience of school.

As well as the peer pressures identified in Emily's account, she also reflects throughout on the pressure she felt to 'hide' her illness, and how the stress this caused exacerbated her CFS/ME

symptoms. This subordinate theme was unique to her experience. For Emily, hiding her illness appears to be a coping mechanism to try to compartmentalise the impacts CFS/ME was having on her life, as she described herself she did not know how else management would work. However, from her own words she describes the illness as something that 'takes over your life' in managing it, and 'confines' you, so it is understandable from her account that trying to do this would have likely been very stressful. This, compounded by the experience of disbelief from people around her regarding her symptoms, meant Emily became more unwell and emotionally impacted by this. This pattern is very similar to the model described by Blease et al. (2016), where it was predicted that adults who experienced stigma relating to their CFS/ME would be more likely to confide in medical professionals in case they experienced social judgements. Emily's account shows her response to what she perceived to be social judgements was to try and compartmentalise her illness to make things work, however this ever-increasing emotional strain ultimately led to her leaving school due to her worsening illness.

Ben's account highlighted how being absent from school meant missing out on a lot of the social experiences of school, throughout his account he used words such as 'weird' and 'strange' to describe his experience. This became a subordinate theme throughout his account, 'school as a strange experience'. Interestingly, Ben highlighted how missing things within school came up in adulthood, for example when having conversations with colleagues around school dinners he had no experience of. Although Ben shared in his account this did not bother him, it simply was a 'weird' fact of the way school was, again it highlights the wider social and emotional impacts of CFS/ME, including how young people recall and share in the wider social understanding of what 'school' is, and what those experiences typically involve. This could be an avenue for future research; although the present study considered a retrospective account of secondary school, the impacts of CFS/ME at times other significant social and cultural markers, such as young adults at university, could be considered.

In both Ben and Emily's accounts, there is a strong sense of their personal resilience and the strategies they used in overcoming challenge while at school, such as taking on a role in advocating for their needs, even if this was uncomfortable for them. Psychological resilience is often described as the dynamic process of adapting to adversity in positive ways (Jindal-Snape & Miller, 2008). Although both Ben and Emily perceive their school experience differently, with

Ben viewing his more positively than Emily, there is a sense to me as an external observer that they have both overcome a lot of adversity in their school experience, although these may not have been felt of as barriers at the time. This finding represents elements of Winger et al. (2014), where children who experienced CFS/ME reported a stronger sense of self and identifying what is important to them. Both Ben and Emily gave examples of how they worked towards goals that were significant to them relating to further and higher education. Despite the views of those around them, perhaps suggesting they should 'aim lower', particularly in their GCSEs, both Ben and Emily have pursued goals into adulthood that are important to them. Although, it should be noted this was not an easy experience, and the researcher does not want to minimise the difficulties participants faced during this time. Rather, this is to acknowledge the resilience they demonstrated in overcoming these challenges throughout their account, particularly when they may have experienced multiple identified barriers to their success, as identified throughout their accounts.

In light of this finding, I went back to the literature to explore the concept of resilience in children and young people with medical needs. The Resilience in Illness Model (RIM) (Haase et al., 2014) was developed to identiy the protective factors that support the development of resilience for adolescents with chronic illness. The protective factors for developing resilience were social support from friends and hospital providers, a positive family environment and familial support, 'courageous coping', which was defined as dealing with challenge with a sense of optimism, and finally the concept of 'derived meaning'. Derived meaning was a concept that adolescents could view their illness within a wider philosphical or spirtual understanding. Risk factors which could negatively impact resilience include illness related distress, which included experiences such as pain and uncertainty during illness, and 'defensive coping'. Defensive coping represented two concepts; firstly dealing with the emotional impacts of illness, and secondly, evasive coping strategies, such as hiding the impacts of illness from others.

The RIM (Haase et al., 2014) gives a useful insight into some of the patterns I oberved in the participants' accounts. Both participants identified the positive impacts of having a supportive peer within school, which reduced their feelings of social isolation. Both Ben and Emily spoke about the positive impacts of their family support as well, and that they felt understood by their wider family support networks.

In terms of the threats to resilience observed in the RIM (Haase et al., 2014), both Ben and Emily experienced illness related distress through both difficult physical symptoms, as well as large periods of uncertainty relating to their illness, such as how they would do in their GCSEs, or if they would be well enough to go to University in the future. Both also experienced feeling unsupported within their hospital care relationships. Extending this concept further, beyond the hospital system, both Ben and Emily experienced some difficulties in their teacher relationships within school. Interestingly, the nature of CFS/ME itself also brought up some risk factors in managing resilience in the area of defensive coping. This is due to the 'hidden' social and emotional impacts of the illness, and the additional risk factors of social isolation linked to this. Emily also described in her account aspects of what could be considered evasive coping strategies to help her manage the demands of the illness within school.

Considering both Ben and Emily's accounts within the RIM (Haase et al., 2014) show ways in which they experienced protective factors, but the many challenges that were present in the school context, as well as the very nature of CFS/ME as an uncertain and often misunderstood illness (Greco, 2012). However, by drawing attention to these factors within participant accounts, the present study has highlighted these potential threats to resilience, and how they could be considered when conceptualising the imapcts of the social and emotional health of children and young people with CFS/ME.

5.1.3 The Impacts of Adults on the School Experience

This theme represents the first of the more systemic factors that impacted on participants' experiences within school. The subordinate themes within this can be viewed in two clusters; those considering the impact of adults, and what impact that had on the young person, and the actions the young person then had to take because of this.

Positive factors that Ben and Emily experienced related to staff knowing them well, who could offer more proactive support in lessons. Staff who had clearly been informed of and understood their physical needs were also more helpful, providing a higher level of support within class. Ben's account linked this to the idea that when staff knew his needs better, they provided a more pro-active type of support.

When school staff did not understand their needs, or did not respond appropriately to their needs, Ben and Emily described the consequences of this placed them into the role of self-

advocate. At times, their accounts suggest this was an uncomfortable experience for both, particularly when having to disobey a teacher who had asked them to do something inappropriate for their medical needs. However, Ben's account suggests he perhaps found it easier to advocate for his needs because of an ongoing reference to his sense of self. Ben seemed assured in his understanding of his illness and seemed confident in his physical limits, he described being asked to do things beyond this as 'stupid'. Emily identifies herself that she was much less confident in the advocate role and it was something she did not feel ready for. She identified this was in part due to her own lack of understanding of what CFS/ME was and the symptoms she was experiencing within school. This has links to the first superordinate theme, 'the complex physical impacts of CFS/ME', as well as 'the social and emotional experience of CFS/ME'.

However, regardless of Ben or Emily perceived themselves to be ready or able to take on the advocate role, it is important to consider that asking any young person to become an advocate for their needs while at school is placing an additional demand on them. This is particularly relevant to children and young people who have CFS/ME, an illness where energy expenditure causes abnormal fatigue responses (NICE, 2007). Arguably, for these young people, there is a role for adults in truly understanding and meeting their needs within the classroom to reduce the additional pressures posed by the advocacy role, which can become a further barrier to engagement within education.

The role of self-advocacy did not come across as significantly in the initial literature research prior to commencing the research. Rowe (2020) had found that adolescents valued professionals who would advocate for their needs, perhaps suggesting that the opposite experience to this, self-advocacy, was a challenge. Brigden et al (2020), found that primary aged children may struggle to advocate for their needs, and feel apprehensive about speaking up to adults. This is particularly interesting, because although this study focuses on younger children, it is arguable that the underlying power dynamic of being a student questioning or challenging an adult remains at any age within school. This dynamic was identified both Emily and Ben, despite their older age range. This could provide an explanation for the pattern seen in both Brigden's study and the present research.

There is a wider research base into the role of self-advocacy for school pupils with SEN. Research suggests that greater self-advocacy skills in school aged students with disabilities are

linked to better employment outcomes in adulthood, as well as higher rates of completing formal education (Roberts et al., 2016). However, much of the research focuses on advocacy in relation to neurodevelopmental differences in children and young people at school, such as ADHD or ASD, and how this will support their independence skills into adulthood (Holzberg et al., 2019). It is not clear if these findings would extrapolate to the self-advocate role in CFS/ME. Neurodevelopmental differences are lifelong experiences and represent something very different to CFS/ME, which is a medical illness from young people may experience a full recovery, despite going through periods where they may be too unwell to partake in many parts of school life (Cairns & Hotopf, 2005). This would mean that advocacy focusing on skills into young adulthood may not be appropriate for their needs, which are likely to change. This is an avenue for further research to consider how self-advocacy is experienced in children and young people with CFS/ME, and if these skills are in fact beneficial to their school and future aspirations, or instead represent a possible source of further pressure within the school environment as the present research suggests.

Both Ben and Emily identified the importance of feeling listened to as impacting on their school experience, which was reflected throughout their accounts. Ben described how he experienced some limited choices in the subjects he was able to pursue at school, and how this reduced his opportunities to explore aspects of learning. Emily also describes a tension between her wishes, which was to prioritise her learning, compared to her hospital staff's aim for her to experience a wider school life, which they considered to be being within school and continuing peer relationships. In Emily's account, she shared how they felt that should be important for her as she was a teenager. However, Emily experienced frustration throughout this process, and a clear pattern was identified in which she was pushing herself to go to school, but in doing so became more unwell. This is particularly relevant, as recent research into clinician's views regarding successful CFS/ME treatment indicated school should be considered part of a holistic illness management plan, with a balanced focus on activities within and outside of school beyond academic work (Parslow et al., 2017). Emily's experience highlights this is not necessarily what she wanted to do, based on her own personal aspirations and goals to get good grades, and the value she placed on this emotionally.

This raises an important consideration in how we do hear the voice of the child in their treatment, and whose voice and views we prioritise in these situations where the child would

like something different to the clinicians around them, or those of staff in positions of authority within school. There is a clear tension here between the pressure that the young people in the present study felt to self-advocate, but also a sense that at times when they did express their needs they were not understood or met. This is a point for those working with children and young people with CFS/ME to consider.

Both Ben and Emily experienced a lack of centralised organisation in elements of their school support. This impacted Emily to the extent that she felt it should be key to part of managing CFS/ME within schools. Emily identified a relationship between having someone in charge and communicating her needs, again linking back to the idea of staff taking on the advocate role as opposed to students (Rowe, 2020). Emily described her experience of explicitly telling staff how she felt, and that she was struggling to cope with school. However, she did not experience a resolution in this. Emily herself linked this to the systemic factors within her school context, wondering if the inconsistency and organisation in staffing meant there was nowhere to escalate what she felt were obvious signs of her distress. In the absence of this role within school, Emily describes how her mother took over this role and took an active role in communicating her needs in school. However, for Emily, the day-to-day reality meant she had to manage within the school environment, and the lack of a school contact put her back into the uncomfortable position of having to advocate for her needs.

5.1.4 Managing the Demands of the Curriculum

This theme is the most divergent theme within the accounts of Ben and Emily's perspective. Ben experienced GCSEs as a turning point in his learning, providing an opportunity to reduce his timetable and focus on his preferred subjects. This allowed him greater flexibility in the curriculum, as well as more free time, to support his physical needs, and he described his attendance at school by this point as comparable to his peers. Ben described earlier pressures in the curriculum of managing the whole range of school subjects available while he was on a phased return to school, particularly in subjects where he would miss a lot of content between subjects, such as languages.

However, for Emily, she experienced an increasing pressure to manage the curriculum, which led to her dropping certain GCSE subjects throughout her studies. Interestingly, during this time, Ben described how he was physically recovering from CFS/ME, whereas Emily describes her symptoms escalating to the point she was withdrawn from school. Although they both had

the same experience of sitting exams, the differentiating factor between them appears to be the impact their illness had on their ability to engage with education at the time.

In Emily's experience of this theme, part-time school is continually referenced as being a strain for her. She was trying to manage a full subject count of GCSEs, while only being in school part-time to do so. This let her in an escalating cycle of coming to school, becoming fatigued then having to catch up with work at home. At this time, Emily reflects her preference would have been to be offered tuition at home, allowing her to focus purely on her grades. In keeping up with part-time school and always having to catch up with the demands of the curriculum, Emily perceived this as being hard work, which became another burden placed on her to manage without adequate support. Home tuition provided Emily respite from this, in that she could work at her own pace and invest her energy where she wanted it to be.

To enable her to receive funding tuition past her GCSEs, Emily went through the EHCP assessment process through her local authority. Emily described this as a difficult experience, because by then she was completing her A-Levels and felt much of her education had passed at this point, again due to the structured nature of school years and when exams are typically sat. Throughout this process, Emily recalled her and her mother having to provide lots of evidence relating to her needs, to demonstrate how CFS/ME is a long-term disability. Emily did not recall or mention meeting an EP during this time, or how she was assessed. The funding received allowed Emily to continue her education, but her account suggests that she is aware this happened outside the 'expected' timescales, and she missed a lot of her previous schooling because of her illness. She received more flexibility in her school experience through this, but only by withdrawing from the mainstream school system.

When reviewing the literature from the initial literature review, there is little that discusses the impact of the curriculum on children and young people with CFS/ME. This could, in part, be explained by the fact that the majority of studies considering the experiences of children and young people with CFS/ME focus on school as a small part of this. The present study just asked young people about their educational experience, specifically in relation to secondary school, so perhaps naturally drew attention to key features of this time period, such as GCSE exams, A brief mention of curriculum pressures was identified by Parslow et al (2017), where clinicians treating children and young people identified that they often recommended patients leave 'mainstream' schools and go to colleges where there was increased flexibility to meet needs

and provide a more individualised approach. The flexibility of the mainstream curriculum was a barrier throughout Emily's account, and when he experienced greater flexibility Ben found this helpful within school. Although flexibility may be a benefit, it is important how this may also impact on other themes identified throughout the IPA. For example, both Emily and Ben experienced a limiting of their aspirations while at secondary school. What would the impacts be of being told where they should go to school or continue further education into adulthood, and what if this did not match their own 'voice' of their own wishes for the future? Additionally, the SEND Code of Practice (DoH and DfE, 2015) positions both young people and their parents, in taking an active role in the decision-making process regarding their education. From a perspective of the legislation and context of education system within England, although curriculum flexibility is well received by the young people in this study, it is important this is considered within the young person's educational rights relating to SEN needs.

5.1.5 Comparison of the IPA Themes to the Meta-Ethnographic Review

The literature review process involved completion of a meta-ethnographic review, which identified key themes regarding how children with CFS/ME were supported within school. These themes were compared to the superordinate themes generated by the present IPA, to consider what the research has added to our understanding of the area, and the generation of possible future areas of interest for research.

Table 15: Comparison of themes identified in the meta-ethnographic review of the existing literature and the present study.

Meta-Ethnographic Review Themes	IPA Superordinate Themes
CFS/ME is a complex illness with a range of needs in school	The complex physical impacts of CFS/ME
Holistic well communicated support gives better outcomes	The social and emotional experience of school
CFS/ME is still poorly understood, which impacts on school staff's ability to meet needs	The impacts of adults on the school experience

The voice of the child or young person can be lost	Managing the demands of the curriculum

The present study adds a new perspective to the current literature, in that it focuses purely on the experience of secondary school aged children with CFS/ME. Although some of the themes from the meta-ethnographic review were represented in the present study, they were represented in greater depth within the IPA.

The complex physical experience of CFS/ME was present in the existing literature and also represented in the IPA. This is perhaps to be expected, given most of the research in the area comes from medical or health related field, and represents what is currently known or typically associated with CFS/ME. This theme is arguably the closest link between the present study and the existing research, and the current study replicated many of these experiences faced by children and young people with CFS/ME.

Both the role of communication, as well as staff understanding of needs, were represented in the study superordinate theme 'the impacts of adult on the school curriculum'. This theme expanded and built on these concepts to include a wider range of systemic factors that impacted on the young person's experiences of education. The representation of this theme also incorporated the concept of the voice of the child. By considering the breadth and depth of participants' experiences, the present study explored the links and tensions between the role of adults and the responsibilities placed on the child. This theme also highlighted the role of the child or young person as their own advocate, which had not been identified widely within the CFS/ME literature.

The understanding of the social and emotional impacts of school were also extended within the present study. Although a range of social and emotional needs have been identified within the literature (e.g. Parslow et al, 2017), the present study extends this by considering these views entirely from the perspective of young adults with CFS/ME within the school system, rather than the perceptions of others such medical staff on what the experience of these might be like. The detailed information relating to this theme demonstrated links between the experience of participants in the present study and the adult literature (e.g. Blease et al., 2016) considering models of illness symptoms and help seeking behaviour in adults. The concept of

resilience and the factors that impact on this were also highlighted in the present IPA, and the possible facilitators and barriers within this in the school context. The results of the present study suggest that the social and emotional impacts of school life with CFS/ME require further research. The hope for the current research is that in identifying the complex and multiple ways in which CFS/ME impacts on social and emotional school life will raise awareness of the possible difficulties for children and young people in this area, and their possible 'hidden' support needs.

In the present study, 'managing the demands of the curriculum' as a standalone theme, represents a new understanding of the experiences of secondary aged pupils with CFS/ME. The fact this theme was experienced so divergently between participants suggests that this theme is a prime topic for further research to gain a more comprehensive understanding of how this theme is reflected in the lives of a wider group of young people.

5.2 Implications for Professional Practice

The implications for practice are drawn from both the gaps and similarities identified by comparing the current findings to the existing literature, as well as the suggestions made by participants during their interview, directly representing their views.

5.2.1 Implications for Schools

The research highlights several ways in which schools can have an impact on the support children and young people with CFS/ME receive. On a practical level, this means ensuring all staff who work with an affected child or young person have a thorough understanding of not only their medical needs, but the impact of these in the classroom. Ideally, this process should be completed by someone who can take charge of the child or young person's care within school, and be a central point of organisation and coherence. These suggestions also fall under the statutory guidance, 'Supporting pupils with medical conditions at school' (DfE, 2015), and represent a duty of schools to meet the needs of these children and young people within their settings. Based on the reflections of young people within school, their views would suggest that it is important all staff who work with them receive training on the young person's needs to receive consistency in support, co-ordinated by this central person. This consistency was identified by the young people as key to providing the best level of support to meet their needs.

Secondly, for schools, the experience of participants within the IPA valued the role of adults who would listen, and crucially, respond to their needs. The young people gave a variety of ways in which this could be achieved, such as by asking them their subject preferences they would like to prioritise attending lessons within their timetable. The variability of needs described by the young people in this study indicate this could change over time and would require a person-centred approach reviewed consistently to ensure subject provision was still appropriate to their needs. Again, this young-person centres approach is recommended by the SEND Code of Practice (DoH and DfE, 2015) and represents placing the young person at the centre of decisions made about their education.

A further consideration raised by young people within the research is the unintended consequences of receiving support within school. Sensitivity is perhaps required from adults in schools, considering how young people can express their needs and if in doing so they may feel 'different' from their peers. The young people who took part in this study identified themselves the difficulties that inappropriate support within school placed on them, including placing additional demands on them having to advocate for their needs. From a school perspective, this raises implications for how medical needs are understood within the setting in relation to understanding inclusion and diversity of learning needs.

Finally, the experiences of the young people indicate that schools should be aware of the wider impacts of CFS/ME on a social and emotional level, which may not initially be obvious. This is particularly relevant when considering the threats to resilience posed by CFS/ME. The literature identifies that schools have a key role in supporting the mental health of children within their settings, particularly when considering how to create emotionally resilient school communities (Glazzard, 2018). Embedding an understanding of resilience at a whole school level, and providing opportunities where challenges can be discussed openly could therefore create a supportive school culture for children and young people with CFS/ME.

5.2.2 Implications for Educational Psychologists

This sections considers the professional implications for EPs when working with this population, in relation to relevant aspects of the core functions of the EP role identified by Fallon et al. (2010).

Assessing the needs of Children and Young people with CFS/ME

As highlighted throughout the analysis, the many impacts of CFS/ME across the curriculum mean it is important to acknowledge they be defined as SEN under the SEND Code of Practice (DoH & DfE, 2015). This means it is likely that an EP would work with this population in assessing the impact of these needs on access to education. This was particularly relevant within Emily's account, where she was identified by her school as requiring SEN support, and eventually received an EHCP to support her A-Level education while at home. However, EP assessment does not just take place at the statutory level (Fallon, 2010), and these considerations are relevant to all levels of EP assessment work with a child or young person.

Secondly, as demonstrated throughout the IPA, the impact of CFS/ME has wider implications across different areas of the Code of Practice, so an awareness of these varied needs would be needed to inform a full assessment of a child or young person's SEN, a typical duty associated within the EP role (Cameron, 2006). An awareness of the potential curriculum demands associated with CFS/ME is also important, to ensure a thorough consideration of learning barriers associated with missing school-based work. EPs should ensure that when considering needs, they are aware of the potential impacts beyond what may be the 'obvious' physical impacts of CFS/ME which may have been highlighted as a barrier to education, such as attendance and missed learning, as identified in Emily and Ben's accounts.

Practically, when assessing children and young people with CFS/ME, EPs should be aware of the potential fluctuations in needs, including the energy levels of a young person or other physical symptoms that may be a barrier to assessment, such as headaches or concentration issues, as described by participants in the IPA.

Supporting Adults to Meet the Needs of Children and Young People with CFS/ME

Reilly & Fenton (2013) provide a model that could help consider ways in which the EP could conceptualise their role in supporting children and young people within schools, through their work supporting children and young people with epilepsy. They suggest EPs can use their scientific and technical knowledge to question about and understand the child or young person's medical needs, and then apply this knowledge in academic settings. This is particularly relevant when assessing children and young people to understand the impacts of their illness in the classroom. In the case of epilepsy, Riley & Fenton describe how school staff may have a basic understanding of the medical needs associated with the illness, but not the wider impacts

the illness has within school. This is similar to the experiences of the young people in the present study, where their physical needs were understood but not the secondary impacts of these. Therefore, for the EP role, their detailed and child-centred positioning could help bridge the gap between medical knowledge and the needs of the individual child or young person within the school context, and how they can best be supported within school. This approach also aligns with the consultative nature of the EP role in supporting adults to meet the needs of children and young people through a more systemic level of work within the school (Nolan & Moreland, 2014). Ben and Emily's accounts raise several factors that could be relevant to the role of the EP, particularly in relation to hearing the voice of the young person, supporting the education and awareness of school staff and in facilitating communication.

Individual Support and Intervention for children with CFS/ME

The role of raising awareness of resilience, and the possible protectors and risks to this in children with CFS/ME, is another consideration for the EP role. Considering the RIM (Haase et al., 2014), there are both systemic considerations in terms of support for the young person, as well as individual factors that influence their coping styles. As well as raising awareness at a systems level of these needs, the EP role could look to offer support at a more individualised level for children or adolescents with a diagnosis of CFS/ME. The EP role is well placed to offer support for social and emotional difficulties within school, using approaches that focus on coping strategies, such as Solution Focused Brief Therapy (Atkinson et al., 2011).

Early Identification of Need

Emily's account highlighted how she felt she received support for her education when she reached an A-Level stage, however her needs had been present throughout secondary school. Emily particularly described how there was not a detailed plan to support her at first. This suggests an opportunity to raise awareness of the impacts of medical needs within education, including CFS/ME. It may be appropriate for EPs to ask questions regarding provision for medical needs, as well as discussing children and young people who have these needs, when having planning discussions within schools. This knowledge could then provide EPs with information regarding children and young people who may require further support, as well as an opportunity of EPs to raise awareness of the needs of this population within school and possible ways in which they could work at an early stage to support these within the education system.

5.2.3 Implications for Future Research

The present study has outlined two themes reflected in the experiences of participants that were not identified in the previous literature. These themes relate to the impact of adults within the school system, and the demands of managing the school curriculum. As the present study has explored themes on a highly ideographic and individualised basis, there could be scope for future survey type research to consider how these themes are represented across the wider population of secondary school pupils with CFS/ME. Further research could also be conducted to explore staff and professional views of the themes generated by this research to address the potential knowledge gaps highlighted by participants, as well as exploring ways in which support can be offered effectively within the school context.

5.3 Critique and Limitations of the Study

5.3.1 Participant Recruitment

I experienced a challenging situation with recruitment for my study. Initially, I had planned to recruit at least three participants, to a maximum of six, for my study. However, this was not possible and I was able to interview two participants who met my sample criteria.

Initially, I approached several of the large ME/CFS charities in the UK. One was not able to advertise my study due to the increased demand on research requests linked to Covid-19, which potentially limited the reach my study advertising could have. Of my initial emails, two national organisations posted my study advert on social media, and one repeated this for me to help generate further interest in my study. I also received offers through EPNET, a professional forum for EPs, to repost my study in support groups that various members were aware of. Although these strategies did help me recruit participants, especially during a time when face to face contact was so restricted, I feel that I could have had more success if I had closer links with more specialist organisations, such as NHS hospitals with clinics to support young people with CFS/ME, so I could be more targeted in my approach. I was not able to use this strategy for my recruitment due to the additional ethical restrictions the University require in recruiting through the NHS considering the timescales of the project, as well as the ethical appropriateness of considering this strategy as my research coincided with the peak of Covid-19 within England.

I also feel that the process of recruiting participants remotely due to social distancing measures was a further barrier. I received several emails from potential participants, or those that knew someone who may be interested in taking part, who wanted to know more about the nature of my study. I received several queries about the nature of my research as the study was from a psychological perspective, and people requested to know more about this and why I was interested in CFS/ME, particularly sharing concerns that I would recognise the biological basis of the illness. People also got in touch to share experiences regarding scepticism of the existence of CFS/ME, or negative reactions they had received from professionals, which made them unsure if they wanted to participate. At the beginning of the research process, I had not anticipated this response. It highlighted the sensitive and highly emotive experiences that some people with CFS/ME have faced, and that recruiting entirely online, without an opportunity to build rapport or informally introduce myself may have been a further barrier to participants feeling able to take part. However, in experiencing these barriers, I feel it indicates the need for further research into the lived experience of those with CFS/ME, so that we can better understand these and provide appropriate support by truly listening to those impacted.

5.3.2 Virtual Interviews

Although virtual recruitment had some drawbacks, as described above, I feel that the use of video interviews made my study more accessible to the population I was working with. For example, video calls meant we could schedule multiple interviews if needed, and participants did not experience additional demands for things such as travelling to a location. I could also meet with participants virtually throughout England, which helped increase my possible participant pool.

5.3.3 The Use of IPA

I was initially drawn to using IPA due to the ideographic nature of the approach, which has enabled me to consider the in-depth experiences of participants in my study. I consider this to be a strength in my research, which fulfilled my research question and allowed me to fulfil my goal of drawing attention to the experiences of an under-represented group in the literature. My study represents the research question I set to address regarding the experience of school with CFS/ME.

Although my study focuses on a small sample, which limits the generalisability of my findings, as Smith et al. (2009) highlight, IPA is about considering the aspects of the human experience in a specific instance. Smith et al urges researchers to think of IPA research as a methodology that can tell us an experience is for a small group of people, which is a valid research endeavour and captures the experiential nature of IPA and my specific research question.

5.3.4 Post-hoc Rationalisation

Post-hoc rationalisation is a psychological process whereby people infer attributions or construct beliefs regarding past actions when asked about them retrospectively (Veit et al., 2019). Therefore, we act 'in the moment' based on the information available to us, but after the event we retrospectively apply emotions and judgements to explain how our previous behaviour was rational (Cushman, 2020). In the present study, the retrospective nature of the account means it is plausible that post-hoc rationalisation could have occurred, as participants sought to explain their experiences after the fact.

Both participants were of an age where they had completed secondary school education several years ago, which therefore would have given them time to reflect on their experiences, allowing for the possibility of post-hoc rationalisation. Interestingly, in both participants' accounts, there are times that suggest they could be undertaking this process, demonstrated by their choices of language. Terms were used such as 'looking back' 'or 'look back at myself', suggesting a process of reflecting and making judgements from their current knowledge of the situation regarding their behaviour at the time. Therefore, when considering the participants' accounts, it is important to acknowledge the possible role of post-hoc rationalisation, and that their feelings or behaviour at the time could have been different to how they perceive them now. However, Summers (2017) argues that post-hoc rationalisation is not automatically an unhelpful process; rather it is a way in which we seek to understand meaning in our experiences. In the current study, participants were recalling difficult personal memories at a time where they described little control over their situation and were not always fully informed of choices being made for them. Therefore, is plausible that this process could support them to understand and describe these experiences.

Researchers have begun to explore how interviews in the social sciences can be constructed to minimise post-hoc rationalisation by supporting participants to tell their account in ways they perhaps would not expect to. These include utilising techniques from cognitive psychology,

such as asking participants to complete interviews in multiple stages, including using completely unprompted 'free talking' periods, and repeating their account in reverse temporal order to help them remember more details (Condie, 2012). Although in the current study interview schedules were kept open ended to yield as much information as possible from participants, it is possible that still maintaining an open structure using some of these techniques could have elicited more details.

5.3.5 Quality Control

I adopted Yardley's (2000) quality control framework, described fully in section 3.3.2. Upon review at the end of the project, reflecting back, I believe I have followed these steps and clearly documented them throughout my research process. Throughout the research I have been conscious of my personal links to the topic area, and constantly reflected on my role in the interpretive process because of this. My interpretations, key decision points and analysis are documented throughout to ensure I maintain a high level of transparency in my analysis.

5.3.6 Personal Reflections and Evaluation

I feel that I adapted pragmatically to the challenges I faced in my research, particularly with regards to participant recruitment. Prior to my research planning, at the early stage of Covid-19, the demands that services and charities would face were unprecedented. As a sole researcher completing a time-limited professional doctorate, my resources were limited to consider alternative methods of recruitment. I drew on the range of resources available to me, such as professional forums to try to publicise my research, but still faced challenges. I was very thankful for the support I received, which helped me to complete my research.

On a professional level, I hope to be able to complete more research and raise awareness of this area. I have made links with other TEPs conducting research nationally in this area of supporting children and young people with medical needs in education. We hope to use our research findings to create training packages for schools and other professionals, including EPs, to raise awareness of good practice in supporting medical needs in schools.

6 Conclusion

The present study used IPA to consider the following research question:

- How do young adults who had a diagnosis of CFS/ME while at secondary school describe and perceive their experiences of education with the illness?

Two participants were interviewed through semi-structured interviews, allowing for an in-depth analysis of their experience.

The themes from the IPA suggest that the experience of secondary school with CFS/ME is complex, and there are many interlinking factors that impact on this experience within the school context. Four superordinate themes were identified which highlight these factors. Two of these themes 'the complex physical impacts of CFS/ME' and 'the social and emotional experience of school' demonstrate that at its heart, the school experience is lived through the complex and vast range of CFS/ME symptoms, which at their worst cause extended periods of school absence. However, although the physical impacts of CFS/ME may be the most 'visible' at first, they are linked to secondary social and emotional impacts on the young person. School support was experienced as related to the physical impacts of CFS/ME, rather than acknowledging these secondary social and emotional consequences of the illness, which could be a form of strain. These physical, social and emotional experience of school with CFS/ME meant that the participants experiences were described and perceived as being different from those of their peers.

Two further themes were identified that represented more systemic influences on the experience young person within secondary school, including 'the impacts of adults on the school experience' and 'managing the demands of the curriculum'. Although these themes focused on factors outside of the young person's control, when things went wrong, such as their needs not being understood by school staff, this then placed a pressure on the young person to try to manage this. The theme 'demands of the curriculum' was experienced differently between both participants, representing the potential variance within the school experience of young people with CFS/ME. This theme represents a new finding in relation to the literature exploring the experiences of young people with CFS/ME, possibly due to the present study focus specifically on school experience.

Throughout these barriers and difficulties both participants experienced within school, a sense of resilience in overcoming these was identified. Through outlining these barriers, the current research aims to raise awareness of the potential difficulties young people with CFS/ME face within secondary school. By identifying these needs, it is hoped that school staff, EPs and other professionals will have a greater insight into the experiences of secondary school pupils with CFS/ME and consider these possible areas when supporting impacted children in their care.

Reflexivity:

Completing this research has been both incredibly challenging and rewarding. I have enjoyed using IPA. I came into the process as an experienced quantitative researcher but a very novice qualitative researcher. IPA gave me enough structure to feel guided, yet enough freedom and choice in how I completed certain steps, particularly when working with a smaller sample size. I feel privileged my participants chose to share their stories with me, and hope my research will bring awareness to this often misunderstood and under-researched condition of CFS/ME.

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Appendices

Appendix A: CASP Qualitative Appraisal Questions and Prompts (CASP, 2018)

CASP Question	Areas to Consider
1) Was there a clear statement of the aims of the research?	• What was the goal of the research? • Why it was thought important? • Its relevance
2) Is a qualitative methodology appropriate?	• Does the research seeks to interpret or illuminate the actions and/or subjective experiences of research participant? • Is qualitative research the right methodology for addressing the research goal
3) Was the research design appropriate to address the aims of the research?	• Has the researcher has justified the research design (e.g. have they discussed how they decided which method to use)
4) Was the recruitment strategy appropriate to the aims of the research?	• Has the researcher has explained how the participants were selected • If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study • If there are any discussions around recruitment (e.g. why some people chose not to take part)
5) Was the data collected in a way that addressed the research issue?	• If the setting for the data collection was justified • If it is clear how data were collected (e.g. focus group, semi-structured interview etc.) • If the researcher has justified the methods chosen • If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide) • If methods were modified during the study. If so, has the researcher explained how and why

	• If the form of data is clear (e.g. tape recordings, video material, notes etc.) • If the researcher has discussed saturation of data
6) Has the relationship between researcher and participants been adequately considered?	• If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location • How the researcher responded to events during the study and whether they considered the implications of any changes in the research design
7) Have ethical issues been taken into consideration?	• If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained • If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study) • If approval has been sought from the ethics committee
8) Was the data analysis sufficiently rigorous?	• If there is an in-depth description of the analysis process • If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data • Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process • If sufficient data are presented to support the findings • To what extent contradictory data are considered

	• Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation
9) Is there a clear statement of findings?	• If the findings are explicit • If there is adequate discussion of the evidence both for and against the researcher's arguments • If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst) • If the findings are discussed in relation to the original research question
10) How valuable is the research?	• If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research based literature • If they identify new areas where research is necessary • If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Appendix B: CASP Appraisal of Studies

Study 1: Brigden, Shaw, Barnes, Anderson, & Crawley (2020)

CASP Question	Yes/ No/ Don't know	Score
1) Was there a clear statement of the aims of the research?	Yes	1
2) Is a qualitative methodology appropriate?	Yes	1
3) Was the research design appropriate to address the aims of the research?	Yes	1
4) Was the recruitment strategy appropriate to the aims of the research?	Yes	1
5) Was the data collected in a way that addressed the research issue?	Yes	1
6) Has the relationship between researcher and participants been adequately considered?	Yes	1
7) Have ethical issues been taken into consideration?	Yes	1
8) Was the data analysis sufficiently rigorous?	Yes	1
9) Is there a clear statement of findings?	Yes	1
10) How valuable is the research?	Very – novel study, comprehensive views of those involved	1
Total score/10	10	

Study 2: Everett & Fulton (2002)

CASP Question	Yes/ No/ Don't know	Score
1) Was there a clear statement of the aims of the research?	Yes	1
2) Is a qualitative methodology appropriate?	Yes	1
3) Was the research design appropriate to address the aims of the research?	Yes	1
4) Was the recruitment strategy appropriate to the aims of the research?	Yes	1
5) Was the data collected in a way that addressed the research issue?	Yes	1
6) Has the relationship between researcher and participants been adequately considered?	No	0
7) Have ethical issues been taken into consideration?	Yes	1
8) Was the data analysis sufficiently rigorous?	No	0
9) Is there a clear statement of findings?	No	0
10) How valuable is the research?	Insight into teacher views, although limited, with directions for future research listed	1
Total score/10	7	

Study 3: Parslow, Shaw, Haywood, & Crawley (2017)

CASP Question	Yes/ No/ Don't know	Score
1) Was there a clear statement of the aims of the research?	Y	1
2) Is a qualitative methodology appropriate?	Y	1
3) Was the research design appropriate to address the aims of the research?	Y	1
4) Was the recruitment strategy appropriate to the aims of the research?	Y	1
5) Was the data collected in a way that addressed the research issue?	Y	1
6) Has the relationship between researcher and participants been adequately considered?	Y	1
7) Have ethical issues been taken into consideration?	Y	1
8) Was the data analysis sufficiently rigorous?	Y	1
9) Is there a clear statement of findings?	Y	1
10) How valuable is the research?	Very – novel study, comprehensive views of those involved, including how medical staff work	1

	with schools to provide support	
Total score/10	10	

Appendix C: Interview Schedule

Tell me about your diagnosis of CFS/ME?

What was secondary school like for you with CFS/ME?

What, if anything, supported you while you were at school?

What, if anything, was a barrier to you at school?

What would you like adults who work with children to know about CFS/ME?

Appendix D: Ben's Transcript Extract

I: So thinking about secondary school, what was it like to have CFS/ME at that time?

P: Well it feels weird looking back on it now, so obviously I've not intentionally deliberately forgotten about secondary school or anything like that, but it just doesn't crop up in my mind very often. It's only when we have conversations at work like 'what was school dinners like at your place?' and I was like 'oh I literally never set foot in the dining hall in my secondary school' which it's just weird thinking about it. And the other thing is lessons and teachers and stuff like that, sometimes you know it feels like you've been forgotten by certain people, not intentionally I don't think anyone was ever deliberately being horrible or anything

like that. So you go back and a new person had joined the class and they were sitting in your seat, and there weren't enough chairs in the classroom anyway, so you had to spend every lesson that I was there finding a spare chair or somewhere to sit. So it felt like 'oh, we don't expect X to be here' it's like 'oh we forgot to communicate this to people' Some of the teachers were really nice and things like that and were like 'No that's your space, we'll save it for when you're here' but other places just didn't have the same approach to it.

I: So a sense that things had moved on without you when you weren't there. Is there anything staff did at the time that you found really helpful?

P: Yeah, I mean, all (pause) like I say nearly all the teachers were told by the… what's the word… admission person, were really nice and helpful so they were all aware what was wrong with me and that I couldn't do everything all the time, so there were times that I wouldn't be able to stay the whole lesson and would have to leave and things like that. And there were the odd teachers who weren't helpful at all but none of them were particularly intentionally cruel with it either, they just didn't have quite the same understanding of it. So there were some people, in the same instance I was moaning about just there where they were quite happy to say 'oh that's X's spot, make sure you know, that he feels welcome, and I can't say that definitely knew, but I'm sure that a couple of teachers knew what was going on and were helpful with the other pupils in letting them know what was up.

I: What was it like for you at school with your peers and friends being missing from lessons, or not there the whole time?

P: I mean mostly, I think socially it was OK. I had a group of friends that were there for me even when I did disappear for months at a time, and they didn't stop talking to me or anything like that but they knew I was rubbish and might not turn up one day when they were all meeting and things like that so it was quite nice in that respect. But there were lots of.. well not lots of (pause) there were enough incidents of people like 'oh, X is here, I thought he'd died' or something like that you know people saying things like that. And I'm sure it doesn't make you feel the best you could be in those situations.

I: Do you have any memories of how you handled that at the time?

P: Er, well I don't think they was ever said deliberately (pause) spitefully or horribly or anything like that. I don't think I ever really properly reacted to it. It was only later when thinking about it I thought 'wow, that was a ridiculous thing to say to someone', like why would you say that? But (pause) yeah, I'm not very confrontational anyway and I was pretty relaxed with people in situations like that so it's never been something that upset me too much. Erm, but there were the odd digs and that and some kids that would suggest you were making it all up and that there's nothing actually wrong with you, you're just skiving all the time. And, you know, I knew they were wrong, so it didn't really effect or bother me. It didn't happen too much but if actions and stuff like that happened when I was away I don't really know.

Appendix E: Emily's Transcript Extract

I: What was school like for you with CFS/ME?

P: So with the school it was very very hard and it… and I was miserable basically. I was having a very hard time throughout the whole thing. I was getting bullied quite badly and I was very confused because in my heart I didn't want to be at school because I really didn't like it but I felt (pause) I felt like I had to want to be at school to prove I was truly unwell because I thought that admitting I was miserable at school would make it sound like I was making the whole thing up to not be in school.

I: Ok

P: I felt that vulnerable about my illness… er… about it not being believed. Because it is a very strange illness, people don't understand it and I didn't understand it myself so I was just miserable and just trying to get into school and keep up with the work and I was exhausted in lessons (pause) and it's very difficult when you're doing part time school as well to sort of make friendships because you're not a reliable person you're only sometimes there.

I: So you said you were doing part time school, since Year 8 but it was really difficult for you. And then you said that your part time school carried on from there?

P: Yeah, so Easter Year 10 was when I officially stopped going to school, my mum pulled me out, I was just so unwell I was just getting worse and worse (pause) and so… then.. only

then was I offered to have home schooling from the local council. Before then I hadn't been told that was ever an option, the hospital never thought to bring it up with me (erm) because they later said they didn't bring it up because local councils didn't like to offer it and I guess they had a sort of impression that I was coping even though I clearly wasn't. I think I was a bit of a people pleaser as well so I would say a lot of kind of what they wanted to hear I think maybe, but you know, they only had to see the way I basically burst into tears each session (laughs) to see how much I just was not coping.

I: And when you were in school and it was obviously difficult for you, was there anyone in school who was helping you to manage your illness?

P: Erm (long pause) so (pause) the sort of main person in charge you know, the school had a sort of lot of switching around in how it was organized. I did eventually end up with the SEN (long pause) maybe, it wasn't immediate, it might have even been at the start of the Year 9, it was a while, and I was with the SEN and she was looking out for me in the sense that (pause) I had a place I could go in school when I needed a rest and also she was, you know, she would do emails for me and things but (pause) she didn't necessarily take charge of things you know, with emailing the hospital for example. No, there wasn't someone who was overseeing my care, I think it was the hospital that said the SEN department didn't email them back and so just basically communication was poor between them and the hospital. I had a form tutor who erm who would sort of check in on me but it would it would very much be like 'how are you doing' and I'd be like 'well I guess I'm doing OK but it's hard, I'm missing a lot of lessons and it's hard to keep up' and there wouldn't really come any resolution of that. I think there was a lot of me sort of talking about things but not really any resolutions. I mean much later on, maybe the start of Year 10, the SEN department did have a meeting about caring for children with CFS and ME at the school because there was me and a couple of other kids of different ages, but I don't think they were as, I don't know (pause) but nothing really came of that. There were offers from other teachers, there was a teacher whose son had ME and he said I could sit in his office. There was a lot of sitting in offices, but that was incredibly uncomfortable you know, when you're a sort of teenage girl and you don't feel like you belong in a lot of these places. It took a while for me to feel like I belonged in the SEN department because it just, there wasn't really anything for me so I just felt out of place basically. And luckily I did have a friend who stuck by at school and I probably wasn't a very good friend for her to have as I wasn't there

very much, would constantly miss lunchtime… but the hard thing about when I would stay for lunch was because I couldn't… I haven't even talked about walking round the school yet, gosh…. But I couldn't stand up… so all the kids go and stand on the basketball courts and talk to each other, but I couldn't stand up so I would have to go and sit to the side and so she would always come and sit with me, she had a packed lunch too like me as I couldn't stand in the queue for the school dinner line and I was given a pass card to skip the line for school dinners but you just… you know….. it's just… I felt the idea of skipping the line and having everyone look at me I felt sort of uncomfortable even… I didn't have much confidence, very shy, also having to go and eat by yourself which you don't want to do so (pause) because I didn't have any other friends apart from her really, I had a couple of people but not sort of solid people. So walking around the school was a big problem, it's a massive school. Like 10 minutes between ends and you'd only have 5 minutes to walk between lessons so sometimes it would just be impossible. And even though I did… all the teachers were made aware I was unwell, I wasn't able to (long pause) I don't know where I was going with that thought……. The teachers knew I was unwell but I still felt a pressure to you know, be on time for lessons. Things weren't… the teachers were never really explicit where you know, saying 'we understand' or something. So for homework for example, I did have explicit permission from the SEN department or the head of department or something to be able to hand in homework late and stuff like that. So they did give me that and I had permission to not do any homework that wasn't essential. But of course every teacher thinks their homework is the most essential (laughs) so…. That was very… but then again I felt uncomfortable around that and I would still have my mum write me a note if my homework was coming in late, even though they should all know I felt very on my own still

Appendix F: Example of Ben's Coded Transcript

Reflections in repeated reading	Initial noting Descriptive/linguistic/conceptual comments	Transcript	Emergent Themes
		So thinking about secondary school, what was it like to have CFS/ME at that time?	
Mixed experience, strangeness of being there but not. Missing lots of 'typical' experiences'	The experience is described as 'weird' looking back. Not intentionally deliberately forgotten, emphasis on what wasn't done Missing key aspects of school life, and the strangeness of that Being gone, and school moving on without the pupil Inconvenience at the time of being in school, but not prepared for, the expectation is	Well it feels weird looking back on it now, so obviously I've not intentionally deliberately forgotten about secondary school or anything like that, but it just doesn't crop up in my mind very often. It's only when we have conversations at work like 'what was school dinners like at your place?' and I was like 'oh I literally never set foot in the dining hall in my secondary school' which it's just weird thinking about it. And the other thing is lessons and teachers and stuff like that, sometimes you know it feels like you've been forgotten by certain people, not intentionally I don't think anyone was ever deliberately being horrible or anything like that. So you go back and a new person had	School as a strange experience Sense of being 'forgotten' in school Inconsistency and poor communication between staff

Moving on without	that the pupil is not at school. Does this impact on sense of belonging in the school community? 'We' don't expect 'you' to be here, outside of the class group? Lack of communication to staff to expect the pupil in school today. If staff aren't prepared for a pupil's return after absence, does this impact on learning opportunities? Positive experience of someone saving 'your' space. Sense of identity and ownership in the classroom by having 'your' space There was variability in the staff approaches to maintaining the pupil's space	joined the class and they were sitting in your seat, and there weren't enough chairs in the classroom anyway, so you had to spend every lesson that I was there finding a spare chair or somewhere to sit. So it felt like 'oh, we don't expect X to be here' it's like 'oh we forgot to communicate this to people' Some of the teachers were really nice and things like that and were like 'No that's your space, we'll save it for when you're here' but other places just didn't have the same approach to it.	

		So a sense that things had moved on without you when you weren't there. Is there anything staff did at the time that you found really helpful?	
Uncertainty in support, idea of being spoken about, where is the voc? Contradiction, who knew what?	Self correction between 'all', a pause then 'nearly all' He describes staff as being nice and helpful and aware of his needs Teachers who weren't aware are framed as not having 'the same understanding' The difference between staff may be linked to the communication and understanding? 'Moaning about' – is there some discomfort in voicing the negatives? Describes how he thinks his teachers helped provide	Yeah, I mean, all (pause) like I say nearly all the teachers were told by the… what's the word… admission person, were really nice and helpful so they were all aware what was wrong with me and that I couldn't do everything all the time, so there were times that I wouldn't be able to stay the whole lesson and would have to leave and things like that. And there were the odd teachers who weren't helpful at all but none of them were particularly intentionally cruel with it either, they just didn't have quite the same understanding of it. So there were some people, in the same instance I was moaning about just there where they were quite happy to say 'oh that's X's spot, make sure you know, that he feels welcome, and I can't say that they definitely knew, but I'm sure that a couple of teachers knew what was going on and were helpful with the other pupils in letting them know what was up.	Staff understanding and awareness had an impact on the level of support received

	information to his peers to understand 'what was up' What was his role in informing peers 'what was up?' How was this managed or communicated? What did he want shared?		
		What was it like for you at school with your peers and friends being missing from lessons, or not there the whole time?	
Positive, supportive peers Contrast, my shock (I heard myself gasp on the audio)	Description of supportive peer relationships, which included maintaining social contact outside of school Label of being 'rubbish' when may be unable to attend social events Reframing and evaluation of language around lots of/enough	I mean mostly, I think socially it was OK. I had a group of friends that were there for me even when I did disappear for months at a time, and they didn't stop talking to me or anything like that but they knew I was rubbish and might not turn up one day when they were all meeting and things like that so it was quite nice in that respect. But there were lots of.. well not lots of (pause) there were enough incidents of people like 'oh, X is here, I thought he'd died' or something like that you know people saying things like that. And I'm sure it doesn't make you feel the best you could be in those situations.	CFS/ME impacting on social experiences outside school Lack of understanding from peers led to difficult social situations

	Peers could show a lack of understanding and make insensitive comments Reinforcing the message that you have been away from school a long time, so long ago peers think you 'have died'. It has been so long you have been forgotten, which is an unpleasant feeling.		
		Do you have any memories of how you handled that at the time?	
Hesitance, trying to understand? Hindsight and differences in adulthood?	Now views these comments as more 'ridiculous' than spiteful. At the time, he was unbothered by the comments. Temporal sequence of at the time not bothered, but after the event realizing the significance of what was said	Er, well I don't think they was ever said deliberately (pause) spitefully or horribly or anything like that. I don't think I ever really properly reacted to it. It was only later when thinking about it I thought 'wow, that was a ridiculous thing to say to someone', like why would you say that? But (pause) yeah, I'm not very confrontational anyway and I was pretty relaxed with people in situations like that so it's never been something that upset me too	Peers lack of understanding Role of self-advocacy The 'hidden' school experience when absent - communication

Confidence in self	Peers could have negative attributions, 'skiving' Overcoming these doubts and difficult peer times through sense of self Uncertainty of what was said when not at school – were there 'hidden' factors that influenced him on return to school	much. Erm, but there were the odd digs and that and some kids that would suggest you were making it all up and that there's nothing actually wrong with you, you're just skiving all the time. And, you know, I knew they were wrong, so it didn't really effect or bother me. It didn't happen too much but if actions and stuff like that happened when I was away I don't really know.	

Appendix G: Extract of Emily's Coded Transcript

Reflections from repeated reading	Initial noting Descriptive/linguistic/conceptual comments	Transcript	Emergent Themes
		I: What was school like for you with CFS/ME?	
Difficult emotional experience and disbelief	Emotional impacts of managing made her miserable Negative peer impacts, bullying Pressures of school – the hidden aspect of CFS/ME, struggling to be believed	P: So with the school it was very very hard and it… and I was miserable basically. I was having a very hard time throughout the whole thing. I was getting bullied quite badly and I was very confused because in my heart I didn't want to be at school because I really didn't like it but I felt (pause) I felt like I had to want to be at school to prove I was truly unwell because I thought that admitting I was miserable at school would make it sound like I was making the whole thing up to not be in school.	Emotional impacts of managing CFS/ME in school
		I: Ok	
Use of word vulnerable – strong emotion	How were people around Emily making her feel safe and acknowledged at school? What did others understand about her illness?	P: I felt that vulnerable about my illness… er… about it not being believed. Because it is a very strange illness, people don't understand it and I didn't understand it myself so I was just miserable and just trying to get into school and keep up with the work and I was exhausted in lessons (pause) and it's very difficult when you're doing part time school as well to sort of make	Lack of understanding from others about the illness Social impacts of not being there

	Difficulty of maintaining friendships when not in school	friendships because you're not a reliable person you're only sometimes there.	
		I: So you said you were doing part time school, since Year 8 but it was really difficult for you. And then you said that your part time school carried on from there?	
Escalation of difficulties – why weren't needs met sooner?	Left school in first year of GCSEs due to health Escalation and absence seems to have triggered this procedure of offering tuition 'Coping even when I wasn't' She reflects on her own role as someone who may be a 'people pleaser', but who was making her feel safe in school to hear her voice? She recognises the disparity in her physical appearance and emotional state, why wasn't this picked up? What was this like?	P: Yeah, so Easter Year 10 was when I officially stopped going to school, my mum pulled me out, I was just so unwell I was just getting worse and worse (pause) and so… then.. only then was I offered to have home schooling from the local council. Before then I hadn't been told that was ever an option, the hospital never thought to bring it up with me (erm) because they later said they didn't bring it up because local councils didn't like to offer it and I guess they had a sort of impression that I was coping even though I clearly wasn't. I think I was a bit of a people pleaser as well so I would say a lot of kind of what they wanted to hear I think maybe, but you know, they only had to see the way I basically burst into tears each session (laughs) to see how much I just was not coping.	Leaving school due to illness Role of home tuition Hidden pressures of managing CFS/ME Not hearing the voice of the young person

		I: And when you were in school and it was obviously difficult for you, was there anyone in school who was helping you to manage your illness?	
	Changes in school staffing had an impact Wait to be identified as having SEN Sense of practical support being offered, but not emotional support and not anyone 'in charge' Poor communication 'What would 'in charge' look like and what would be different? What was the emotional impact of asking for help and not receiving it? If Emily is asking for	P: Erm (long pause) so (pause) the sort of main person in charge you know, the school had a sort of lot of switching around in how it was organized. I did eventually end up with the SEN (long pause) maybe, it wasn't immediate, it might have even been at the start of the Year 9, it was a while, and I was with the SEN and she was looking out for me in the sense that (pause) I had a place I could go in school when I needed a rest and also she was, you know, she would do emails for me and things but (pause) she didn't necessarily take charge of things you know, with emailing the hospital for example. No, there wasn't someone who was overseeing my care, I think it was the hospital that said the SEN department didn't email them back and so just basically communication was poor between them and the hospital. I had a form tutor who erm who would sort of check in on me but it would it would very much be like 'how are you doing' and I'd be like 'well I guess I'm doing OK but it's hard, I'm missing a lot of lessons and it's hard to keep up' and there wouldn't really come any resolution of that. I think there was a lot of me sort of talking about things but not really any resolutions. I mean much	Inconsistency in staffing Delays in support Physical space in school No one in charge to organise support Support not offered when asked for

	help, can she really look like she is coping as mentioned above? Repetition of missed opportunities, things not changing No physical space for her, apart from sitting in a teachers office – does that make you feel like you belong? The supportive role of a friendship, but the barriers to maintaining that are also difficult Forgotten to mention this significant aspect, so much going on	later on, maybe the start of Year 10, the SEN department did have a meeting about caring for children with CFS and ME at the school because there was me and a couple of other kids of different ages, but I don't think they were as, I don't know (pause) but nothing really came of that. There were offers from other teachers, there was a teacher whose son had ME and he said I could sit in his office. There was a lot of sitting in offices, but that was incredibly uncomfortable you know, when you're a sort of teenage girl and you don't feel like you belong in a lot of these places. It took a while for me to feel like I belonged in the SEN department because it just, there wasn't really anything for me so I just felt out of place basically. And luckily I did have a friend who stuck by at school and I probably wasn't a very good friend for her to have as I wasn't there very much, would constantly miss lunchtime… but the hard thing about when I would stay for lunch was because I couldn't… I haven't even talked about walking round the school yet, gosh…. But I couldn't stand up… so all the kids go and stand on the basketball courts and talk to each other, but I couldn't stand up so I would have to go and sit to the side and so she would always come and sit with me, she had a packed lunch too like me as I couldn't stand in the queue for the school dinner line and I was given a pass card to skip the line for school dinners but you	Continued lack of support Staff who were experienced provided more support The hidden emotional toll of receiving support – feeling 'different' Positive role of social support Physical barriers linked to CFS/ME

	Identified support for the physical needs of ME BUT they seem to have a social/emotional impact of standing out to peers that isn't considered in offering support Physical barriers of the school environment Barriers in staff communication impacting on support – young person in advocate role. Pressures of the young person advocating and negotiating needs – the experience of being put in this position is uncomfortable	just… you know….. it's just… I felt the idea of skipping the line and having everyone look at me I felt sort of uncomfortable even… I didn't have much confidence, very shy, also having to go and eat by yourself which you don't want to do so (pause) because I didn't have any other friends apart from her really, I had a couple of people but not sort of solid people. So walking around the school was a big problem, it's a massive school. Like 10 minutes between ends and you'd only have 5 minutes to walk between lessons so sometimes it would just be impossible. And even though I did… all the teachers were made aware I was unwell, I wasn't able to (long pause) I don't know where I was going with that thought……. The teachers knew I was unwell but I still felt a pressure to you know, be on time for lessons. Things weren't… the teachers were never really explicit where you know, saying 'we understand' or something. So for homework for example, I did have explicit permission from the SEN department or the head of department or something to be able to hand in homework late and stuff like that. So they did give me that and I had permission to not do any homework that wasn't essential. But of course every teacher thinks their homework is the most essential (laughs) so…. That was very… but then again I felt uncomfortable around that and I would still have my mum write me	Social pressures in receiving support Pressure from staff Lack of communication around expectations The pressure of being an advocate for your needs

		a note if my homework was coming in late, even though they should all know I felt very on my own still.	

Appendix H: Table Showing Ben's Emergent, Subordinate and Superordinate Theme Groupings, with Transcript Locations and Key Words

Superordinate Theme	Subordinate Theme	Emergent Themes	Example location in transcript	Key words
Demands of the curriculum	Pre GCSE	• Specific barriers in language subjects • Reduced opportunities • Difficulties in adapting and catching up • Pressures of managing the whole curriculum	173-175 233-240 334-336 163-168	'no idea' 'never happen at school' 'What on Earth is going on?' 'I had no idea about the context'
	During GCSEs	• GCSEs as a turning point • Different to earlier schooling • Narrower curriculum limited opportunities to explore learning	405-409 247-249 238-240	'that far behind' 'nothing to do with school' 'I would have liked the option'
The complex physical nature of CFS/ME	Physical needs in school	• Need for a rest space in school • Need for flexibility in the timetable • Structured phased returns to school	308-315 375-379 208-210 53-60	'little space' 'be flexible' 'built up' 'just couldn't do anything'

		• Symptoms of CFS/ME as a barrier to education • Need for family support • Unable to take part in sports	199-204 531	'come pick me up' 'I can't'
	Impact on attendance	• Significance of illness on attendance • Symptoms impacting on engagement while in school	68-71 7-11	'three or four months off' 'there but not well enough to learn'
	Recovery is fragile	• Recovery is gradual over time • Progression with setbacks • Need for long-term support	208-210 212-213 380-381	'gradually built up' 'minor setbacks' 'start of the plan'
The social and emotional experience of school with CFS/ME	The role of wider social support	• Value of social experiences outside of school • Benefits of family support	138-141 199-204	'really nice of them' 'Mum used to help…'
	School as a strange experience	• Disruption to the 'normality' of school • School was a weird experience • School as an experience in the past	39-42 589-591 76-78 187-192	'normal, well not normal' 'how weird school was' 'doesn't crop up now' 'surreal'

		• Home tuition as a strange experience • School as a mostly positive experience	599-604	'remember it fondly'
	Social exclusion	• Lack of understanding from peers leading to difficult social situations • Desire to blend in	117-127 300-305	'I thought he'd died' 'didn't want attention drawing'
	Reduced aspirations	• Personal expectations of failure in exams • Reduced parental aspirations • Achievement beyond grades • Need to balance attainment vs health • Loss of sports	464-465 454-458 468-472 465 517	'expected to fail' 'gets any grades' 'not the end of the world' 'not going to push myself' 'football team'
The impacts of adults on the school experience with CFS/ME	The young person as an advocate	• The need for the young person to self-advocate • Self-advocacy driving support • Advocating to authority • The responsibility of the young person to self-advocate	523-533 562-569 536-541 412-419	'I know I can't' 'I have to ask' 'interesting experience' 'I would ask if I missed a lesson'

	Do we hear the 'voice of the child?'	• School priorities vs the young person's priorities • Lack of choice	390-402 196-197	'nice if I was asked' 'happened to me'
	Staff communication	• School communication impacted on teacher behaviour • Sense of being 'forgotten' in school • Communication helped to meet needs	356-369 81-89 270-275	'hadn't heard of any issues' 'not expecting you' 'not like the other pupils'
	Consistency of support	• Familiar staff provided more proactive support • Inconsistency and lack of organisation in provision of home learning • Capacity of staff to respond to need could be limited	422-427 570-579 296-299	'better at proactively checking in' 'how much was well planned' 'paid less interest'

Appendix I: Table Showing Emily's Emergent, Subordinate and Superordinate Theme Groupings, with Transcript Locations and Key Words

Superordinate Theme	Subordinate Theme	Emergent Themes	Example location in transcript	Key words
Demands of the curriculum	Playing 'catch up'	• The academic demands of part-time timetables • Pressures in keeping up • Success measured by attendance • Reduced subject opportunities	367 62-63 318 174-177	'always catching up' 'don't know how I did it' 'hours in school' 'I dropped….'
	The (in)flexibility of the school system	• Lack of options for alternative education • Working to a set timescale • The experience of home tuition	408-409 190-191 244-251	'offered tuition sooner' 'they're your GCSEs' 'much better for me'
The complex physical impacts of CFS/ME	Physical needs in school	• School environment was a trigger for physical stress • The need for a rest space in school	133-135 271-273	'walking was an issue' 'a place to go to'

	Impact on attendance	• Not able to keep up with a phased return • Illness progressed over time • Leaving school due to illness	450-451 5-9 94-95	'not getting better' 'worse and worse' 'pulled me out'
The social and emotional experience of school with CFS/ME	The emotional strain of managing CFS/ME in school	• Emotional impacts of giving up preferred activities • Pressures of coping with the illness • School stress impacting on physical symptoms • 'Hiding' the illness • Trying to achieve a balanced school life	65-68 443-447 339-350 153-155 400-402	'pretty miserable hours' 'too much today' 'can't separate them' 'secretive' 'what's the point'
	Social exclusion	• Lack of understanding from peers about the illness • Lack of belonging in the classroom	386-388 375-377 257-259	'peer pressure' 'Seat had been taken'

		• Illness making you 'different'		'No one could relate'
	Reduced aspirations	• Limitation on planning for the future • Adults reducing aspirations	225-227 380-383	'wasn't well enough to go to uni' 'there's not point'
	The role of wider social support	• The need for parental advocacy • The impacts of positive peer relationships	277-280 122-124	'She facilitated all communications' 'luckily I had a friend who stuck by'
The impacts of adults on the school experience with CFS/ME	The young person as an advocate	• The pressure of the advocate role • Need to manage energy demands in school • The role of negotiating with staff • Not ready for the advocate role	482-483 495-498 487-490 487-488	'it felt wrong' 'use blasts of energy well' 'it felt cheeky' 'I wasn't really ready'
	Do we hear the 'voice of the child?'	• Tension between young person and adult goals • Young person not understanding their illness	397-400 87-89 320-226	'I felt frustrated' 'I didn't understand it'

		• The need for adults to listen and act on what is said • The young person felt uncertain about their support	317-318	'they wouldn't have a solution' 'I felt I legally had to go to school'
	Staff communication	• Lack of communication around expectations for the young person • Pressure from staff • Support needs not escalated	137-142 388-392 329-333	'teachers were never really explicit' 'Feeling like you're failing' 'No one raised an alarm'
	Consistency of support	• Lack of initial planning • Lack of organisational systems to provide support • Lack of consistency impacted on support • Irregular support while at home • No one was 'in charge'	21-24 333-336 104-106 177-183 156-168	'the school were very casual at first' 'No one was in charge of me' 'there was a lot of switching around' 'It was kind of sporadic' 'so many heads and no one in

				charge of anything’

Appendix J: Ethical Approval Form

Ethics Approval Submission Form

Name of Applicant:- Charlotte Davies

Are you an undergraduate, postgraduate or staff? PGR

E-mail address:- charlotte.davies@nottingham.ac.uk

Date of submission:-

Applicants home school / department: Psychology

Title of project:- The secondary school experiences of pupils with chronic fatigue syndrome; A retrospective account from young adults ages 18-25 using Interpretative Phenomenological Analysis

Is this a re-submission?

NO

If YES give the reference number of the original submission:- N/A

Will this study involve brain stimulation (TMS or tDCS)? NO

Does the study include repetitive forms of TMS (rTMS)? NO

Will this study involve brain scanning (fMRI or MEG)? NO

<u>This section to be completed by the supervisor or principal investigator</u>

Name :- Sarah Atkinson

E-mail address :- s.atkinson@nottingham.ac.uk

Supervisors home school / department: School of Psychology

Please confirm that this application has your approval YES

Have you read the application to check that is accurate and complete?

YES

Has a similar study been approved by the Committee? NO

If YES give the reference number and submission date. This will speed the review process. Also state how this application differs.

Are all your ethical concerns identified in the application? YES

Declaration by Principal Investigator or Supervisor:

> "*I have read the Ethical Risks Checklist and confirm that no items other than those listed in this submission are relevant to this research*." YES

Signature: 

Date: 24 July 2020

(submission from the supervisors University of Nottingham email address is to be used

as well as a scanned electronic signature)

This section to be completed by the applicant

A. Rationale for the Research Very briefly state the background and purpose of the proposed research (max = 300 words).

Chronic fatigue syndrome (CFS), or myalgic encephalomyelitis (ME), is an illness characterised by persistent fatigue that is not improved by rest or sleep (National Institute for Health and Care Excellence (NICE), 2007). Estimates of prevalence rates of CFS/ME in childhood vary, but recent estimates suggest up to 2% of secondary school aged children are affected (Collard & Murphy, 2019).

For adolescents with CFS/ME, prolonged school absence is common; research suggests they miss on average a year of schooling, with the mean duration of illness being 38 months (Rangel et al., 2000). Initial scoping literature searches looking at the impacts of CFS/ME on school aged children found little research from an educational perspective. This lack of research into education is reflected in the medical literature; little information is available to support professionals in comparison to other conditions with a similar prevalence rate, such as ADHD, suggesting a knowledge gap in how schools can effectively support pupils with CFS/ME (Newton, 2019).

Adolescents perceive CFS/ME to significantly impact on their own future career or study aspirations (Sankey et al., 2006), but at present the literature does not appear to capture these experiences adequately to help inform education professionals as how best to support them overcome these significant barriers to their aspirations. As most children recover from CFS/ME (Cairns & Hotopf, 2005; Rangel et al., 2000), albeit with significant disruption to their schooling at a crucial time in their school career, this raises questions to consider the impact this had on children who have been able to meet their future aspirations (e.g. attending university or work). By asking young adults about their experiences of secondary school education, this study aims to provide an insight into the needs of this population from their own perspective, which can be used to inform professionals supporting children with CFS/ME in secondary school to support positive outcomes for this group.

B. Procedure Give a complete description of the procedure (max = 1000 words). For web-based studies also provide the URL of the study and the URL of the software used (e.g., BOS, Qualtrics).

The proposed research questions are experiential in nature and look to understand this for the individuals involved in the research. Interpretative Phenomenological Analysis (IPA) is therefore an appropriate methodology to examine the research question.

Purposive sampling will be used to recruit participants. The proposed study will recruit young adults between 18-25 who experienced an episode of heightened CFS/ME symptoms as diagnosed by a medical professional while they were at secondary school. This may include participants who were diagnosed at an earlier age but experienced an episode of heightened CFS/ME symptoms while at secondary school. Participants may or may not be experiencing CFS/ME symptoms in the present, this reflects the cyclical nature of the illness, especially considering that most children are more likely to make a full recovery (Cairns & Hotopf, 2005). The study aims to recruit six participants as suggested for using IPA, small sample sizes are commonly used within IPA and this figure has been suggested as appropriate for professional doctoral research (Pietkiewicz & Smith, 2014)

Participants will be recruited through advertisements placed through the social media channels of national organisations and charities that support people with CFS/ME (recruitment poster details shown in appendix A). Both the ME Association and ME Research UK advertise research studies via their social media channels, this is organised by emailing a brief description of the study to the organisations who then post the advertisement on their social media channels. This will have no links to any social media of the researcher. There are also several local support groups in the East Midlands who have social media channels and mailing lists that they use to contact members who have consented to receive information. The recruitment poster (appendix A) will be forwarded to local organisations to see if they would advertise the study to their mailing list and social media channels. The researcher has no links or affiliations to any of these groups.

The study recruitment poster clearly outlines the scope and key details of the study to potential recruits. Participants are directed to contact the researcher via her university contact

details if interested in participating, making this an opt in process. Any interested parties will then be sent an information sheet replying via email if they wish to proceed further with the study. If any participants contact the researcher once recruitment is complete, they will be informed of this via email. The names and email addresses of potential participants will only be known to the researcher, all contact will be made through the university's email system. Contact will only be made in relation to the research study.

Data will be collected through semi-structured interviews. Once recruited to the study, participants will be emailed the consent forms to sign and return to the researcher, as well as a reminder of the study information sheet. If happy to proceed with the research, suitable times will be arranged for the initial video interview between participant and the researcher, with at least one week's notice given to participants as a 'cooling off' period so they have time to consider their participation further. Upon the start of the interview, participants will again be reminded of their right to withdraw and the aims of the study.

Due to the current social distancing measures across the UK, the proposed study will use video interviews with participants using Microsoft Teams video conferencing software available through the University of Nottingham. The interview will be audio recorded by the researcher.

Following participation in the research, participants will be emailed a debrief letter. They will notified of the latest date at which they can contact the researcher to withdraw their data from the study before analysis begins. The debrief letter also informs participants they will be contacted via email once data analysis is complete to ask if they would like to discuss the analysis with the researcher as is commonly used in IPA studies, this is optional and participants can opt to withdraw from this step but remain in the rest of the study.

C. Items from the Ethical Risks Checklist. Explain how any of the following issues will be handled within your research to ensure ethically sound procedures (max = 300 words per item). Delete those items that do not apply.

3. Recruitment of people in a specially vulnerable state (e.g. depressed, anxious, bereaved etc).

4. Participants being investigated for a problem which has received medical, psychiatric, clinical psychological or other similar attention.

Points 3 and 4 may relate to the proposed study, as participants may still be experiencing symptoms of CFS/ME and therefore have their own individual needs for rest breaks during the interview process. The following steps will be taken to ensure participants' possible medical needs are met:

- Participants will be asked about any access requirements they may have that the researcher will adhere to
- Participants will be reminded of their right to withdraw without penalty at the beginning of interviews
- Interviews will have scheduled rest breaks, if required, and participants can request a break at any time
- Participants will be invited to choose when is most comfortable for them to arrange the interview depending on how their symptoms may fluctuate over the day/week
- If participants wish, the interview will be scheduled in two shorter time slots to avoid a potentially longer session which could be fatiguing

24. Recall of personal memories.

26. Discussion or investigation of personal topics (e.g. relationships, feelings of success and failure) or any other procedure in which participants may have an emotional investment.

Points 24 and 26 relate to the proposed study, as participants are asked to describe their circumstances of having an illness during secondary school. To end the interview on a positive note, the researcher will share strengths they have identified with participants from their interview discussion.

Participants will also be given a full debrief sheet with information regarding general mental health wellbeing via the NHS if they experience any increased distress because of participating, including urgent care information. Participants are urged to contact their

GP or healthcare provider if they have any concerns regarding their health after participating in the study.

28. Possible identification of participants (e.g. when reporting results).

Participants will be identified by a pseudonym when writing up data. Any identifiable information, such as if they disclose the name of their secondary school, will also be given a pseudonym. Any highly personal information that could identify participants will be removed from any write up.

Other ethical considerations relating to the researcher's role as a Trainee Educational Psychologists (TEP):

Although the researcher is also a TEP, the proposed project considers the retrospective experiences of a young adult population. Therefore, this is not a population with who the researcher would encounter through her TEP role so there is no risk information form her TEP role could be used in the proposed research. The interviews will be conducted remotely via video link, and therefore do not bring the researcher into direct contact with participants, and as participants are adults can all provide informed consent for this. Participants will be emailed consent forms and information sheets prior to the study taking place and reminded of this information at the start of their interview.

Participants will be recruited through the organisation external to the LA which minimises confusion between the researcher's LA and researcher roles.

The rationale for the project came from the researcher's personal diagnosis of CFS/ME during her doctoral studies. When researching her own treatment, she found statistics indicating the increasing prevalence in children, which led her to consult the literature for her own professional development. When no research could be found, the idea for a research proposal was developed from there. The Local Authority (LA) hosting the researcher's TEP practice placement are aware of the research and have supervised the development of the research questions as a key stakeholder. They will not have direct access or influence that could impact on participant's right to withdraw as recruitment is external to the LA.

The aim of the research is to inform professional educational psychology practice to support children with CFS/ME, participants will be made aware of these aims through

the participant information sheets to decide if they give informed consent to take part. They will be made aware of the dual role of the researcher.

D. Attachments Checklist.

Please confirm that the following are attached or indicate that they are not relevant to your research. Forms should be jargon-free and written in a style easily understandable by the participants of your study. The standard templates for Information Sheets and Consent Forms are downloadable from the Ethics workspace. Debrief statements or procedures are necessary for most research, not just that involving deception (see Guidance). Give your reasons for any departure from these standard procedures.*

1. Access and Recruitment letters (to participants, parents, schools etc)

N/A

2. Template or example of recruitment posters (See Guidance Notes)

Attached

3. Information Sheet for Participants.

Standard Form Attached.

4. Consent Form (Please use the current template)

Standard Form Attached.

5. Debrief Statement/Procedure (see Guidance Notes)

Attached.

6. Examples of test materials, questionnaires etc. if these are not widely available and contain or deal with ethically sensitive material. Do not attach materials

which the Committee are likely to have easy access to (e.g. widely published questionnaires) or neutral test materials.

Attached

Appendix K: Ethical Approval Letter

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

School of Psychology
The University of Nottingham
University Park
Nottingham
NG7 2RD

T: +44 (0)115 8467403 or (0)115 9514344

SJ/tp

Ref: **S1277**

Monday 24th August 2020

Dear Charlotte Davies and Sarah Atkinson,

Ethics Committee Review

Thank you for submitting an account of your proposed research '**The secondary school experiences of pupils with chronic fatigue syndrome; A retrospective account from young adults ages 18-25 using Interpretative Phenomenological Analysis**'

That proposal has now been reviewed by the Ethics Committee and I am pleased to tell you that your submission has met with the committee's approval.

Final responsibility for ethical conduct of your research rests with you or your supervisor. The Codes of Practice setting out these responsibilities have been published by the British Psychological Society and the University Research Ethics Committee. If you have any concerns whatever during the conduct of your research then you should consult those Codes of Practice. The Committee should be informed immediately should any participant complaints or adverse events arise during the study.

Independently of the Ethics Committee procedures, supervisors also have responsibilities for the risk assessment of projects as detailed in the safety pages of the University web site. Ethics Committee approval does not alter, replace, or remove those responsibilities, nor does it certify that they have been met.

Yours sincerely

Professor Stephen Jackson
Chair, Ethics Committee

Appendix L: Study Advert

Research participation opportunity: The retrospective secondary school experiences of young adults with CFS/ME

The University of Nottingham is conducting a study to consider the experiences of young adults who had symptoms of CFS/ME while at secondary school. You can still participate if you no longer have CFS/ME symptoms.

The study will involve a video interview lasting approximately an hour to describe your experiences of having CFS/ME while at secondary school. There will be an optional follow up interview to discuss the study results.

We are looking for volunteers:

- Aged between 18-25
- Who had a diagnosis and symptoms of CFS/ME during secondary school
- Able to complete a video interview with a researcher at a time convenient for you (this can be completed over multiple sessions if needed)

If you would like further details please contact the researcher via charlotte.davies@nottingham.ac.uk

Thank you,

Charlotte Davies

Appendix M: Study Information Sheet

School of Psychology

Information Sheet

The University of Nottingham

UNITED KINGDOM · CHINA · MALAYSIA

Title of Project: The secondary school experiences of pupils with chronic fatigue syndrome; A retrospective account from young adults aged 18-25 using Interpretative Phenomenological Analysis

Ethics Approval Number: S1277

Researcher: Charlotte Davies – charlotte.davies@nottingham.ac.uk

Supervisor: Sarah Atkinson – s.atkinson@nottingham.ac.uk

This is an invitation to take part in a research study considering your experiences of having chronic fatigue syndrome/ ME while at secondary school.

Before you decide if you wish to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

If you participate, I will arrange a video interview with you using Microsoft Teams. During this interview, I will ask you questions about your experiences of having CFS/ME at secondary

school. We can take rest breaks as needed in the interviews and arrange them at a time that is suitable for you. I will audio record these interviews and transcribe the data. When I transcribe your data, I will use a pseudonym to protect your real identity and remove any potential identifying information. Only I will have information regarding your real identity.

Once I have analysed all the participant data you can take part in an optional interview, again on Teams, where we talk about the analysis and your thoughts on this.

The whole procedure will last approximately one hour for the initial interview, and around 45 minutes if you take part in the follow up conversation.

Participation in this study is totally voluntary and you are under no obligation to take part. You are free to withdraw at any point before or during the study. All data collected will be kept confidential and used for research purposes only. It will be stored in compliance with the Data Protection Act.

As we are having an online video interview, we are obliged to make you aware that there is always a potential risk of intrusion by outside agents, for example through hacking, and therefore the possibility of being identified.

If you have any questions or concerns please don't hesitate to ask now. I or my supervisor can also be contacted after your participation at the above address.

If you have any complaints about the study, please contact:

Stephen Jackson (Chair of Ethics Committee)

stephen.jackson@nottingham.ac.uk

Appendix N: Consent Form

School of Psychology

Consent Form

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Title of Project: The secondary school experiences of pupils with chronic fatigue syndrome; A retrospective account from young adults aged 18-25 using Interpretative Phenomenological Analysis

Ethics Approval Number: S1277

Researcher: Charlotte Davies – charlotte.davies@nottingham.ac.uk

Supervisor: Sarah Atkinson – s.atkinson@nottingham.ac.uk

The participant should answer these questions independently:

- Have you read and understood the Information Sheet? YES/NO
- Have you had the opportunity to ask questions about the study? YES/NO
- Have all your questions been answered satisfactorily (if applicable)? YES/
- Do you understand that you are free to withdraw from the study? YES/NO

(at any time and without giving a reason)

- I give permission for my data from this study to be shared with other researchers provided that my anonymity is completely protected. YES/NO
- Do you agree to take part in the study? YES/NO

"This study has been explained to me to my satisfaction, and I agree to take part. I understand that I am free to withdraw at any time."

Signature of the Participant: Date:

Name (in block capitals)

I have explained the study to the above participant and he/she has agreed to take part.

Signature of researcher: Date:

Appendix O: Debrief Form

School of Psychology

Debrief Information

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Title of Project The secondary school experiences of pupils with chronic fatigue syndrome; A retrospective account from young adults ages 18-25 using Interpretative Phenomenological Analysis

Ethics Approval Number or Taught Project Archive Number: ***S1277***

Researcher(s): Charlotte Davies – charlotte.davies@nottingham.ac.uk

Supervisor: Sarah Atkinson - s.atkinson@nottingham.ac.uk

Thank you for taking part in the study. If you have any questions, please contact me or my supervisor on the above email addresses.

I will now transcribe the data from our interview and other participants over the next few weeks. Once this is complete, I will email you to ask if you would like to take part in an optional follow up interview to talk about the data analysis.

If you decide you wish to withdraw your data from the study for any reason, please let me know by (Date), otherwise your data will be included in the analysis.

If the study has caused you any distress, the NHS has advice that can be found at:

https://www.nhs.uk/conditions/stress-anxiety-depression/. For urgent advice, guidance can be found at https://www.nhs.uk/using-the-nhs/nhs-services/mental-health-services/dealing-with-a-mental-health-crisis-or-emergency/.

If you have any concerns regarding your physical or mental health following the study please speak to your GP or healthcare provider.

Thank you again for taking part.